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Transforming lives : caregivers for an Alzheimer's patient construct support

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**TRANSFORMING LIVES: CAREGIVERS FOR AN ALZHEIMER'S PATIENT
CONSTRUCT SUPPORT**

**A Thesis
Presented to
The Faculty of the Department of Communication Studies
San Jose State University**

**In Partial Fulfillment
of the Requirements for the Degree
Master of Arts**

**by
Mindi Ann Golden
August 1995**

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ABSTRACT

TRANSFORMING LIVES: CAREGIVERS FOR AN ALZHEIMER'S PATIENT CONSTRUCT SUPPORT

by Mindi Ann Golden

This thesis is a case study which explores the relationship between a primary and hired caregiver for a person with Alzheimer's. Specifically, this thesis describes how a primary and hired caregiver experience and negotiate support within their relationship. This study introduces the social constructionist perspective to support research. It also focuses on the primary/hired caregiver relationship, which has been neglected in previous caregiving research.

The primary and hired caregiver participating in this study kept diaries in which they documented episodes they found supportive. They were then interviewed regarding general categories of support obtained from the diaries. The interview data illustrated that support is constructed within a reflexive communication process. The episodes recorded in the caregiver diaries create the process and the process enables the episodes to be constructed as support. The interview data also illustrate that reflexivity within the support process transforms the caregivers' lives.

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Chapter 1

Statement of the Problem and Literature Review

Caring for an ailing loved one is a task we all may face. We hope the shouldering of such care will be a temporary task. More accurately, we hope our spouses, parents, grandparents, and other loved ones face temporary illnesses. Despite these hopes, many people find themselves caring for loved ones with illnesses that are far from temporary. Alzheimer's disease is such an illness and it alters not only the patient's life, but the life of the caregiver.

The debilitating nature of the disease makes caregiving for people with Alzheimer's a formidable task. The overwhelming nature of such care leads some primary caregivers to hire an in-home caregiver. Previous research has focused on the effects of temporary respite services on primary caregivers for Alzheimer's patients, but hiring a caregiver to provide long term respite creates a unique relationship which has been ignored. The effects of support on primary caregivers has also been a topic for investigation, but support between primary and hired caregivers has, again, been ignored. The purpose of this research is to investigate social support as it is experienced and negotiated within the primary/hired caregiver relationship.

Rationale

This research is significant for three reasons. The first point of significance is my focus on caregiving for Alzheimer's patients. Caregiving for Alzheimer's patients presents a unique communication context. Those things which are talked about and done in the Alzheimer's care context differ from those things which are talked about and done in other contexts. Research focusing on the Alzheimer's care context is significant because it has the potential to benefit

caregivers who confront the disease on a daily basis. Caring for Alzheimer's patients is unique due to the extensive assistance and supervision they require. The task is so strenuous that it has been termed a 36-hour day (Mace & Rabins, 1991).

If someone has never cared for an Alzheimer's patient or never known someone who provides such care, these 36-hour days can be hard to imagine. Alzheimer's disease is characterized by confusion and forgetfulness; what was once familiar to an Alzheimer's patient may now be foreign. For example, a person with Alzheimer's may become lost in his or her own home. As their minds deteriorate, people with Alzheimer's may also have difficulty carrying out routine tasks. Mace and Rabins (1991) describe an Alzheimer's patient named Mary and the difficulty she has with the routine task of taking a bath:

For Mary the bath became an experience of terror. The tub was a mystery. From day to day she could not remember how to manage the water: sometimes it ran away, sometimes it kept rising and rising, so that she could not stop it. The bath involved remembering so many things. It meant remembering how to undress, how to find the bathroom, how to wash. Mary's fingers had forgotten how to unzip zippers; her feet had forgotten how to step into the tub. There were so many things for an injured mind to think about that panic overwhelmed her.

What makes an Alzheimer's patient's confusion and forgetfulness so trying for a caregiver is not just the physical assistance the patient requires, but the patient's reaction to his or her own frustrations. When Alzheimer's patients become confused, they often become agitated and fearful. Their reaction to this fear can be heartbreaking for caregivers. For example, an Alzheimer's patient may wake up in the middle of the night and become agitated when he or she perceives a spouse of fifty years as a stranger in his or her bed. Unfortunately for the spouse, reminding the Alzheimer's patient that they are married and

have been married for fifty years may do little if any good. An Alzheimer's patient's reaction to fear can not only be heartbreaking, it can be physically and emotionally traumatic for a caregiver. This was the case for a women who tried to take her sister to a doctor's appointment:

Even though Miss Ramirez had told her sister over and over that today was the day to visit the doctor, her sister would not get into the car until she was dragged in, screaming, by two neighbors. All the way to the doctor's office she shouted for help and when she got there she tried to run away. (Mace & Rabins, 1991, p. 37-38)

In addition to the resistance Miss Ramirez's sister displays, Alzheimer's patients may react by hitting or kicking the person with whom they are agitated.

As the disease progresses, Alzheimer's patients require more and more care. They need assistance with bathing, dressing, toileting, eating, and walking. An Alzheimer's patient ultimately can not be left alone. For a caregiver, this is a time of fatigue. All day, every day a caregiver assists the patient physically, but also copes with the patient wandering away, hoarding food or other belongings, repeating questions or behaviors, persistently following the caregiver, and sometimes hurling insults at the caregiver (Mace & Rabins, 1991). The consuming nature of Alzheimer's care provision also leads to social isolation for the caregiver. Fatigue and isolation, combined with feelings of anger and grief, may lead to the deterioration of a caregiver's own mental and physical health. The unique nature of this caregiving and communication context warrants this investigation.

The second point of significance for this study is the introduction of the social constructionist framework to the study of caregiving and support. Thus far, research has focused on health outcomes related to a caregiver having or lacking support; however, the conceptualizations of support guiding previous

research are open to serious criticism. The social constructionist perspective overcomes these criticisms by viewing support as a discursive process. Rather than assuming what constitutes support or seeking to discover what is supportive, the social constructionist perspective asks how something becomes supportive. Support is viewed as an emergent property that arises out of interaction between people in social contexts. This research seeks to discover how support is accomplished in communication.

My specific focus on primary and hired caregivers is the third point of significance for this research. If support is a property arising out of interpersonal communication, the communication between primary and hired caregivers is an appropriate context for investigation. Previous research has focused on primary caregivers for Alzheimer's and dementia patients, but the relationship between primary and hired caregivers has been neglected. This relationship deserves attention because, while 80-90 percent of care is currently provided in home settings by spouses and adult daughters, informal support is expected to diminish in coming years (Office of Technology Assessment, 1987). This decrease will result in more reliance on formal care services. "Formal long-term care services for persons with dementia are provided in nursing homes, board and care facilities, day care centers, mental health facilities, or individuals' homes" (Office of Technology Assessment, 1987, p. 42). Despite the fact that a minority of primary caregivers currently use such services, projected increases in formal care warrant attention to the primary/hired caregiver relationship.

My focus on the relationship between hired and primary caregivers is also significant because an overwhelming number of primary caregivers testify to

the importance of formal care services. In an Office of Technology Assessment (1986) survey,

96 percent [of family caregivers surveyed] said that a paid companion who can come to the home a few hours each week to give caregivers a rest is essential, very important, or important; 94 percent said that home health aide services--that is, a person paid to provide personal care such as bathing, dressing, or feeding--are essential, very important, or important; 93 percent said that a paid companion who can come to the home and provide overnight care is essential, very important, or important; and 87 percent said that visiting nurse services--a registered nurse to provide nursing care--are essential, very important, or important. (p. 89)

While the cost of formal care prevents widespread access to these forms of aid, the positive responses of those who do utilize such services indicates its importance.

In addition to the increasing use of help services and the positive response of those using such services, my own observations and curiosity have led to my focus on the primary/hired caregiver relationship. As the granddaughter of an Alzheimer's patient, I have witnessed the relationship between a primary caregiver and several hired caregivers. My grandmother has employed individuals to provide daily care for my grandfather for many years. What has been interesting to me is that, although the hired caregivers have done essentially the same job, their relationships with my grandmother and the ensuing household atmosphere have been dramatically different. From my perspective, when there is a positive relationship between my grandmother and a hired caregiver, the household, despite the circumstances, is a pleasant place for the caregivers and for visitors like myself. When the relationship is lacking, the household is strained and uncomfortable for the caregivers as well as for others. This personal observation has led me to wonder how these

positive or negative relationships come about. The increasing use of formal care, primary caregiver response to formal care services, and my observations regarding the impact of caregiver relationships all justify examining support between primary caregivers and hired care providers.

In this chapter, I, first, summarize relevant statistics regarding Alzheimer's and describe the disease. Second, I review previous caregiving literature. Third, I examine support from sociological, psychological, and message-centered perspectives; present a selected sample of research guided by each of these perspectives; and explore the criticisms lodged against them. Fourth, I develop the theoretical framework guiding this research. This chapter ends with my research questions.

Chapter 2 explains the methodology employed to answer my research questions. I justify the methodology in light of the research questions and the theoretical framework guiding this research. In addition to methodology, I describe recruitment procedures, study participants, and I present modifications resulting from the pilot study.

Chapter 3 details my findings. This chapter is organized around themes garnered from diaries and interviews which are described in chapter 2. The themes identified in participant diaries serve to address my first research question, while themes identified in an interview transcript provide the basis for answering my second research question.

Chapter 4 addresses the implications and limitations of this research. Theoretical implications for the study of support and social constructionism are discussed. Methodological and practical implications are also addressed. The limitations presented pertain to the scope of this project and my methodology.

Alzheimer's Disease

Alzheimer's disease is a form of senile dementia which affects a significant number of people. "Dementia refers to a syndrome of progressive impairment of memory and other cognitive abilities, which can have a variety of causes" (Zarit, Orr, & Zarit, 1985, p. 9). Of these various causes, "Alzheimer's disease is...the most prevalent degenerative dementia, found in 66 percent of all cases" (Office of Technology Assessment, 1987, p. 9). Current estimates suggest that four million Americans are afflicted with this disease (Query & Arneson, 1993) and over half of nursing home residents age 65 and over are Alzheimer's patients requiring a significant amount of aid with ADL's--activities of daily living (Centers for Disease Control and Prevention, 1992). Alzheimer's disease is expected to rise in prevalence as the population ages (Office of Technology Assessment, 1987).

Alzheimer's disease hinders normal brain functioning (Zarit, Orr, & Zarit, 1985; Fasano, 1986; Riordan & Whitmore, 1990). Normally, electrochemical messages travel from nerve endings, along a projection called the axon, to a brain cell. Smaller projections called dendrites stem from the cell body. The electrochemical messages are transmitted from cell to cell via the dendrites. The dendrites of different cells do not come into contact; messages are chemically carried across a gap called the synapse. The entire structure, from nerve ending to dendrite, is called a neuron. There are approximately one hundred billion neurons in the brain and "the extraordinary range of mental abilities we all have--our memories, dreams, ideas, consciousness, and so on--are all due to...the activity of the many neurons that comprise the brain" (Riordan & Whitmore, 1990, pp. 34-35).

Two abnormalities characterize the neurons of Alzheimer's patients. The first abnormality is the appearance of tangles among protein fibers within the cell body. The second abnormality is the presence of plaques. "Plaques are masses of degenerated cell matter which occur in the spaces between cells and interfere with the messages that are sent from cell to cell" (Zarit, Orr, & Zarit, 1985, p. 12). Tangles and plaques result in the "death" of neurons where they appear. As Zarit et al. (1985) explain,

If you think of a normal cell as a tree [the axon being the trunk and the dendrites being roots], then the tangles are like a disease from within and the plaques are like a pest outside. What happens to the cell is very much like what happens to a tree being defoliated. It swells and becomes gnarled; then it shrivels to a stump. (p. 12)

The degeneration of brain cells which marks Alzheimer's disease occurs deep in the brain and results in loss of mental function. The rate of disease progression varies from patient to patient, but all reach a completely dependent state. Most Alzheimer's patients pass through three recognizable stages.

The first stage in the progression of Alzheimer's disease is memory loss (Weiner, 1987). Memory loss may begin with mild forgetfulness such as misplacing keys or forgetting an appointment. In the latter portion of this stage, memory loss becomes debilitating. Alzheimer's patients may not remember if they ate recently or may become hopelessly lost when surroundings which were once familiar are suddenly forgotten. An Alzheimer's sufferer may also struggle to carry on a conversation as words are forgotten.

The second stage of Alzheimer's disease sees increased deterioration. A person with Alzheimer's shows signs of confusion and disorientation as well as changes in personality and irritability (Weiner, 1987). "[He or she] may do unexpected things, like putting clothes on backwards or eating unsuitable foods

such as flowers” (Weiner, 1987, p. 28). At this stage a person with Alzheimer's also loses sense of time and is unable to carry out routine chores. An Alzheimer's patient may also become violent and hostile.

An Alzheimer's patient will finally enter the third stage of the disease which is total loss of ability. The patient loses all recognition of himself or herself as well as others. He or she becomes completely dependent, needing to be bathed, dressed, and fed. At this stage, an Alzheimer's sufferer “may not recognize the physical need to urinate or defecate and may need to be taken to the bathroom regularly” (Weiner, 1987, p. 28). Alzheimer's robs its victims of their mental capacities and of their very being.

Confronting the loss of being in another, especially a loved one, is difficult for those who provide care. Caregivers provide physical care, attempt to cope with behaviors on the part of the Alzheimer's patient such as hoarding and belligerence, confront their own grief as they watch their loved one deteriorate, and may become ill themselves as they are drained by the life-consuming nature of care provision. The nature of caregiving for Alzheimer's patients has led to a body of research focusing on variables which contribute to and mediate caregiver burden.

Review of Caregiving Literature

The majority of caregiving literature has focused on primary caregivers for dementia patients. This focus is appropriate because no other disorder places so much stress on those who must care for its sufferers (Zarit, Orr, & Zarit, 1985). “While the current treatments for dementia patients cannot alleviate the primary medical problems that plague the patient and family, there are procedures which can modify the stress experienced by family members” (Zarit

et al., 1985, p. 69). Caregiving research has sought to discover variables contributing to caregiver stress as well as the "procedures" which may alleviate it. This literature review is divided into three sections which represent the variables most investigated by previous researchers. These sections are: 1) caregiver and patient characteristics, 2) social support, and 3) respite services.

Caregiver and Patient Characteristics

The impact of primary caregiver and dementia patient characteristics on the caregiving experience has been one area of investigation. The characteristics receiving the most attention from researchers have been caregiver gender, the patient's level of impairment, and the patient's place of residence.

Caregiver gender. Caregiver gender is one factor which appears to influence individual reactions to caregiving. Male caregivers have reported overall higher morale than female caregivers which may be due to reduced emotional involvement with the illness; increased willingness to leave the house, although it requires leaving the patient unattended; and/or unwillingness to admit distress (Gilhooly, 1984). Harper and Lund (1990) found husbands acting as caregivers report lower levels of burden than wives and daughters functioning in the same capacity. Parks and Pilisuk (1991) found female caregivers report higher levels of stress and anxiety than men, but both groups report equal levels of depression. Barber (1993) found female caregivers rank higher than male caregivers in terms of burden and relationship strain; however, this result did not hold when caregiver age and patient age were controlled.

Patient impairment. The Alzheimer's patient's level of impairment has also been a variable for study. While researchers generally expect a caregiver's

sense of burden to increase as level of patient impairment and required care increases, this belief is not consistently supported. Gilhooly (1984) found no significant correlation between level of impairment and caregiver morale or mental health. An Alzheimer's patient's level of mental impairment also has no major effect on the primary caregiver's sense of burden (Zarit, Reever, & Bach-Peterson, 1980; Pearson-Scott, Roberto, & Hutton, 1986; Barber, 1993).

Cattanach and Tebes (1991) differentiated between the impact of a patient's cognitive and functional impairment in their study of caregivers. Cognitive impairment is defined as the degree to which an elder is unable to perform a set of intellectual tasks, while functional impairment refers to the extent to which the elder is unable to perform activities of daily life. "Caregivers of cognitively impaired elders, functionally impaired elders, and nonimpaired elders did not differ on measures of psychological distress, depressive symptomology, physical symptoms, number of hospital visits, number of physician visits, or number of days sick in bed" (Cattanach & Tebes, 1991, p. 251). Again, these findings went against the researchers' expectations.

While some research has indicated level of impairment has no direct effect on caregiver well-being, factors stemming from impairment or caregiver reaction to impairment have been found to impact the caregiver. Caring for a disruptive or abusive spouse and caring for a spouse who is withdrawn and non-responsive have been identified as impacting the marital relationship which, in turn, raises a caregiver's sense of burden (Barber, 1993). Hannappel, Calsyn, and Allen (1993) found a relationship between subjective response to the patient's level of impairment and caregiver depression. In this case it is not the objective degree of impairment the patient displays, but the caregiver's

degree of upset due to the impairment which mediates depression.

Parris-Stephens, Kinney, and Ogrocki (1991) differentiated among types of impairment, and compared the impact these stressors had on caregivers whose relatives lived in their home or in a nursing home. "Stressors stemming from care recipients' asocial or problematic behaviors were more potent predictors of well-being among in-home caregivers, and stressors stemming from care recipients' memory loss and confusion were the best predictors among the nursing home caregivers" (Parris-Stephens et al., 1991, p. 222). Despite the link between patient impairment and caregiver well-being, impairment, again, did not appear to be a direct cause for caregiver stress. Rather, "stress due to the care recipient's behavior problems was most strongly associated with disruptions in caregivers' interpersonal relations" (Parris-Stephens et al., 1991, p. 222). Thus a patient characteristic--nature of impairment--leads to change in the amount or nature of the caregiver's social contact. This change, in turn, affects well-being.

Harper and Lund (1990) discovered differences between male and female caregivers in terms of the type of impairment which functions to directly increase their sense of burden. "Wives caring for their husbands in the home are particularly strained by dementia symptoms within the affect category, symptoms such as aggression and changes in personality" (Harper & Lund, 1990, p. 250). Husbands serving as in-home caregivers for their wives did not report the same category of symptoms as being troublesome. Instead, the patient's deterioration in orientation was linked to their sense of burden (Harper & Lund, 1990). This finding was altered under certain circumstances, however. When children were living in the home, male caregivers did report affect

symptoms as contributing to a sense of burden (Harper & Lund, 1990). This finding is likely a result of concern for the child's safety or recognition that a small child may be unable to cope with or understand the situation.

Patient's place of residence. While most caregiving takes place in the home, many dementia patients are institutionalized. The impact of the dementia patient living with the primary caregiver or in a nursing facility is another patient characteristic which has received attention in the caregiving literature. Because institutionalization is generally a final resort when the burden of caregiving becomes too great, caregivers for dementia patients living in a nursing home are expected to report a lesser sense of burden and rank higher than in-home caregivers in terms of well-being. As with research on the impact of patient impairment, the results of this research have not been as clear as expected.

Gilhooly (1984) found co-resident caregivers had slightly lower morale and poorer mental health than primary caregivers not living with the dementia patient, but co-resident caregivers were also older, caring for more impaired individuals, and less likely to be employed elsewhere. Analysis was not conducted to determine the effects of these additional variables. Other investigations offer contradictory results. While some have failed to reveal any difference between in-home and nursing home caregivers in terms of subjective burden, objective burden, relationship strain, and depressive symptoms (Parris-Stephens et al., 1991; Barber, 1993), others found burden scores to be consistently higher among caregivers who lived with the dementia patient (Harper & Lund, 1990).

Parris-Stephens et al. (1991) divided "hassles" related to caring for a

dementia patient into four domains: 1) assistance with activities of daily living, 2) care recipients' behavior, 3) care recipients' cognitive functioning, and 4) lack of caregiving support from family members and friends. Both in home and nursing home caregivers identified the dementia patient's decline in cognitive functioning as most stressful and, surprisingly, nursing home caregivers reported higher levels of stress in all four domains (Parris-Stephens et al., 1991). When the number of problems occurring within each domain were not controlled, in-home caregivers did report more stress. Two possible explanations for these results are offered. First, in-home caregivers may become used to these hassles, and therefore find them less stressful than nursing home caregivers. A second explanation is that nursing home caregivers are less able to cope with these hassles. An inability to cope with hassles may explain why the dementia patient was originally placed in a nursing facility.

Caregiver sex, level of patient impairment, and patient's place of residence have received the majority of attention in terms of the impact of caregiver and patient characteristics on the caregiving experience. Despite this emphasis, other caregiver characteristics are recognized as having potential impact and have received some attention. Blood relation to the dementia patient has correlated with poorer mental health (Gilhooly, 1984; Hannappel et al., 1993). "Older spouses experience more depression than younger non-spouses" (Hannappel et al., 1993, p. 47). Caregivers with other employment tend to have higher morale and better mental health (Gilhooly, 1984; Gonyea, 1990; Lechner, 1993). White caregivers report more negative life changes than black or Hispanic caregivers (Lechner, 1993). With the exception of gender, it is

difficult to draw any conclusions regarding the impact of patient or caregiver characteristics on the caregiving experience. Those variables which have received considerable attention have not had consistent effects, while other variables simply have not received enough attention for a conclusion to be drawn.

Social Support and Caregiving

The effects of social support as well as lack of support have received a great deal of attention in the caregiving literature. The impact of social support on caregivers is unclear due to inconsistent definitions and means of measurement (Kuhlman, Skodol-Wilson, Hutchinson, & Wallhagen, 1991). Despite lack of agreement regarding the construct's definition, support is generally expected to correlate with caregiver well-being and a reduced sense of burden. While some research supports this assumption, other findings demonstrate mixed results.

Pagel, Erdly, and Becker (1987) examined the relationship between helpful and upsetting aspects of social networks and caregiver depression. Pagel et al. (1987) hypothesized that helpful and upsetting aspects of social networks would independently predict depression of caregivers for Alzheimer's patients. While network helpfulness and upset did not appear to predict depression independently, a relationship among the variables was established. "Care givers who rated their networks as helpful had depression scores that increased steeply with increasing upset; however, care givers who rated their networks as not very helpful had depression scores that were relatively unaffected by increasing upset" (Pagel et al., 1987, pp. 797-798). Apparently caregivers who are used to or expect their network to provide help are

negatively affected when the network violates the norm or expectation and is instead a source of upset. Conversely, caregivers who do not find their network particularly helpful are not as likely to suffer negatively when they incur upset from network members. Therefore, the dimension of support which emerged as critical in this study was an individual's expectations regarding a social network's function.

Baillie, Norbeck, and Barnes (1988) found that caregivers lacking an adequate degree of social support were at greater risk of psychological distress, but social support did not have a buffering effect on the relationship between perceived stress and psychological distress. In this study, social support referred to satisfaction with emotional support, acceptance in the caregiver role by family members, contact with others, and tangible help. Psychological distress referred to the presence of any or all of six mood states: anxiety, depression, anger, vigor, fatigue, and confusion. "[Perceived stress] included stress arising from the elder person's behavior, communication ability, emotional or mental state, or relationship with the caregiver; time demands in caregiving; physical or task aspects of caregiving; effects on other family members; and financial considerations" (Baillie et al., 1988, p. 219). Caregivers included in this study provided care for individuals with physical and mental afflictions, but those caring for Alzheimer's or dementia patients were particularly vulnerable. Those caring for mentally impaired individuals, who have been providing care for an extended time, and who have low social support have the highest risk of psychological distress or depression (Baillie et al., 1988).

Hartman-Ellis, Miller, and Given (1989) found a positive relationship

between perceived social support and caregiver well-being. Two dimensions of social support, embeddedness in a network and the perception that the network is providing needed resources, were considered. Hartman-Ellis et al. (1989) report "social support can reduce the sense of family abandonment and also improve perceptions of health. Embeddedness in communication networks...works to increase perceptions of social support and directly influences the caregiver's sense of well-being" (p. 223). While a social network is needed, the perception of available support is at the forefront of importance in terms of impact on the caregiver.

Clipp and George (1990) report similar findings in that "caregivers with high stable support report the highest self-rated health, the lowest use of psychotropic drugs, and the lowest number of sick days" (p. 109). In addition, caregivers with the lowest number of stress symptoms and the highest reports of life satisfaction are those who perceive themselves as having stable, high support (Clipp & George, 1990). Objective measures of support--instrumental assistance--were also considered in this study. Patterns of instrumental support bore no relationship to the physical health of caregivers, but mental health was affected. Caregivers receiving high, stable levels of instrumental support reported greater life satisfaction than those not receiving adequate levels of support (Clipp & George, 1990).

Vitaliano, Russo, Young, Teri, and Maiuro (1991) tested a model of caregiver distress where social resources and vulnerability interact to determine level of burden. Variables in this model were defined as follows: social resources included quantity of and satisfaction with supports; vulnerability referred to caregiver gender, age, physical health, and level of

anger or anxiety; and burden was defined as distress in response to caregiver experiences. The proposed relationship among variables was supported. "Caregivers with high scores on the Social Resources factor...were less burdened than caregivers with low scores on these variables" (Vitaliano et al., 1991, p. 399). "In addition, vulnerable caregivers without resources were at even greater risk for future burden than were vulnerable caregivers with resources" (Vitaliano et al., 1991, p. 399). This research demonstrated the independent effects of vulnerability and support, but also demonstrated how they affect one another. Vitaliano et al. (1991) explain that high vulnerability factors such as anger or anxiety may undermine a caregiver's ability to access social resources, thus furthering his or her sense of burden.

As previously noted, the dementia patient's impairment does not appear to be directly linked to caregiver stress; rather, disrupted social contact or other factors stemming from the condition impacts caregiver well-being. Lechner (1993) found "support from family and friends significantly reduced the [caregiver's] work and family role conflicts and unwanted changes in their social, personal, and financial lives" (p. 465). In this study, support was defined as "the total level of assistance (informational, emotional, and concrete help) received from an individual, group, or agency that helps the individual deal with the stressful life event" (Lechner, 1993, pp. 461-462). Because this definition included formal and informal support systems, both were examined and both positively impacted the caregivers' perceived level of stress.

Thompson, Futterman, Gallagher-Thompson, Rose, and Lovett (1993) focused on individuals caring for frail family members, not Alzheimer's patients. They investigated the relationship between the number of people who were

available to provide six types of support--intimate interaction and confiding, positive feedback, advice, material aid, physical assistance, and social participation--and caregivers' perceptions of burden. Only one type of support, lack of social participation, emerged as a mediator of caregiver burden. Individuals not having social interactions free of talk about caregiving report more social life restrictions as well as more tension and conflict with the frail elder. "They also report a marked sense that caregiving was leading to emotional strain, [and] the feeling that the task of caregiving had become arduous and upsetting" (Thompson et al., 1993, p. 252).

Support groups have been linked to lower levels of objective and subjective burden as well as higher morale. Gonyea (1990) differentiated four dimensions of support group participation: 1) membership status, 2) membership length, 3) frequency of meeting attendance in the past year, and 4) linkages with other members outside of group meetings. Objective burden was defined as the extent of changes the family member experiences in his or her life and household as a result of caregiving while subjective burden indicated the caregiver's emotional reactions to the caregiving experience. "Morale... tapp[ed] three factors: agitation; attitudes towards one's own aging; and lonely/dissatisfaction" (Gonyea, 1990, p. 24). All four aspects of the support group variable correlated with a lower sense of objective burden and all but the fourth dimension, linkages with other members outside of group activities, were related to lower perceptions of subjective burden. Support group membership and contact with members outside of the group meetings were also associated with higher reported morale.

Caregivers not perceiving themselves as receiving an adequate amount of

support from family and friends report a greater sense of burden, rank low on indices of mental health, and perceive their physical health as poor (Pearson-Scott, Roberto, and Hutton, 1986; Clipp & George, 1990). Strangely, in at least one study caregivers who reported receiving more than enough support rated similarly in terms of burden with the group receiving inadequate support (Pearson-Scott et al., 1986). According to Pearson-Scott et al. (1986) these results could reflect the fact that individuals experiencing more stress receive more support. Another explanation might be the inappropriate nature of the 'support' offered by family and friends or an inadequate conceptualization of the support variable.

Some caregiving research supports the assumption that lack of support correlates with caregiver distress while adequate support correlates with caregiver well-being; however, there are anomalies. In some cases researchers identify several forms of support and only one type correlates with caregiver well-being. In other cases no relationship is demonstrated between support and caregiver mental or physical health. In almost every case, researchers define and operationalize support differently, thus it is difficult to compare their findings. While much research points toward the benefits of support and the harms of inadequate support, inconsistent definitions and findings indicate these benefits or harms are far from certain.

Respite Services

Some caregivers for Alzheimer's patients utilize respite services. Respite can be defined as "a service or group of services that provides caregivers temporary periods of relief and rest away from the patient" (Lawton, Brody, Saperstein, 1989, p. 8). An Alzheimer's patient may be transported out of the

home for respite, as is the case for adult day care, or respite workers may come to the patient's home. A distinction must also be made between long-term respite (for example, the placement of the patient in an institutional facility for two weeks) and short-term respite (for example, a hired caregiver coming to a patient's home for short periods of time). While research indicates respite is viewed positively by caregivers, its relationship to other variables is not clear. Respite services do not appear to improve the psychological well-being of all caregivers. In the majority of studies, caregivers' mental health does improve during respite, but the improvement does not last once caregiving responsibilities are resumed.

Quayhagen and Quayhagen (1988) found respite services affected the well-being of husband, wife, and daughter caregivers differently. "Well-being was assessed in three ways: life satisfaction, perceived physical health, and emotional health (or happiness)" (Quayhagen & Quayhagen, 1988, p. 392). While respite was positively related to the well-being of daughters caring for an impaired parent, "respite had little if any association for wives, and a negative association for the husband caregivers" (Quayhagen & Quayhagen, 1988, p. 395). These results indicate respite does not affect caregivers in a universal manner. Other variables which may moderate the relationship between respite and well-being are feelings of guilt associated with relinquishing care to another individual and level of caregiver burden.

Lundervold and Lewin (1987) conducted a case study of four caregivers for Alzheimer's patients. Three of these caregivers received respite and one did not. Respite was operationalized as four to six hours of in-home patient care by a senior services agency once per week. This service did not result in

significant changes in caregiver reports of burden, depression, or stress (Lundervold & Lewin, 1987). Perceived health, as measured by a 10 point scale where 0 equaled the worst health rating and 9 the best health rating, was affected however. "In the year preceding respite care, mean caregiver perceived health rating was 4. Following the receipt of in-home respite care, mean perceived health ratings increased to 6" (Lundervold & Lewin, 1987, p. 210). The mean number of visits these caregivers made to their physicians also decreased after receiving respite care (Lundervold & Lewin, 1987).

Conlin, Caranasos, and Davidson (1992) also compared primary caregivers utilizing respite services to caregivers not receiving such services. Respite was provided two days a week for ten weeks for the test group while the control group (caregivers not currently receiving respite) were to begin utilizing such services after the study. "During the ten-week study period, mean scores on the Relative's Stress Scale of study group caregivers decreased from 42.1 to 38.6, while scores of control group caregivers increased from 33.4 to 36.2" (Conlin et al., 1992, p. 1097). The Relative's Stress Scale contains three subscales: personal distress, life upset, and negative feelings. The difference between the two caregiver groups appears to be primarily attributable to the personal distress dimension as it was the only dimension to reach statistical significance. Differences in the negative feelings subscale approached statistical significance, but no study and control group differences were found in the life upset subscale.

Lawton, Brody, and Saperstein (1989) found no relationship between respite services and improved caregiver well-being. In this case "well-being was measured by 5 composite scores of caregiving attitudes, an index of

caregiver health, and 3 measures of psychological well-being" (Lawton et al., 1989, p. 11). Although respite had no significant effect on caregiver well-being, "the evaluation given to respite service by its recipients was a resounding endorsement" (Lawton et al., 1989, p. 15). Gilhooly (1984) had a similar finding in that day hospital care did not correlate with caregiver well-being, but was frequently mentioned as a source of help. It appears caregivers may value the time respite frees for them, although well-being is not moderated. The results of these studies may also be linked to the way in which well-being is operationalized as Gilhooly (1984) found home help and visiting nurse services significantly correlated with high caregiver morale and mental health.

Graham (1989) found no reported reduction of burden by caregivers who placed an Alzheimer's patient in adult day care. Caregivers completed a burden instrument seven days prior to the use of day care. The instrument was then readministered in the fourth week of day respite care. Of those caregivers included in the study "postplacement burden scores increased for eight, decreased for six, and did not change for one" (Graham, 1989, p. 28). Several possible explanations for these unexpected findings were offered. Some caregivers acknowledged feeling guilty about placing the Alzheimer's patient in day care and, for some, the use of respite brought about the realization that institutionalization of the patient may be near. Some caregivers also indicated they were not able to utilize day care as often as they wished due to the center's hours of operation, financial considerations, and difficulties coordinating transportation. In addition, some Alzheimer's patients did not adjust well to day care and this difficulty may have precluded a reduction in caregiver strain.

Larkin and Hopcroft (1993) found primary caregivers did benefit from a short term institutional respite program, but these benefits were short-lived. This program involved placing the Alzheimer's patient in a hospital, nursing home, or residential care facility for two weeks. Twenty-two caregivers participating in this respite program were interviewed three days prior to respite admission, three days prior to respite discharge, and fourteen days after respite discharge. "Caregiver stress scores on the symptom dimensions of hostility, anxiety, depression, and obsessive-compulsiveness were significantly reduced [at the time of the second interview]" (Larkin & Hopcroft, 1993, p. 134). Caregivers cited improvement in sleep patterns and the opportunity to take a vacation or engage in social activities as the benefits of respite. Despite these findings, Larkin and Hopcroft explain that

unfortunately for the caregivers, symptom relief was like respite itself: a rather short-lived phenomenon. Thus as caregivers resumed their daily caregiving tasks, the relief of respite was not sustained. Although overall caregiver stress was lower two weeks postrespite...as compared to the two weeks before respite..., the score was not statistically significant. (p. 136)

Adler, Ott, Jelinski, Mortimer, & Christensen (1993) also found the relief of institutional respite to be short-lived. Caregivers experienced a decrease in burden and depression between two weeks prior to respite and the time of the dementia patient's release from respite care (Adler et al., 1993). The positive effects of respite were not lasting however. "While transient improvement in burden and depression for caregivers was noted, by two weeks post-respite, caregiver depression scores returned to pre-respite values" (Adler et al., 1993, p. 71). Adler et al. argue that if institutional respite is intended to provide a break from caregiving or offer temporary stress relief, its goals are being met.

Beyond institutional respite, primary caregivers report finding informal

respite from family and friends helpful. In one study, having persons stay with the Alzheimer's patient so the caregiver could run errands, take a trip, rest, or participate in social activities was the form of caregiving assistance most appreciated by primary caregivers (Scott et al., 1986). Query and Arneson (1994) found neighbors and adult children were frequently mentioned as providers of caregiving assistance. Children were recognized as able to replace the primary caregiver, thus offering relief from continuous care, while neighbors were recognized as offering support--such as taking a patient to day care--that allows the primary caregiver to attend to other responsibilities of daily life (Query and Arneson, 1994).

The results of the respite literature are mixed. Caregivers appear to value informal and formal respite, but respite's measurable effects are questionable. Some studies correlate respite with a reduction in caregiver stress and an increase in caregiver morale and mental health. Other studies indicate no relationship between respite and caregiver well-being. Still, other studies indicate there are benefits garnered from respite, but these benefits are short-lived or are only attained by some caregivers. The discrepancies in existing findings make it difficult to draw any conclusions regarding the impact of respite on caregivers for Alzheimer's patients.

Much research has focused on caregivers for Alzheimer's patients. This literature review indicates that female caregivers appear to experience more stress and burden than male caregivers, but findings regarding social support and respite have not been so clear. The primary goal of my research is to contribute to the caregiving support literature; however, it is also a contribution to the respite literature because employing a hired caregiver is a form of respite

for a primary caregiver. In the next section, I explore the theoretical perspectives which have guided previous support research and the criticisms lodged against them. This will illuminate the reasons for inconsistencies in previous caregiving support research. Such an exploration will set the stage for the social constructionist framework which guides my research because it overcomes previous criticisms and accounts for prior research findings.

Social Support

As a construct, social support has been viewed from sociological, psychological, and message-centered perspectives. Each perspective evolved from criticism lodged against the perspective which preceded it. The psychological perspective evolved out of criticism of the sociological perspective and the message-centered perspective evolved out of criticism of the psychological perspective. In this section, I will explore the assumptions of the sociological, psychological, and message-centered perspectives; offer a selected review of literature guided by each; and present criticisms of each perspective.

Sociological Perspective of Social Support

The sociological perspective equates social support with an individual's social network. For example, Sarason, Levine, Basham, & Sarason (1983) define social support as "the existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us" (p. 127). Network definitions consider the presence of other people in our lives supportive. Research guided by the social network or sociological perspective has focused "on how the size, density, multiplexity, and other features of an individual's social network correlated with varied indices of health and well

being" (Burleson, Albrecht, Goldsmith, & Sarason, 1994, p. xv).

Selected literature review. Some research guided by the sociological perspective has sought to understand the relationship between social networks and psychiatric conditions. Tolsdorf (1976) compared the social networks of medical patients to the networks of psychiatric patients identified as schizophrenic. The groups were found to hold different attitudes toward social networks. As a whole, the medical group held a positive network orientation. This orientation is described as "a set of beliefs or expectations held by the subject that it is safe, advisable, and in some cases necessary to confide in the social network and draw on it for advice, support, and feedback in a stress situation" (Tolsdorf, 1976, p. 413). Conversely, the psychiatric group held a negative network orientation. This orientation is defined as "a set of expectations or beliefs that it is inadvisable, impossible, useless, or potentially dangerous to draw on network resources" (Tolsdorf, 1976, p. 413).

These divergent attitudes toward social networks left the medical group better able to cope with stressful life events than the psychiatric group. Tolsdorf (1976) explains the causal relationship between network orientation and psychological functioning:

The psychiatric subjects experienced some significant life stress with which they attempted to cope using individual mobilization. When this strategy failed, they chose not to mobilize their networks, relying instead on their own resources, which had already been shown to be inadequate. This resulted in more failure, higher anxiety, a drop in performance and self-esteem, followed eventually by a psychotic episode. (p. 415)

Contrary to the psychiatric group, medical group members mobilized their networks when individual resources failed and, in every case, the stressful situation was kept within manageable limits (Tolsdorf, 1976).

Hammer, Makiesky-Barrow, and Gutwirth (1978) also address the relationship between social networks and schizophrenia. Hammer et al. (1978) explain that "the risk of schizophrenia increases as a function of genetic relationships to schizophrenic kin...; but it is also clear that both conceptually and quantitatively, this association is insufficient, by itself, to account for the occurrence of schizophrenia" (p. 522). While an individual may have a genetic predisposition to the development of schizophrenia, other social variables intervene; therefore, the positive or negative nature of these variables becomes significant.

Hammer et al. (1978) define schizophrenia as a "manifestation of a broader phenomenon characterized by reduced cultural predictability" (p. 537). Individuals learn cultural expectations via feedback from social networks. "The hypothesized social background of schizophrenia is...that the networks of...schizophrenic individuals typically fail to provide adequate feedback for the development or maintenance of behavior modes that are congruent with the behavior and expectations of the social group" (Hammer et al., 1978, p. 538). In Tolsdorf's (1976) research, psychiatric patients essentially rendered themselves 'networkless' because they held a negative network orientation. In Hammer et al.'s (1978) research, individual networks were not serving a vital purpose. In both cases, mental health outcomes are linked to the social support functions of networks.

The effects of a social network on individuals coping with physical ailments has also been a focus of research. Droge, Arntson, and Norton (1986) demonstrate the positive effects of membership in epilepsy self-help groups. Self-help groups are viewed as planned social networks which serve as

substitutes for deficient natural support systems (Droge et al., 1986). Epileptics feel stigmatized due to societal misunderstanding and prejudice. "The higher the perceived level of stigmatization, the higher is the perceived level of external fate control and professional control and the lower is the perceived level of internal control" (Droge et al., 1986, p. 156). Droge et al. (1986) argue "social support is an important alternative to the psychological approach in the attempted solution of nonmedical problems of people with epilepsy" (p. 143). Self-help groups utilize the resources of their members through the sharing of personal experiences. Rather than remaining patients or clients, epilepsy self-help groups allow members to be the experts (Droge et al., 1986). The effect of the social network in this case is the return of a sense of personal control.

Social network research has also established a relationship between social ties and overall health status. Hibbard (1985) found having more social ties, being more trustful of others, and perceiving more control were all associated with better health. Health status was operationally defined as participants' ratings of their own health status on a self-assessment instrument and the mean annual rate of doctor visits for chronic conditions. A significant relationship between social networks and health was established, but the size of the network necessary to achieve this relationship was moderated by perceived locus of control. For individuals who perceive control externally, more social ties are related to better health, but under conditions of internal perceived control, having more social ties appears to be of little health benefit. Individuals with an external locus of control are less able to access resources of network members, so larger networks enable them to compensate for their less efficient mobilization. Individuals with an internal locus of control are better

able to access resources from their network members and, therefore, can achieve health benefits with fewer ties.

Gallo (1982) established a relationship between specific network variables and elderly health. Variables included in the study were: 1) size--the number of contact points in the network; 2) frequency--the number of interactions between the respondent and each network member over a given period of time; 3) density--the extent to which links among network members exist; 4) distance--geographical distance between the respondent and a network member; 5) content--whether the contact is a family member, friend, neighbor, et cetera; 6) intensity--perceived closeness of the relationship; 7) homogeneity--the similarity of network members in terms of demographics; 8) duration--how long the relationship has existed; and 9) directedness--who initiates contact. Increased network size, homogeneity, an equal amount of directedness between respondent and network members, density, and increased distance each independently correlated with better health. When "all of the network dimensions were combined in an aggregate score...results were more dramatic than for dimensions taken alone...[as] a strong relationship was shown between the combined network variables and health status" (Gallo, 1982, p. 72).

Berkman and Syme (1979) established a relationship between social networks and mortality. Their study was a follow up to a 1965 population survey in Alameda County, California. Mortality records for original respondents were obtained and the remaining respondents were surveyed. "Four sources of social contact [were] examined: 1) marriage; 2) contacts with close friends and relatives; 3) church membership; and 4) informal and formal group associations" (Berkman & Syme, 1979, p. 188). "With few exceptions,

respondents with each type of social tie had lower mortality rates than respondents lacking such connections" (Berkman & Syme, 1979, p. 188). In an effort to consider alternative explanations for higher mortality rates among those lacking social ties, other independent variables were evaluated.

Berkman and Syme (1979) found

the association between social ties and mortality was...independent of self-reported physical health status at the time of the 1965 survey, year of death, socioeconomic status, and health practices such as smoking, alcoholic beverage consumption, obesity, physical activity, and utilization of preventive health services. (p. 186)

Beyond specific mental and physical conditions, research guided by the sociological approach to support has focused on the relationship between social networks and psychological well-being. Phillips (1981) examined the impact of specific network variables on the reported happiness of men and women. "By regressing an index of avowed happiness on eight network and social participation variables and on a measure of stressful life events...an estimate of their relative effects [was obtained]" (Phillips, 1981, p. 121).

Network size was found to have the greatest impact on the avowed happiness of men while number of social contexts--marriage, live-in relationship, activity in a workplace, school attendance, participation in a church or other organizational activity--had the greatest impact on the avowed happiness of women (Phillips, 1981). When background variables--race, age, and income--were introduced, network size retained its importance for the self-avowed happiness of men, but number of social contexts dropped to fourth place for women. Number of social contexts fell behind: 1) range of socializing--the number of activities in which the respondent had participated over the previous 3 months including having a guest for lunch or dinner, going to someone else's

house for lunch or dinner, someone visiting the respondent, going out with someone, and meeting someone outside one's home; 2) kin majority--having over 50 percent kin in one's network; and 3) income.

Heller and Mansbach (1984) also adopted a sociological perspective when they sought to discover the effects of social support on the life-satisfaction of elderly women. Three aspects of social network were specified in this study: 1) network structure, which refers to size and density; 2) network functions, which refers to the network member providing companionship support, emotional support, and/or problem solving support; and 3) network quality, which is defined as the level of intimacy shared with network members (Heller & Mansbach, 1984). Network size was found to be related to life satisfaction, but density was not. "For elderly women who are likely to lose network members with age, the amount and frequency of their contacts are of greater importance than the density of existing links among network members" (Heller & Mansbach, 1984, p. 108). Participants in this study also distinguished between the type of support sought from different individuals. While relatives were sought for companionship, they were not turned to for emotional support or problem solving. Neighbors were frequently cited as filling the problem-solving need.

Whether the goal is to assess the link between social support and specific psychiatric conditions, social support and physical health, or social support and perceived well-being, the sociological approach to social support has a theoretical commonality. The sociological approach equates support with the existence of an individual's social network. Specifically, researchers seek to correlate network variables, such as size, density, or frequency of contact, with

health indices. Researchers approaching support from this theoretical perspective concern themselves with outcomes related to the adequacy of these network variables.

Critiquing the sociological perspective. Some sociological research has failed to confirm the correlation between network variables and mental health or life satisfaction (Conner, Powers, & Bultena, 1979; Cohler & Lieberman, 1980). These inconsistencies helped set the stage for criticism of the sociological perspective. Criticism has centered around the exclusive focus on social networks. Critics argue it is not the mere presence of other individuals, but satisfaction with support they provide that promotes well-being. Not all social ties are health promoting; therefore, the quality and meaning of social relationships need to be considered (Burleson et al., 1994).

Without subjective analysis, researchers are unable to explain how people with a social network can suffer from a lack of social support. Gilhooly (1984) provides an example of a caregiver who must endure visits from family members with whom there is conflict over the placement of a dementia patient in a nursing home. The content of communication in this case is not supportive and does not lend itself to the caregiver's well-being. Despite the existence of a social network, the caregiver suffers from a lack of support. According to Burleson et al. (1994), recognition of the need to examine subjective perceptions of the quality of support was the impetus for the psychological perspective of social support.

Psychological Perspective of Social Support

The psychological perspective of social support shifts importance off objective social ties and on to the subjective perceptions of individuals. If

support is perceived, there must be a social network, but the existence of these social ties is no longer the focus of study. Shumaker and Brownell (1984) define social support as "an exchange of resources between two individuals which is perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (p. 13). Most psychological, or cognitive, definitions focus solely on the receiver's perception, but Shumaker and Brownell expand their definition to include the provider. This is an example of a psychological definition because support is located in the mind of an individual.

Intention and perception are the keys to psychological definitions of support. Intent is the psychological antecedent which is supposed to lead to behaviors that are classified as support. For example, an individual might tell a friend that he or she did not receive a promotion at work. The friend may respond by saying, "You'll get another chance." After the friend verbalizes this message, the upset individual may think, "Who cares about another chance? I'm disappointed now." For the friend, the message is perceived as supportive. For the upset individual, the message is perceived as unsupportive. From the psychological perspective, support is a mental representation. This is why no distinction is made between an interaction being supportive or not supportive based on the congruence or incongruence of intent and perception. An exchange is supportive so long as one involved individual perceives it as such; support is determined by the sender, the receiver, or both.

Those subscribing to a psychological perspective may conceive of support as an enduring trait or as a temporary state of mind. This means support "may be regarded as a relatively stable personal feature of the recipient...[or] social support may denote a more transient individual state of mind" (Veiel &

Baumann, 1992, p. 4). The trait perspective has become the focus of psychological research and is associated with health outcomes. Researchers approaching support from this perspective are not concerned with the perception of specific exchanges. What is important is where most of the exchanges fall (Shumaker & Brownell, 1984). An individual's sense of support is a result of where the majority of exchanges are perceived on the helpful-neutral-harmful continuum. If the majority of exchanges are perceived as helpful, support is perceived and positive health outcomes are expected. The opposite is expected if the majority of exchanges are perceived as harmful.

Selected literature review. Psychological support research has focused primarily on the perception of support, not on intent. One focus of research guided by the psychological perspective has been the relationship between perceived support and physical ailments. Grissett and Norvell (1992) investigated the relationship between perceived support and bulimia. "Bulimic women reported significantly less perceived social support from both friends and family...and more negative interactions" (Grissett & Norvell, 1992, p. 295). In light of previous research indicating support's mediation of stressful life events, the authors hypothesized a relationship in which perceived lack of support is a risk factor for bulimia. Specifically, they hypothesized that

the bulimic woman's perceived lack of support may make her particularly vulnerable to certain types of stress and contribute to the development and maintenance of bulimic symptoms. For example, bulimic individuals may binge and purge in an attempt to avoid feelings of isolation...rather than utilizing their support system to cope with these and other stressors. (Grissett & Norvell, 1992, p. 296)

Hancher-Kvam and Lyons (1991) explored how the perception of support correlated with the health status of individuals with diabetes. Participants in this

study indicated they perceived support from family or friends, but not necessarily from both. There was a stronger correlation between well-being and perceived support from friends than between perceived familial support and well-being. Perceived familial support was higher for noninsulin-dependent participants than for those who are insulin-dependent and noninsulin-dependent individuals scored higher on a measure of well-being than did the insulin-dependent individuals.

Gender differences in the perception of support and well-being were also examined in the Hancher-Kvam and Lyons (1991) research. Men perceived greater familial support, while women reported more support from friends, although men reported being healthier than the women. This correlation is somewhat unexpected in light of the strong correlation between perceived support from friends and overall health. Men did report use of problem-focused coping strategies, while women reported employing wish fulfillment and detachment strategies. The difference in overall health between men and women may be due to their utilization of these strategies.

Helgeson (1993) also investigated the effects of perceived support, but focused on its impact, versus the impact of received support, on patient adjustment three months after a cardiac event. Received support refers to specific supportive acts which have occurred while perceived support is the extent to which individuals believe support is available to them. Perceived support emerged as significantly more important to adjustment than received support. "The receipt of informational support prior to illness was associated with an increase in distress following illness, whereas the perceived availability of informational support following illness was associated with a decrease in

distress" (Helgeson, 1993, p. 834). Perceived versus received emotional support functioned much the same way. Perceived availability of emotional support predicted increased life satisfaction, whereas the receipt of emotional support predicted decreased satisfaction. Similarly, the perceived availability of instrumental support predicted reduced distress while lack of such a perception led to increased distress.

Research focusing on the mediating effect of perceived support has not focused solely on individuals with specific medical conditions. Gore (1978) investigated the mediating effects of perceived support on the physical and mental health of individuals who were subject to involuntary job loss. Participants in this study were two groups of men who were employed by companies which shut down. One company was located in an urban area, while the other was located in a rural area. Gore (1978) found

the rural terminees and controls had a significantly higher mean value on the support measure than the urban respondents. This was partly due to reports of higher kinship support and affiliation, which reflected the ethnic cohesion of the largely Polish-American sample. (p. 161)

Individuals perceiving less social support while unemployed had higher cholesterol ratings, reported more illness symptoms, and reported a higher sense of economic deprivation. Gore (1978) argues that rather than perceived support mediating life stress, lack of perceived support exacerbates life stress. "Unemployment...means the inability to make instrumental accomplishments. Thus it might be interpreted that this loss, in the absence of self-worth maintained through supportive relationships, contributes to negative health responses" (Gore, 1978, p. 164).

This selected literature review illustrates the focus of psychologically-based

social support research. Research investigating the impact of perceived support on individuals with various pathologies and the impact of perceived support on individuals in a situation conducive to life stress places support in the mind of an individual. An individual's general sense of being supported serves as the independent variable in these investigations. These studies are guided by a trait perspective in that how this general sense of support, or lack of support, came to be is not critical; what is critical is the general state of mind. This perspective enhances the social network model because a network must exist for support to be perceived, but the previously neglected dimension of subjective perception is taken into account.

Critiquing the psychological perspective. Criticism of the psychological perspective focuses on how a general sense of support, or lack of support, arises. Recall that messages must be placed on the helpful-neutral-harmful continuum. Where the majority of messages fall on this continuum determines an individual's general state of mind regarding support. How certain messages come to be identified as helpful or supportive is the focus of criticism for this perspective, as well as a point of criticism for cognitive studies in general.

Cognitions were initially thought to be formed through reinforcement accounts. Reinforcement accounts essentially function as hypothesis testing (Gergen, 1989). For example, the offering of solutions to a problem may be perceived as supportive. Future experiences where solutions to a problem are offered are weighed against that perception. The initial perception of support may be reinforced or challenged based on ensuing experiences. A hypothesis regarding what is supportive is formed and that hypothesis is then tested.

A second model explaining the formation of cognitions is cognitive mapping.

Cognitive mapping presumes “that unconstrained observation of the external world will enable the individual to develop conceptual templates, cognitive representations or other mental systems that capture important features of the real world” (Gergen, 1989, p. 467). For example, exposure over time to objects or actions in the real world will lead to a cognitive map or general category called “support.” Actions which belong in this category can then be recognized. Cognitive mapping assumes an order to the real world, an external reality, which can be recognized and represented mentally.

Reinforcement account and cognitive map explanations are subject to criticism because both models fail to explain “how the individual would come to recognize the features, objects or configurations of events of the world at the outset” (Gergen, 1989, p. 468). Neither approach can account for the origin of a hypothesis or category regarding support. “Reinforcement accounts fail to offer a satisfactory explanation of conceptual development, because reinforcement cannot function without a conceptual structure already intact” (Gergen, 1989, p. 467). Similarly, a cognitive map of support can not be formed without some fore-structure of understanding regarding the nature of support.

This criticism can be applied to the previous example of support where an individual is upset because he or she did not receive a promotion. Recall that upon hearing that the individual was upset, his or her friend said, “You’ll get another chance.” According to the reinforcement account model, the upset individual would have previous experiences that led to a hypothesis that says, “When someone avoids my immediate upset and looks to the future, it is not supportive.” When the friend’s message is not perceived as supportive, this hypothesis is reinforced. What this model is unable to explain is how this

hypothesis originated. The same is true of cognitive mapping. The upset individual may have a cognitive map of supportive behaviors and a cognitive map of unsupportive behaviors. Over time, experiences have been compiled and these categories formed. "Focusing on the future rather than on the immediate upset" may be found in the unsupportive category and the friend's response is, therefore, identified as such. Again, the question the cognitive map theory can not address is how the supportive and unsupportive categories originated.

The cognitive perspective moves beyond equating support with objective social ties and considers the subjective perception of the individual. This evolution enhances the social network approach, but proves incomplete. Although researchers guided by this perspective focus on a general state of mind, they can not ignore the placement of messages on the helpful-neutral-harmful continuum as the source of perceived support. The shortcomings of reinforcement account and cognitive map explanations leave these researchers unable to explain how social support is identified. This opens the door for yet another evolution in the investigation of social support--an evolution to a message-centered perspective.

Message-Centered Perspective

Viewed from the message-centered perspective, "social support is not simply there to study. Support and its cognitive and affective correlates are accomplished in talk" (Zimmermann & Applegate, 1994, p. 52). While the sociological perspective views support as intrinsically tied to networks and the psychological perspective focuses on a subjective sense of support, the message-centered perspective argues social support should be studied as a

communication phenomenon. Studying support as communication means “studying the *messages* through which people both seek and express support; studying the *interactions* in which supportive messages are produced and interpreted; and studying the *relationships* that are created by and contextualize the supportive interactions in which people engage” (Burleson et al., 1994, p. xviii). The message-centered perspective encompasses the sociological and psychological models because network relationships and a subjective sense of support are viewed as products of communicative episodes.

Selected literature review. One goal of message-centered support research has been to discover what individuals in specific situations identify as supportive and unsupportive. Lehman and Hemphill (1990) sought to discover what support attempts individuals with multiple sclerosis (MS) found helpful or unhelpful. Expressions of love, concern, and understanding were regarded as most helpful, while minimization was cited as especially unhelpful. Minimization refers to: 1) behaviors which belittle the impact or importance of MS, 2) questioning the severity of the patient’s illness due to their healthful physical appearance, 3) challenging or denying the existence of MS, 4) discussing miracle cures, 5) not recognizing the amount of effort needed to cope, and 6) not providing needed or wanted assistance. Respondents also cited the provision of practical assistance as helpful while contact with other MS patients and maximization by others was not perceived as such. Maximization includes “being overly protective, ...catastrophizing MS or its consequences, and being treated in a patronizing manner” (Lehman & Hemphill, 1990, p. 568).

Peters-Golden (1982) compared behaviors disease-free individuals

believed to be supportive to the perceptions of these behaviors by breast cancer patients. The investigation revealed that

the disease experience of the cancer patients...differs greatly from that which is hypothesized by the healthy population. The latter's misconceptions lead to a lack of fit between...support needs as identified by the patients and the quality of...support provided by the healthy individuals. (Peters-Golden, 1982, p. 487)

Healthy individuals hold a set of assumptions regarding what behaviors are appropriate for cancer patients as well as for themselves. These assumptions actually lead to diminished support as perceived by the cancer patient.

Lack of fit between support attempts and perceived support can be demonstrated through several examples. First, disease-free individuals believe one of their most important roles is to encourage or cheer-up the cancer patient, while the patients identify this behavior as the one they most dislike (Peters-Golden, 1982). In addition, disease-free individuals bring certain expectations regarding the appearance and abilities of cancer patients to interactions. When support attempts are framed by these expectations, patients report "being made to feel as if they are acting (and feeling) inappropriately...[and] report being made to feel incompetent to perform ordinary tasks which they are fully able to do" (Peters-Golden, 1982, p. 489). The healthy population's emphasis on the loss of the patient's breast rather than focusing on the fact that the woman has cancer is also one of the most widely cited complaints. A support attempt fails when the healthy individual focuses on what he or she wrongly assumes to be the most significant aspect of the disease for the patient.

Dakof and Taylor (1990) expanded upon the Peters-Golden study. In this case respondents were not limited to breast cancer patients. More importantly, network members were categorized by their relationship to the cancer patient

and respondents were asked to identify supportive and unsupportive behaviors members of each category performed. Behaviors classified as esteem/emotional support--physical presence; expressed concern, empathy, or affection; calmly accepted patient's cancer; expressed a special understanding because of being a similar other; [and] was pleasant or kind--were most frequently identified as helpful, particularly when these behaviors came from intimate others such as a spouse, family member, or friend (Dakof & Taylor, 1990). Although other cancer patients were valued for their esteem/emotional support, they were particularly valued as role models and, along with physicians, for helpful information, and optimism regarding the prognosis or the patient's ability to live with cancer. Nurses were valued for esteem/emotional support more than for informational support.

Just as esteem/emotional support was most frequently cited as helpful, low or misguided esteem/emotional support was most frequently cited as unhelpful from intimates. Behaviors falling in this category include expressing too much worry or pessimism; expressing little empathy, concern, or affection; avoiding social contact with the patient; and rude or inappropriate behavior. As might be expected, misguided or absent informational support was perceived as least helpful from physicians and other cancer patients.

The onset of illness is not the only time support attempts are made by others. Lehman, Ellard, and Wortman (1986) investigated what support attempts were helpful or unhelpful for individuals who had lost a spouse or child in a motor vehicle accident within the past four to seven years. "The four support tactics most commonly identified as unhelpful were giving advice, encouragement of recovery, minimization/forced cheerfulness, and identification with feelings"

(Lehman et al., 1986, p. 441). Even though respondents knew the intent of these behaviors was to offer support, they did not find them helpful. "Contact with a similar other was identified most often as helpful. Respondents also found expressions of concern, the opportunity to ventilate their feelings, involvement in social activities, and the mere presence of another person to be helpful" (Lehman et al., 1986, p. 442). These behaviors were never identified as unhelpful.

Identifying what messages are or are not supportive for a given population is not the only form of message-centered support research. Comforting is one form of support and comforting inquiries rooted in the constructivist paradigm are also message-centered. "Comforting communication can be defined as the type of communicative behavior having the intended function of alleviating, moderating, or salving the distressed emotional states of others" (Burleson, 1984, p. 64). Constructivist researchers have employed a hierarchical coding system to evaluate the degree to which comforting messages acknowledge, elaborate, and grant legitimacy to the feelings and perspective of a distressed individual (Burleson & Samter, 1985).

There are nine levels in the comforting strategy hierarchical coding system and these levels fall into three categories. Numerically high categories and levels are attributed with a greater degree of sensitivity than those comforting strategies which are numerically low in the hierarchy. The three levels in the coding system are: 1) denial of individual perspectivity, 2) implicit recognition of individual perspectivity, and 3) explicit recognition and elaboration of individual perspectivity (Burleson, 1984). The three levels of comforting strategies included in category one are: 1) the speaker condemns the feelings of the

other, 2) the speaker challenges the legitimacy of the other's feelings, and 3) the speaker ignores the other's feelings (Burleson, 1984). The three levels composing category two are: 1) the speaker attempts to divert the other's attention from the distressful situation and the feelings arising from that situation; 2) the speaker acknowledges the other's feelings, but does not attempt to help the other understand why those feelings are being experienced or how to cope with them; and 3) the speaker provides a non-feeling-centered explanation of the situation intended to reduce the other's distressed emotional state (Burleson, 1984). The final category of comforting strategies includes: 1) the speaker explicitly recognizes and acknowledges the other's feelings, but does not discuss the source of the feelings or the nature of the situation; 2) the speaker provides an elaborated acknowledgment and explanation of the other's feelings; and 3) the speaker helps the other gain a perspective on his or her feelings and attempts to help the other see these feelings in relation to a broader context or the feelings of others (Burleson, 1984).

One example of comforting research utilizing the coding hierarchy is Burleson's (1982) investigation of comforting strategies used by children and adolescents. In this study, "12 subjects (six males and six females) from each grade, 1 through 12, responded to 4 hypothetical situations in which a same-sex friend was experiencing some form of emotional distress" (Burleson, 1982, p. 1578). The results of this study point toward both age and sex differences in the use of higher level comforting strategies. First, "older children and adolescents were more likely than younger children to use strategies that acknowledged and legitimized the other's feelings and perspective" (Burleson, 1982, p. 1585). Second, females consistently used more high-level comforting

strategies than males.

Burleson and Waltman (1987) also used the coding hierarchy to determine if fifth and sixth grade students using higher level comforting strategies were more popular with their peers. Thirty-two fifth graders (15 male and 17 female) and 40 sixth graders (21 male and 19 female) responded to two hypothetical comforting situations. There was little variation in the comforting strategies used by these preadolescents. The majority of students employed the strategy of redirecting the upset other's attention from the distressing situation. Burleson and Waltman (1987) found no relationship between comforting skill and status among peers, but explain this may be due to the identified lack of variation in preadolescent comforting skills.

While there are various forms of message-centered research, they all share a common perspective. This perspective identifies communication as central to support. In research which seeks to discover what is supportive to individuals in specific contexts, the message itself is equated with support. In research which assesses the quality of support attempts, the degree to which a message is adapted to the receiver is the key to support. This perspective represents an evolution in the study of support because the psychological model fails to explain how a general sense of support comes about. The message-centered perspective roots a general sense of support in communication with others.

Critiquing the message-centered perspective. Message-centered studies represent a shift from viewing support as an enduring trait to a focus on specific messages. Research focusing on messages individuals find supportive or unsupportive still places support in the minds of individuals; a message is perceived as supportive or unsupportive. The shortcoming of such research is

that how messages come to be perceived as supportive or unsupportive is unknown. Comforting research, which focuses on the quality of support attempts is subject to the same criticism. Naive evaluators have ranked support strategies in a manner which is consistent with the constructivist hierarchy (Burleson & Samter, 1985), but how these strategies come to be identified as more or less supportive is, again, unknown.

In seeking to understand support in the primary/hired caregiver relationship, a theoretical perspective which addresses *how* support is created will be utilized. In order to avoid the shortcomings of previous support research, this investigation will be rooted in the social constructionist framework. Social constructionism is not concerned solely with determining if a message is supportive; social constructionism is concerned with how something *becomes* supportive.

Social Constructionist Perspective

Meaning has traditionally been thought of ostensively; a word or action represents a single, specific meaning. This is the perspective of the message-centered approach to support research; a message either is or is not supportive. Social constructionism rejects this traditional notion because no word or action is naturally tied to its ostensive definition. As Wittgenstein (1968) explains, "With different training, the same words would have effected a quite different understanding" (p. 5). In addition, despite conventions of language use, "an ostensive definition can be variously interpreted in every case (Wittgenstein, 1968, p. 14). For example, the offering of solutions to a problem may be interpreted as support or it may be interpreted as domineering. Because meaning arises out of interpersonal negotiation, it is also possible to

interpret multiple behaviors as one kind of act (Gergen & Gergen, 1982). The offering of solutions to a problem, listening, and loaning money are very different acts, but all may be interpreted as support. The social constructionist perspective replaces ostensive meaning with the notion of meaning in use.

Meaning in use posits that meaning is negotiated between individuals and emerges within dialogue. "From the constructionist position the process of understanding is not automatically driven by the forces of nature, but is the result of an active, cooperative enterprise of persons in relationship" (Gergen, 1985, p. 267). This perspective privileges language in that language is viewed as the locus of meaning. While the cognitive perspective views language as a means for transmitting private thought, the constructionist perspective elevates language and postulates that individual thoughts themselves are "derived from interpersonal discursive processes" (Harré & Gillett, 1994, p. 27). In addition, "the workings of each other's minds are available to us in what we jointly create conversationally" (Harré & Gillett, 1994, p. 27). The reflexive relationship between the co-construction of meaning and the co-construction of thought makes language an active entity rather than a passive tool.

The social constructionist approach to language focuses on speech acts. "Speech acts are actions that we perform by speaking. They include compliments, insults, promises, threats, assertions, and questions" (Pearce, 1994, p. 104). Although speech acts such as "paying someone a compliment" are identifiable, there are no set ostensive meanings for any given speech act. "An utterance that meets all the criteria for performing a speech act today might not have done so at another point in the past and may not at some point in the future" (Pearce, 1994, p. 113). For example, a speech act which counts as

support at one point in time may not have counted as supportive in a past situation and may not count as supportive in all situations yet to come.

This fluidity of meaning arises because the contexts within which speech acts are performed are constantly recreated. There is "a fully reflexive relationship between contexts and the acts that occur in them" (Pearce, 1994, p. 114). Context affects the interpretation of speech acts as well as which speech acts may appropriately be performed. At the same time, "contexts are made by specific actions" (Pearce, 1994, p. 114). Two aspects of context, social and historical, are critical to the study of social support.

Social context impacts the negotiation of meaning. "The way in which one understands the identity of the individuals, their psychological makeup, the context of the interaction, and so on, all bear on the allowances that can be made in describing the acts in question" (Gergen & Gergen, 1982, p. 149). An individual may intend to offer support by recommending the wife of a recently diagnosed Alzheimer's patient begin seeing a psychiatrist. If the woman knows the individual making this recommendation has an impaired relative and has gone to a psychiatrist in order to work through her own anger, she may respond in a way that indicates this advice is supportive. If the woman knows the individual has no experience with Alzheimer's and has never been to a psychiatrist, she may interpret this recommendation differently. Likewise, if this advice were offered in the context of a private lunch it may be interpreted differently than if it were given at a holiday party. Thus it is not simply words, but words as interpreted within a social context which create meaning.

Historical context also impacts the negotiation of meaning. "It may be said that the manner in which the contemporary activities can be described depends

importantly on one's understanding of the history of the participants" (Gergen & Gergen, 1982, p. 150). In the above scenario, if the individual recommending psychiatric counseling and the wife of the Alzheimer's patient have a history of turning to one another for guidance in times of crisis, the advice may well be interpreted as support. If, instead, the history of this relationship is one of animosity, the advice may be interpreted as mean-spirited. The variety of meanings ascribed to the same utterance or action within differing social and historical contexts indicates that "rather than words themselves having a meaning, words are... best thought of only as a means in the making of meanings" (Shotter & Gergen, 1994, p. 17).

Viewed from the constructionist perspective, speech acts are indeterminate. "Speech acts are never completed; they are always evolving, open to reconstruction based on what you or other people do, and not necessarily in the immediately following event" (Pearce, 1994, p. 123). This assumption has implications for the study of support because no utterance has meaning until it is responded to by another individual. Shotter and Gergen (1994) explain:

In their responses to another person's utterance, listeners act out of their own fore-structures of understanding: Hence their objections, questions, elaborations, and so on do not depend upon the preexistence of any common understandings between them and the speaker but are part of the activity of constructing a shared understanding in, and appropriate to, the context of their conversation. (p. 16)

For example, a hired caregiver may decide to purchase over-the-counter medication when the Alzheimer's patient he or she cares for has a slight cough. The hired caregiver may intend this to be supportive because the primary caregiver does not have to be troubled with a detail of daily care. According to the social constructionist framework, this action is not supportive until the

interpretation is confirmed by the primary caregiver. If the primary caregiver, upon finding out about the situation, thanks the hired caregiver for taking care of the problem, the hired caregiver's meaning is affirmed. If the primary caregiver responds angrily and indicates he or she should be consulted in all matters relating to the patient's health or the administering of medication, the hired caregiver's meaning would be altered.

This process of individuals constructing meaning within everyday conversation is what Pearce (1989) calls coordination. Meaning is not tied to the intent of an individual, it is dependent upon people responding to one another. This concept recognizes that speech acts are inherently interactive; people link their actions together. Shotter (1993) explains that

no matter how systematic the speech of each may be while speaking, when one has finished speaking and the other can respond, the bridging of that 'gap' is an opportunity for a completely unique, unrepeatable response, one that is 'crafted' or 'tailored' to fit the unique circumstances of its utterance. (p. 53)

Despite the coordination which takes place between interlocutors, it is believed that actual shared understanding is quite rare (Shotter, 1993). For this reason the stories we tell to explain our understanding of speech acts may be quite different. The telling of such stories is what Pearce (1989) calls coherence. So while we as human beings must coordinate, the fact that we do coordinate in no way assumes we imbue communicative exchanges with the same meaning (Pearce, 1989).

Exploring social support from a social constructionist perspective requires an understanding of what counts as a speech act. The focus on negotiated meaning within talk is not meant to conjure up an image of disembodied dialogue. Pearce (1994) explains that

the quality of your voice, the rate of your speech, the accent with which you pronounce words, and the inflections of your voice all comprise messages that constitute interpersonal communication. In addition, your facial expressions, body posture, gestures, even the extent to which you touch or do not touch your interlocutor is part of the conversation. (p. 132)

Nonverbal communication which accompanies speech acts influences meaning. For example, a primary caregiver may tell a hired caregiver he or she is doing a good job, but may sound terse when making the statement. The nonverbal communication which accompanies the primary caregiver's assessment influences the meaning of those words.

Viewed from the social constructionist perspective, support must be understood as an integer in a meaning system (Gergen & Gergen, 1982). Meaning is social rather than ostensive or locked away in a private world of perception. "The rules for 'what counts as what' are inherently ambiguous, continuously evolving and free to vary with the predilections of those who use them" (Gergen, 1985, p. 268). When approached from this perspective, support is accomplished between individuals, and how that support is constructed and reflected in talk becomes the focus of study. As Deetz (1994) explains, "We have to move from studying 'communication' phenomena as formed and explained psychologically [and] sociologically...and produce studies that study psychological, [and] sociological... phenomena as formed and explained communicationaly" (p. 568).

Research Questions

The arduous nature of caregiving coupled with the desire to avoid patient institutionalization leads some primary caregivers to hire an in-home caregiver. Hiring an in-home caregiver does not, however, relieve the stress of watching a loved one deteriorate. Primary caregivers must also concern themselves with

the quality of care their loved one receives and may feel guilt over the decision to relinquish the daily care provision role. Primary caregivers may even continue to perform some caregiving duties. Likewise, a hired caregiver's lack of blood relation does not make the care of an Alzheimer's patient easy. For these reasons, support is an issue in this relationship and the following research question is asked:

RQ1: What do primary and hired caregivers for people with Alzheimer's disease identify as support in their relationship with one another?

It is appropriate to introduce the social constructionist perspective to this research because it will illuminate how support is negotiated in talk. Thus, the following research question:

RQ2: How is what primary and hired caregivers identify as support negotiated in talk?

Chapter 2

Method

The goal of this study is to describe support as it is experienced and negotiated by primary and hired caregivers for people with Alzheimer's disease. "For too long in the history of communication scholarship, we have focused on what messages refer to, or the effects they have, without examining what messages are or how their articulation creates social realities for speakers and audiences" (Lindlof, 1995, p. 22). In other words, research has focused on ostensive meaning and prediction. Because my goal is description rather than prediction, I employed a qualitative research method. "Qualitative inquirers strive to *understand* their objects of interest. ...Understanding does not entail or require knowledge of how to predict or control a phenomenon" (Lindlof, 1995, p. 9). The methods described below enabled me to understand what caregivers experience as support and how that support is negotiated in discourse.

The Diary/Diary-Interview Method

The method I selected for this research is the diary/diary-interview method. This method overcomes the problems I would face engaging in direct observation of the caregiving context. Because I am outside of the primary/hired caregiver relationship, I can not identify what communicative events count as a negotiation of support. To make such an interpretation, I would either have to become employed as a caregiver--an impractical option--or become a primary caregiver--a situation which is not a matter of choice. I could engage in direct observation and question caregivers about interactions as they occurred; however, this too is impractical. "Some activities occur only

intermittently over long stretches of time, or so spontaneously that direct observation would be inefficient" (Lindlof, 1995, p. 120). Primary and hired caregivers do not interact constantly and which interactions or how many interactions are interpreted as supportive is unknown.

The Diary

Rather than compiling field notes myself and waiting for a communicative exchange in which support was negotiated, I had caregivers document their support experiences in a diary. "A diary is a chronological log of events and/or perceptions recorded by a participant. It is normally kept for a standard period, such as a week, with entries made soon after events of interest have happened" (Lindlof, 1995, p. 120). Duck (1991) acknowledges diaries are a useful method of data collection when "the self-reported data of subjects...has been intentionally prompted to address a question [the] researcher has in mind" (p. 142). Diaries allowed primary and hired caregivers to provide accounts of supportive communication and offer their interpretations of events as they occurred.

In their diaries, primary and hired caregivers described times when, in interaction with one another, they felt supported. The caregivers were instructed to record three to five episodes during the course of one week. They were encouraged to write freely about the episodes, although specific information was required. Caregivers were instructed to: 1) identify where they were when the episode occurred, 2) identify who else was present, 3) explain what they were doing when the episode occurred, 4) explain what the other individuals present were doing, and 5) be specific regarding what each individual said. As Zimmerman and Wieder (1977) suggest, I informed the

caregivers that whatever is notable to them is of interest to me. They were not to avoid recording a communicative event because it seemed mundane (See Appendix A for a copy of the instructions included in the diaries and a copy of a diary page).

The Diary Interview

After caregivers recorded supportive episodes in their diaries, they were interviewed. Themes identified in the diaries provided the basis for my interview schedule (See Appendix B). "The diary interview converts the diary--a source of data in its own right--into a question-generating and, hence, data-generating device" (Zimmerman & Wieder, 1977, p. 489). Interviews were audiotaped. In addition to probing for detail regarding the episodes recorded in the diaries, I asked the caregivers to explain how social and historical factors contributed to their identification of these episodes as support.

I modified the diary/diary interview method by interviewing the primary and hired caregivers together. Interviewing the caregivers together provided the opportunity for ongoing social action as caregivers essentially renegotiated support by talking about past negotiations. The interview allowed me to hear stories of support, hear how negotiation occurred, and witness negotiation firsthand. Interviewing the participants together also gave the caregivers the opportunity to learn what one another found supportive.

Data Analysis

Both the diaries and a transcription¹ of the diary interview were thematically analyzed. Thematic analysis followed the steps articulated by Peterson et al. (1994):

1. Search for individual themes in each transcript;
2. Develop each of the themes identified in step one;

3. Determine relative significance of themes;
 4. Search for oppositions among themes, and thematic hierarchies;
 5. Compare thematic hierarchies and oppositions across transcripts.
- (p. 206)

This means of analysis allowed me to move from detailed experiences provided by the participants to more general observations regarding support in a specific primary/hired caregiver relationship.

Each diary was analyzed prior to the diary interview. Analysis, first, began with examining each statement in each of the diaries. Topically related utterances were clustered. For example, several instances where the hired and primary caregiver helped the Alzheimer's patient together were clustered. The second step involved identifying key properties of the utterances in each cluster. This step involved what Glaser and Strauss (1967) call constant comparison and led to specific categories of statements. To continue the previous example, the essential characteristic of teamwork encompassed utterances which described both parties working together to help the Alzheimer's patient. The third step required identifying which categories were most fundamental to the process of support. The fourth step involved identifying relationships between categories. For example, "the opportunity to be alone" and "help with coping and adjustment" were identified in one diary. This step involved developing a hierarchy where the hired caregiver enabling the primary caregiver to be alone leads to her coping and adjustment. The fifth step in the Peterson et al. (1994) system involved looking for thematic similarities between diaries.

Analysis of the interview transcript followed the same steps as the diary analysis. First, topically related individual utterances were clustered. For

example, several statements regarding a previous hired caregiver were clustered. Second, essential characteristics within each category were identified. For example, "the previous caregiver's inability to handle the Alzheimer's patient alone" was identified as one category within the large cluster of utterances pertaining to the previous caregiver. Third, categories which were fundamental to the support process were identified. Fourth, relationships between categories were established. For example, a relationship between "the hired caregiver being a part of the family" and "the hired caregiver going beyond the call of duty" was identified. The fifth step in the Peterson et al. (1994) system was eliminated because there was only one interview transcript.

Recruiting

My original goal was to have three caregiver dyads participate in this research. One resource for participant recruitment was a support group leader at an adult day care center. The group leader approached three primary caregivers in one of her groups. She told them I was doing a master's thesis on the relationship between primary and hired caregivers. She also told the caregivers that if they participated in the study, they would be asked to keep a diary and would be interviewed. All three primary caregivers were interested in participating. At this point the group leader gave me the primary caregivers' names and phone numbers.

I contacted each primary caregiver by telephone in order to explain my research topic and what would be required of them if they participated. In one case the primary caregiver said both she and her hired caregiver would participate. Because the caregivers live a significant distance from my home, I

arranged to send the diaries to them and call on the day they would begin recording support episodes (See Appendix C for the instructions sent with the diaries). When I called to confirm that the caregivers had received the diaries, I again explained what they were to do and I scheduled a date for the diary interview. In the second case, the primary caregiver agreed to participate and informed me of the best time to contact the hired caregiver. Upon contacting her, the hired caregiver also agreed to participate. As with the first dyad, I arranged to send the diaries and called on the day they would begin keeping them. When I made this call, I was informed the Alzheimer's patient had become ill and the caregivers might not be able to participate. When I checked back with the primary caregiver one week later, the Alzheimer's patient had not improved. The primary caregiver still wanted to help, but she did not believe they would have time to keep the diaries; therefore, I was unable to include these caregivers in the study. The third primary caregiver I contacted was unable to participate because her husband, the Alzheimer's patient, slipped into a coma between the time the support group leader approached her and the time I called her.

With only one dyad, I again contacted the support group leader. She indicated a fourth woman in one of her groups who employs help. I contacted this caregiver and, although she was somewhat unsure as to how she would write about everyday things that are supportive in a diary, she agreed to participate. The woman she employs to assist her with her husband also agreed to participate. As with the previous participants I sent the diaries and called when they received them to reiterate the instructions and answer any questions. A date for the interview was also arranged. When I arrived to pick

up the diaries on the morning of this scheduled interview, the primary caregiver had her diary, but told me the hired caregiver had not done hers. The primary caregiver was quite distraught and was still willing to be interviewed. She also asked if just interviewing the hired caregiver would be of use. Rather than trying to modify my methodology, I chose to cancel the interview and thanked the primary caregiver for her efforts.

Two other sources, the director of a gerontology center at a major hospital and the director of an Alzheimer's activity center, were tapped for recruitment assistance. I was referred to the gerontology center by a case manager who places hired caregivers and I was referred to the activity center by a local chapter of the Alzheimer's Association. Both contact people asked me to create a flyer which could be distributed to potential participants. I was contacted by one primary caregiver who received the flyer from the gerontology center. She was not recruited, however, because the hired caregiver she employs did not think she would have anything to document in the diary. Having exhausted my recruiting possibilities, this research became a case study.

Participants

The primary and hired caregiver who participated in this study have been together for five months. The primary caregiver is a Caucasian female and her husband is in the middle stage of Alzheimer's disease. The Alzheimer's patients' speech is impaired, he sometimes suffers from anxiety attacks, and he does not fully comprehend what is going on around him. He is, however, able to walk and perform activities of daily living with assistance. It was apparent to me that the Alzheimer's patient is somewhat lucid because he was present during my interview with the primary and hired caregiver. During the interview

he contributed brief remarks about the hired caregiver. In addition, he gave the hired caregiver a pat on the arm or grasped the hired caregiver's hand when he referred to the hired caregiver as his friend. The Alzheimer's patient also extended his hand to his wife when she talked about the fact that they still like to hold hands and have private time together.

The hired caregiver in this dyad is a Filipino male and lives with the primary caregiver and her husband 7 days a week, 24 hours a day with the exception of Saturday morning to Saturday evening. Prior to the hired caregiver moving in, the primary caregiver did not have live-in help, but a "sitter" who came Monday through Friday from nine to five. The hired caregiver worked at a hospital for three years prior to his employment with this couple. The hired caregiver's wife is a nurse's aid and he indicated that he also has some caregiving knowledge because of her work.

Pilot Study

A pilot study was conducted prior to the recruitment of the caregiver dyad. A primary caregiver and a caregiver she employs, both of whom are known to the researcher, served as participants for the pilot study. The primary caregiver is a Caucasian female whose husband has passed through the three stages of Alzheimer's disease and is fully impaired. She has employed caregivers to provide daily care for her husband for eight years. The hired caregiver is a female of Mexican descent and has worked for the primary caregiver for two years. I sent the pilot study participants their diaries, but the additional instructions which were sent with latter participants' diaries (Appendix C) were not included because these were the result of a problem identified in the pilot study. The pilot study interview was conducted in the primary caregiver's

home. In addition to support-related questions, I asked the caregivers to identify any difficulties they had as participants.

One difficulty was identified by the the hired caregiver in the pilot study. English is her second language and she was unsure what was meant by the word support. She was concerned that she was not writing about the “right” things. She explained that in Spanish, support means many things; therefore, it would have been helpful for her to know what I meant by support. The hired caregiver recruited as a participant for the actual study is a non-native speaker of English; therefore, this problem was a concern. In order to address this problem, I added an assurance to the diary instructions. I informed the caregivers that there are no wrong answers. If they feel supported by something the other person says or does, then it “counts” as support.

A second problem was identified after I transcribed the pilot study interview. Although I had thematically analyzed the diary entries, I proceeded to interview the caregivers about each episode they recorded and did not question them about the categories I identified until late in the interview. This led me to ask “Why” rather than “How” questions for a good portion of the interview. Cobb (1994) explains “Why” questions seek to discover the true inner reasons for people’s actions. It would seem “Why” questions also seek to discover the reasons for assigning a given meaning to an utterance; therefore, asking “Why” questions adopted a psychological perspective. Asking “How” questions regarding the categories I developed after analyzing the diaries informed me of the discursive processes through which support was negotiated. “Why” questions tie support to a message while “How” questions acknowledge messages become supportive. Realizing this error, I reduced the number of

questions pertaining to specific diary episodes and focused on “How” support was negotiated in discourse, not “Why” a message was supportive.

Chapter 3

Findings

My first research question--What do primary and hired caregivers for people with Alzheimer's disease identify as support in their relationship with one another?--is answered by the thematic analysis of the caregiver diaries. My second research question--How is what primary and hired caregivers identify as support negotiated in talk?--is answered by the thematic analysis of the caregiver interview. I will first present the episodes recorded in the hired caregiver's diary and the theme identified to partially answer the first research question. Second, I will present the information recorded in the primary caregiver's diary as well as the identified themes pertaining to the first research question. Third, I will use themes identified in the interview to describe the social construction or negotiation of support in this relationship.

Support for the Hired Caregiver

Rouel², the hired caregiver in this case study, made three diary entries. The first entry describes a specific support episode. The second entry describes two related episodes which occurred on the same morning. The third entry described an evening more generally.

Rouel's first diary entry described an incident which occurred just after breakfast one morning. The person with Alzheimer's, John, was still sitting at the kitchen table, but he became very sleepy and could not hold his head up. Rouel and Sarah, the primary caregiver, got on either side of John in order to hold him up and help him to the den where he could rest in his lounge chair. In addition to helping John walk, both Rouel and Sarah coached him saying, "Keep walking, turn right, turn right again, turn around, sit down." Once they got

him to his lounge chair, John was able to take a nap. Rouel explained that after a five to ten minute nap, John is fine again. Rouel identified this episode as support because, "It was important that we both worked together to get him to take his nap."

Rouel's second diary entry described two similar incidents which both occurred on the same morning. First, John was agitated in the morning, so Sarah and Rouel helped him to his lounge chair so he could rest. Sarah stayed with John while Rouel went to get a wet wash cloth to wipe John's face. Rouel explained that this helps soothe John when he has an anxiety attack or becomes agitated. Both Rouel and Sarah continued to sit with John so if one of them needed to leave the room, they could. This episode was identified as support because, "We seem to always know when we...need each other which is very comforting."

The second support episode of the morning occurred approximately one half hour later. After breakfast, John needed another nap. This diary entry does not detail whether Sarah and Rouel coached John to his chair or to bed, or if one of them helped him to his chair or to bed. What Rouel identifies as support, instead, is that he and Sarah took turns staying with John while he rested. After John woke up, Rouel helped him shower and dress. When John was comfortable, Sarah left to do her marketing.

As previously mentioned, Rouel's third diary entry describes an entire evening. Two specific episodes are described and general statements regarding support are made. The first episode Rouel describes in this entry is an opportunity he had to rest. Sarah and John were watching a movie in the den, so Rouel watched television in the living room. He did this so Sarah and

John could “stay together.” This was identified as support because “I was able to rest and knew if [Sarah] needed me I would be there for her.”

The second episode Rouel describes in this entry occurred after Sarah and John finished watching their movie. Sarah started making a salad for dinner when John started having mood changes. Sarah and Rouel got John into his chair in the den. Rouel then got a wet wash cloth to cool John's face and put a cassette in the stereo to calm John. After this, Sarah stayed with John while Rouel went to the kitchen. Rouel finished making the salad, set the table, and warmed dinner for Sarah and John.

The remainder of this final entry describes the evening's events after John and Sarah finished eating. Rouel and John watched basketball on television while Sarah took a shower. Rouel then helped John get ready for bed and by eight-o'clock Sarah and John had retired to their bedroom for the evening. Rouel then ate his dinner and had the rest of the evening to himself. He explains in the diary, “We have a schedule and we seem to know just when to help each other.”

All of the entries in Rouel's diary shared one essential characteristic--teamwork. He and Sarah work together when it comes to John's care. They worked as a team to coach John to his chair; they both stayed with John when he was agitated, thus enabling one another to leave if necessary; they took turns sitting with John when he napped; and Rouel was able to rest when Sarah was with John. The importance of teamwork was reinforced by Rouel's general remarks regarding “knowing when to help one another” and the “importance of working together.” This theme indicates that what Rouel finds supportive in his relationship with Sarah is that they work as a team.

Support for the Primary Caregiver

Sarah also made three diary entries. Her first two entries described specific support episodes. Her third entry described the difference she sees in her life now that Rouel works for her. The first episode Sarah recorded occurred away from home. Sarah usually shops alone, but because it was a nice day, Rouel and John went with her to the mall and to the grocery store. At the market, Rouel and John followed Sarah with the cart. After about twenty minutes, John became tired, so Rouel said he would take John to the car while Sarah went through the check stand. Sarah explained that, "Just knowing [Rouel] was with [John] was a big relief for me." Because Rouel took John to the car, Sarah was able to finish her marketing and did not have to tend to John's immediate needs.

The second episode Sarah recorded also occurred away from home. Sarah, John, and Rouel all went to a movie and when the picture began the sound was very loud. The extreme volume was upsetting to John. Because Rouel was with them, Sarah was able to go to the theater lobby and tell someone that the volume needed to be turned down. The employee Sarah spoke to said she would notify the manager, but the sound was not lowered. Sarah left John and Rouel once again in order to request the volume be lowered. By this point, John was so upset that he wanted to leave. Sarah ultimately went to the lobby three times before the volume was lowered. All three of them then enjoyed the movie.

As noted, Sarah's third diary entry describes the difference she sees in her life now that Rouel has come to work for her. She began the entry by explaining that she still sleeps in the same bed with her husband, so some

nights are better than others. On the morning Sarah recorded this entry, she told Rouel she had a great sleep the night before and that her life was so much better now that he had come to live with her and John. She also told him that he was a wonderful caregiver to John and to her as well. Rouel told Sarah he was very happy with them and that they were very kind people.

Sarah also wrote that she was very run down before Rouel came to live with her and she cried a lot when she talked with friends and her family. She just could not help crying. Now that Rouel is with her, she feels stronger and does not cry anymore. She is also able to go out alone and does not have to worry about John because she knows he is well taken care of. Sarah indicated her daughter, son, and their children are also happier now that Rouel is there. Sarah wrote, "I thought I would just hate having someone live in and my life would be more miserable than ever." Rather than being miserable, her life has taken a turn for the better.

Sarah continued this entry with some thoughts about her life with her husband. She wrote, "My husband is 78 years old and still very good looking and the picture of health. We will be married 56 years in one week and we are so grateful for all the beautiful years we have had. We did a lot of traveling [and] cruising...We have had good friends and a wonderful life." Although Sarah would prefer to have her life continue as it was, Rouel's presence has helped her adjust to the changes in her life. She wrote, "I can't change the way [John] is and I am coping and I feel [Rouel] has been very important to my adjustment."

I identified two themes in Sarah's diary. The first theme is the opportunity to be alone, either briefly or for longer periods of time. Rouel gave Sarah the

opportunity to be alone briefly in the market and in the theater. In these cases being alone meant she could tend to the things she needed to do and also know that John was taken care of. Sarah also wrote more generally about the fact that she can get out alone and know that John is all right. For example, Sarah mentioned in her diary that she normally does the marketing alone. Rouel makes this possible.

The second theme I identified in Sarah's diary is Rouel's help with coping and adjustment. There is a hierarchical relationship between this category and the first whereby Sarah's opportunity to be alone contributes to her coping and adjustment. Several of Sarah's diary entries share the essential characteristic of Rouel helping her cope and adjust. She wrote that Rouel is a caregiver to her as well as to John. She wrote that she does not cry anymore, she feels stronger, and she is not so run down. Sarah also noted that she has adjusted to her life and Rouel has been an important part of her coping. Sarah's diary indicates that what she identifies as support in her relationship with Rouel is that she is able to cope and adjust. At least one important way this is performed is that Rouel gives Sarah the opportunity to be alone, whether it be briefly or for a longer period of time.

The Negotiation of Support in Talk

Sarah and Rouel negotiate support with one another everyday. An example of support negotiation is the incident Sarah recorded in her diary pertaining to the market. In the interview, Rouel explained that he was the one who noticed John was getting tired at the market. He suggested that he take John to the car to rest. Sarah said that she responded to Rouel by saying, "That'll be fine. Here's the key to the car. I'll be right there. I'm all ready to check out, so I'll just

get there as soon as I can." This is the negotiation of support in conversation. Rouel made a suggestion he thought would be positive and appropriate. Sarah responded in a way that confirmed his meaning and communicated her approval. Both Sarah and Rouel saw this as support, but for different reasons. For Sarah, this episode was supportive because she was able to finish the marketing and know that John's needs were being met. For Rouel, his patient is his first priority. To watch John and attend to his needs is doing his job. Doing his job well is how Rouel supports Sarah.

What became most interesting in my interview with Rouel and Sarah was not their descriptions of these everyday negotiations of support, but the negotiation that took place as they talked about their relationship with one another. The individual episodes Sarah and Rouel recorded in their diaries are not inherently supportive; they create a support process (See Appendix D) and are, in turn, constructed as support in the context of this larger process.

The support process first begins with Rouel being there when Sarah needs him. The second and third parts of the process bear a reflexive relationship to one another. Rouel being there for Sarah leads to him not just being an employee, but being a part of the family. Being a part of the family leads to Rouel going beyond the call of duty. Rouel going beyond the call of duty reinforces Sarah's view that Rouel is part of the family. This reflexive loop leads to the fourth part of the support process, which is coping and adjustment. The support process itself is reflexive in that the individuals who are able to cope and adjust act back into the process in a way which recreates it.

The Hired Caregiver is There When the Primary Caregiver Needs Him

Sarah's life was very different before Rouel came to live with her. She was

helping John with his activities of daily living, ADL's, and this was wearing her down. Sarah explained:

I was doing all that for [John] besides everything else and it just was too much for me all of a sudden. You know my children could see me getting run down and they wanted me to get somebody in to help.

In addition to helping John at home, Sarah had to take him with her when she went out. Sarah told me, "There were times before [Rouel] that I used to take [John] everywhere with me because I didn't like to leave him alone. So I had him to the beauty shop when I'd go, I'd take him to the market." Caring for John at home and away from home took its toll on Sarah. She was so emotionally upset that she could not even talk on the phone to her friends; she would just cry.

Sarah is not the only one who saw the impact caregiving had on her. Sarah's granddaughter, Amy, witnessed the change in her. Sarah had called Amy before I arrived for our interview to ask if she could keep John occupied while she and Rouel spoke with me. Amy is a high school senior and could not come until she finished working with her chemistry tutor. Amy arrived halfway through our interview and tried to get John to go in the other room with her, but he insisted she join us at the table. Since she was there, I asked her for her insights into her grandmother's situation. Amy described her grandmother's state of being before Rouel's tenure. She said her grandmother had lost a lot of weight and she remembered thinking, "God, Grandma looks too thin. ...It's time to put on some weight."

Seeing a physical change in her grandmother was hard for Amy, but she was not alone in terms of the impact of Sarah's situation. Sarah not having help was hard on her entire family because she had to turn to her children for

assistance. Sarah's daughter, who is Amy's mother, lives only five minutes away, but Sarah didn't like always having to call her for help. She explained, "I don't like to bother my daughter, because she works hard, late on a Sunday...or [on] a week night. They need their evenings and I don't like to bother them, but sometimes I really had to." Amy said that caregiving was most draining on her grandmother, but the situation was emotionally straining for the entire family. She said, "It was just too much for us to handle."

Sarah did employ a caregiver prior to Rouel, but that caregiver was unable to relieve her burden. The previous caregiver, Mary, could not help John with his ADL's, so Sarah had to continue her draining routine. Sarah explained that Mary could not give John a shower or take him to the bathroom, so she was still doing all that work. Mary did stay with John when Sarah went to the beauty shop or to her Mah-Jongg game, but she was unable to assist John without Sarah's help. Sarah told me:

If I had to go somewhere, she'd stay with [John]. But she couldn't really handle him alone. ...If they wanted to go for a walk, we'd both go with him because she was afraid if he had his little shaking spell or something, she wouldn't be able to hold him up. She was a little person.

Mary simply was not able to relieve Sarah of the caregiving duties which were wearing her down. Sarah said she and John got along very well with Mary and when she came over in the morning they would all sit around with coffee and English muffins. Mary was more like company than a caregiver offering Sarah respite.

Amy also saw the limitations in Mary's ability to help her grandmother. She saw the impact this had on Sarah's ability to go out. Amy observed:

It used to be that Grandma wouldn't go out. More than anything else. That she was home. And I think that when [Mary] was here, as wonderful as she

was, she wasn't there, she couldn't help Grandpa to walk or whatever because...she was an older woman too and she wasn't strong. You know, so she couldn't help him.

Neither Amy nor Sarah criticized the work Mary did. As Amy put it, "She did exactly what she was being paid to do." Mary just was not capable of physically helping John and her inability to handle him alone meant Sarah still had to worry when she did go out.

As Sarah became more strained, her children suggested that she get live-in help. Sarah had never had live-in help and did not think she would like it. I asked her why she was apprehensive about assistance of this nature and she explained that she was emotionally upset at the time and just did not think she would like having an extra person in the house. Sarah apparently felt an extra person living in her house would be more trouble or hassle than help. She may also have felt uncomfortable having a stranger always be around. Despite her apprehension, Sarah did ultimately hire Rouel as a live-in caregiver.

Rouel has more than eased Sarah's apprehension. The live-in situation has worked because Rouel is there when Sarah needs him, but Rouel and Sarah also have a good sense of when they do not need one another. For example, Rouel alone assists John with his ADL's. Sarah told me:

[Rouel] helps [John] with his shower and he watches over [John] while he shaves and if he misses a couple places, [Rouel] will help him. And he helps him dress and I pick out...what [John] should wear most of the time. And [Rouel] helps him dress.

Assistance with ADL's is a task Rouel handles alone. Sarah explained that she and Rouel just know they need to work together when John has an anxiety attack or something out of the ordinary, but routine tasks do not require both of them. For example, Rouel just takes over when it comes to the ADL's; she does

not even go in the bathroom when John is having a shower now.

Just as Sarah knows when she is not needed, Rouel knows that when Sarah is with John, he does not need to stay. Sarah explained that they often help John to his lounge chair to rest. She said:

If I stay in there...after he's resting or sleeping, then it isn't necessary for [Rouel] to stay in there. But if I needed him...I would call him. But if he knows I'm with [John] while he's sleeping for the five minutes, it isn't necessary for him to stay in there and he just seems to know it.

Knowing when to help and when not to help is one reason the live-in situation has worked for Sarah and Rouel.

Rouel is also there for Sarah in situations which are out of the ordinary. For example, my interview with Sarah and Rouel was on the day of the week Sarah plays Mah-Jongg. John's brother usually takes him to lunch on these days, but on this particular day, he could not do it. Sarah said Rouel was right there when she needed him; he was perfectly willing to give up this time he would normally have to himself and stay with John. Sarah also spoke of Rouel's willingness to help if there is a problem during the night. Sarah explained, "[Rouel] sleeps in the den and [John] and I sleep in the bedroom. But [Rouel] has said, 'If you ever need me in the night, just wake me up. ...You need help, I'm here for you.'" So far Sarah has not needed Rouel during the night, but just knowing he is there is supportive to her.

In addition to Rouel's being there when Sarah needs him, the live-in situation works because Rouel is respectful of Sarah's time with her husband. Sarah explained:

He's quiet. He knows when [John] and I want to be alone without telling him. ...[John] has been a wonderful husband and we still love to hold hands...and [Rouel] just senses that. ...I'll tell him to sit down and look at television, but he won't do it.

Sometimes I'll say, "Why don't you eat dinner with us?" And he says, "No, I like to eat later." And that's the way he does it.

Sarah was worried about live-in assistance, but the job Rouel does is a relief to her and there are no new stressors to replace the old burden because of the nonintrusive way he does his job. Rouel's assistance and his nonintrusiveness are supportive to Sarah.

The Hired Caregiver is Part of the Family

Because Rouel's presence has been a positive rather than a negative addition to Sarah's life, she sees him not as an employee in her home, but as part of her family. In the course of the interview, Rouel said many times that he is treated like a member of Sarah and John's family. Although Rouel sleeps at Sarah and John's home and is there during the night if he is needed, he is generally finished with his job at eight-o'clock every night when John goes to bed. Rouel said that when he is finished with his job, Sarah tells him, "Thank you very much. You are helping me." This is one way Rouel knows he is doing his job well, but he says it is more than that. He said Sarah makes it possible for him to do his job because she is a "very kind person." Rouel said he is happy with Sarah and John and that because they are kind to him, he feels like he is a part of their house and home.

Rouel realizes he is doing a job and he is being paid for it, but he explained that he does not do his job solely for the money. He said, "I do my job because I [have made] a family. That's the most important." Rouel compared his previous job as a caregiver at a large hospital to his job with Sarah and John, "First I have a good job. I earn money. It's important. And now I am happy because I have a job and I find a good manager. They make me a part of their

family.” Rouel could make money as a caregiver anywhere, but money is not the key to his happiness with Sarah and John. For Rouel, this job differs from other caregiving contexts because he is not just an employee; he is part of a family. Rouel explained, “if your employer is good to you, you can do [the job] and be happy.”

The teamwork that Rouel documented in his diary is one way this sense of family is performed. When John has an anxiety attack, Sarah and Rouel work together to take care of a person they both care about. Rouel explained that he can take care of John alone, but John is better when he and Sarah work together. This is because Sarah will hold John’s hand and say, “Honey, I’m here, calm down. It will be all right.” Sarah soothes John while Rouel tries things like wiping his face with a wet washcloth, putting John’s favorite music on the stereo, or bringing John some orange juice. Rouel said his English is not always good, so John understands better when Sarah is there, but more important is the fact that she is John’s wife and she is able to calm him when he is anxious. Rouel said this teamwork is good for Sarah, good for himself, and good for his patient; he can do his job easily when he has this type of support.

Sarah also sees teamwork as one way Rouel being a part of their family is performed. Sarah agreed that teamwork is support for Rouel because he is able to leave the room while she soothes John. She explained:

If [John’s] shaking or upset, then I hug him and I kiss him and I smooth his hair and his brow and hold his hand or comfort him and [Rouel] can go to the bathroom maybe and get a wet washcloth and sponge his face and that quiets him down. And he just knows to do it. I don’t even have to tell him to do it, you know.

In addition to support for Rouel, however, Sarah sees teamwork as support for herself. She said:

I don't feel as upset [as] when I was alone with him and these things used to happen. ...It's a big support to know he's here. ...God forbid we'd have to go to a hospital. He would be here for me and go with me and I know it.

He's right there, you know. He doesn't rest until [John's] back to being himself. He's right there waiting and I know it. I don't have to say anything. He wouldn't just leave me alone if something wasn't right with [John]. He's right there.

Part of what contributes to a sense of teamwork for Sarah is that she does not have to tell Rouel what to do. Rouel and Sarah work together to figure out what will help John. During the interview, Rouel and Sarah negotiated something they are going to do from now on because they have discovered its helpfulness:

Rouel: He misses [Sarah]

Sarah: Today? Today he missed me?

Rouel: Yeah. "Where is my wife?" [I told him], playing Mah-Jongg.

Sarah: I'm going to write a note from now on. The other day I wrote a note [saying] where I was and I left it there and...then when he missed me, [Rouel] showed it to him. I think that's kind of a good idea.

Not telling Rouel what to do may contribute to a sense of family for both Rouel and Sarah. While an employee is someone to whom one gives instructions, a friend or family member is someone with whom one negotiates effective care strategies.

Sarah identified a second way a sense of family is performed. She says Rouel and John are not just caregiver and patient, but friends. Sarah mentioned watching televised sports, especially basketball, as something John and Rouel enjoy doing together:

I love to see them together looking at basketball or looking at sports because [John] always loved sports and I never was that much crazy about

it, so when I see them together looking at a football game or basketball game, I'm really happy.

This friendship was also confirmed by John. I went to Sarah's home for my interview with her and Rouel. Sarah tried to get John to watch television in the other room, but he knew I was there to talk to them and wanted to join us. All four of us sat at the kitchen table. John understood Sarah was talking about Rouel. Throughout the interview John would grasp Rouel's arm or hand and say, "He's a great guy." When John did this, Rouel would return the touch and smile at John. Rouel said, "He's my best friend."

Rouel's affinity for John was evident to Sarah when there was a crisis situation. One behavior caregivers for Alzheimer's patients must cope with is wandering. John and Sarah have a second home in Palm Springs and they often go there for extended weekends. On one of these weekend trips, John wandered off. Sarah described Rouel's reaction when they discovered John was missing:

[Rouel] was so supportive. He ran all over the neighborhood while I was driving all over the neighborhood. ...He was running. When he came back, he had to take all his clothes off because he was wringing wet from running and looking. He was just as worried about [John] as I was.

Sarah explained that she and John used to walk a lot in Palm Springs. John must have wanted to go for a walk and, as Sarah explained, "Just like that, he disappeared." John was missing for almost an hour. Sarah suggested at one point that Rouel stay at home in case John came back while she was driving around. Rouel said that he could not do that; he had to help look for John. Sarah explained, "[Rouel] was right there. He didn't stop and [Rouel's] the one who found him." While Sarah's appreciation at the time communicated that

Rouel's assistance was supportive, Rouel's concern for John's well-being contributed to the sense of family they all share. It is this sense of family which provides a broader context for support in this relationship.

A third way a sense of family is performed is that Sarah's family has established a relationship with Rouel and Rouel's family has established a relationship with Sarah and John. Rouel's wife and daughter have come to Sarah's home to meet her and John. In addition, Sarah says:

His wife even sends cooking home for [Rouel] and also for us. And his daughter too. Makes some delicious food and I always, you know, if he serves it I'll say, "That's delicious." We're so lucky. ...I'm always calling his wife and thanking her and I try to send something over to her that's American type food and she calls up to thank me.

Just as Sarah has a relationship with Rouel's family, Rouel has a relationship with Sarah's children and grandchildren. Amy described her family's relationship with Rouel:

I took an immediate liking and I know my parents did too. I know that my brother did. ...We all like [Rouel]. ...He's a part of the family now. And it's like, you know, if I saw Grandma and Grandpa without [Rouel], I'd like, "Wait. Where's [Rouel]?" ...It's like I expect to see [Rouel]. You know, and I'm happy that he's here. It's not like, "Well, God, why does it have to be [Rouel]? Why can't it be somebody who's nicer?" I don't think there could be somebody nicer.

Rouel is not just an employee whose relationship with his employer goes no further than the performance of his duties. He has become part of a family and this sense of family is evidenced and reinforced by Rouel and Sarah's teamwork, Rouel and John's friendship, and Rouel and Sarah's relationships with one another's family.

The Hired Caregiver Goes Beyond the Call of Duty

Rouel being a part of Sarah and John's family leads to the third part of the

support process which is that Rouel goes beyond the call of duty in the things he does for Sarah and John. Sarah finds the extra things Rouel does supportive, but Rouel says she makes what he does possible because she treats him like family. Rouel explains, "You know I do [everything] because [Sarah] is a good lady and [John] is a good man. All that I do is because they are kind to me." I asked Rouel how it came about that he did things not directly related to caring for John. He said he found himself sometimes not having anything to do; he would just be sitting around. Rouel said he wanted to do something for Sarah, he wanted to help, because Sarah and John had made him like family. His way of helping was to find extra things to do.

In talking about how Rouel goes beyond the call of duty, Sarah said, "I think he takes more care of me. He does an awful lot for [John], but he also does an awful lot for me. He's a wonderful man." Sarah explained several ways in which going beyond the call of duty is performed:

[Rouel]...has taken over most of my duties. Before I know it he's washing clothes and drying clothes and folding clothes.

I try to help him a little bit when I can, but he's so fast at doing everything. Before I know it, it's done. He even puts our pills in our pill dish.

He does go overboard helping me. He shouldn't do some of the things that he does because he does the dishes after breakfast and lunch and dinner. And I could do that. But he just takes over and does it.

I get up, after I wash in the morning, and I come in here at seven-o'clock, he's got my coffee ready. I always thank him. And he's got the table set and he makes, [John] always has cold cereal with sliced banana and fruit or juice and lately I've been having Cream of Wheat. He's learned how to make Cream of Wheat the way I like it. It's all ready and waiting. I'm very spoiled. I should be doing some of these things.

Rouel and Sarah have created a reflexive system. Sarah treats Rouel like a

part of her family. This is supportive to Rouel and makes him happy, so he wants to make Sarah happy by doing things for her. He goes beyond his caregiving duties for John, essentially becoming a caregiver for Sarah as well. Sarah finds this supportive and tells Rouel that she appreciates all he does. This reinforces the happiness Rouel feels and he continues to feel like a part of Sarah and John's family.

Sarah is not the only one who notices that Rouel goes beyond the call of duty. Amy is also very aware of all that Rouel does for her grandmother. In terms of helping her grandmother, Amy has noticed that Rouel helps with daily tasks and chores. She explained:

I know that Grandma doesn't have to cook anymore. [Rouel] does cook for them. ...Not saying grandma doesn't cook, but I'm seeing, you know, when and if Grandma needs to take a load off, [Rouel] can help. He is definitely there to do it.

Like in Palm Springs, he comes into, you know, when we were eating dinner, he came in and started clearing the dishes and I was really surprised because usually...we all do it as a family. He came in and started helping and I was like, "Wow." ...I was really impressed.

Amy views Rouel's assistance with household chores as support for her grandmother because it relieves Sarah of having to do them herself.

Amy also believes Rouel goes the extra mile when it comes to helping her grandfather. Amy compared Rouel to the previous caregiver her grandmother employed. Sarah had already explained that Mary was there from nine to five and was more of a sitter. Amy believes there is quite a difference between the way Mary and Rouel treat her grandfather. She explained the difference she saw the first time she met Rouel:

[With Mary] it was more [like]..."He can get over it." But that was just my view, I don't know, [because] I wasn't here all the time. It just seemed like with

[Rouel] he's very supportive. Just "Come on [John]. You can do it. Wake up. Come on. Here's some orange juice." You know, "Let me wipe down your [face], Let me massage you. Let me do this. Let me do that. Let me do this for you. Let me make you as comfortable as you can." ...I was really impressed.

For Amy, going beyond the call of duty does not just entail doing extra work that is not what Rouel was hired to do. Going beyond the call of duty also means going beyond helping John dress or shower; it means giving extra energy and attention to her grandfather.

Rouel does things which are not directly related to helping John and he brings a great deal of energy and enthusiasm to those tasks which are directly related to caregiving. These actions are talked about as going beyond the call of duty and are supportive to Sarah and her family. Sarah feels that Rouel takes care of her as well as John. Sarah's family sees how happy Sarah is with Rouel and how much he does to take care of two people they love.

Coping and Adjustment

The previous three aspects of the support process--the hired caregiver being there when he is needed, the hired caregiver being a part of the family, and the hired caregiver going beyond the call of duty--all lead to coping and adjustment. As the primary caregiver and John's spouse, Sarah probably suffers the most burden. For her, coping and adjustment means this burden is somewhat lifted. In her diary, Sarah noted her coping and adjustment since Rouel has been with her. In our interview, I asked her to tell me what she meant by coping and adjustment. She told me, "I'm just like a new person. I can smile and laugh and I used to cry a lot. I don't cry anymore."

Amy also sees a tremendous difference in her grandmother since Rouel has come to work for Sarah. She said:

Since [Rouel] got here, Grandma can go out and do what she wants. She can go shopping if she wants to. We went out to lunch the other day and we had a really nice afternoon...and that's nice because she doesn't have to worry.

Amy also says her grandmother has gained back the weight she lost. She told me, "She looks healthy and she's as lively as she was before. She seemed to have lost personality before, ...you know, more quiet, and it seems that now she's happier." Amy absolutely attributes the change in her grandmother to Rouel. She said:

You look at Grandma, you look at [Rouel], you can tell that they're happy. ...He's overall just a wonderful person. And I don't think it needs to be said. Everybody knows it. ...You just look at it and you say, "This is a really good situation."

Sarah is not the only one who is able to cope and adjust. Her children and grandchildren also benefit from the support process. Sarah told me her daughter and her son were always worried prior to Rouel joining the household. She says, "Now, ...none of us are that worried." The worry Sarah mentions is likely worry for her own well-being as well as John's. Now that Rouel is there, everyone can see that Sarah is not so distressed; she and John are both well taken care of.

John is also a beneficiary of the support process. Sarah, Amy, and Rouel all believe John's state of being has improved since Rouel joined the household.

Rouel said:

When I came to start my job, [John] is very weak. ...Now in the past one month or two month[s]...he's strong. We walk together. ...Now he is very, very strong. Before [John] was sick like that, but now...it's all right.

In addition to John being stronger, Sarah says John's anxiety attacks used to be a lot worse, but they are better since Rouel came to them.

Amy made it clear that these changes in her grandfather are not small changes only someone who lived in his home would notice; the benefit to her grandfather has been apparent to her family as well. She said:

I remember there were times when...we'd call Grandma's house, she'd say "Oh,...it was a bad day." And we started to notice that there were more bad days than there were good days. And now it seems like more often it's been a good day than anything else. Every time I talk to Grandma,...[I ask] "How's Grandpa doing today?" [She tells me,] "Oh, he's been really good today." ...There have been more good days since [Rouel] has come along.

Amy also considers her grandfather a very funny person and says they always have a great time together. She feels the best thing about him is his outgoing personality. Amy believes Rouel has helped restore that personality. She explained:

Because there's emotional support...I think that everybody's happier. You know, and Grandpa seems happier and he seems more upbeat more of the time than he was before. Not to say that [Mary] wasn't doing her job, but [Rouel] really, it's different because [Rouel] is really giving the support that he needs to.

Finally, the support process helps Rouel cope and adjust. Rouel has had other caregiving jobs and knows how to carry out the tasks of caregiving, such as helping someone with their ADL's. The support process has helped Rouel adjust to the new caregiving setting with Sarah and John. He feels comfortable in their home and cares about both of them. This helps him cope with the demands of his job. Supervising and caring for someone is draining and Rouel does it 24 hours a day. While many people would call the job Rouel does extremely difficult, the support process enables Rouel to call his caregiving job "easy."

For Sarah and her family, coping and adjustment are not automatic

byproducts of having a hired caregiver. This is evidenced by the difference between Sarah's experiences with Mary and Rouel. It is also evidenced by Amy's description of the difference between her, and her family's, reaction to Mary and Rouel. For Rouel, coping with his job and adjusting to a specific caregiving setting are also not automatic. This is evidenced by the distinction he draws between his current position and previous caregiving work. Finally, coping with Alzheimer's and adjusting to a hired caregiver is not automatic for John. This is evidenced by the difference in his health since Rouel has been with him. Coping and adjustment is only possible because of the support Sarah and Rouel have negotiated in the other parts of the process.

Summary of Findings

As noted at the outset of this chapter my first research question--What do primary and hired caregivers for people with Alzheimer's identify as support in their relationship with one another?--was answered by the caregiver diaries. Rouel identified teamwork as supportive in his relationship with Sarah while Sarah identified her ability to be alone as well as her ability to cope and adjust as supportive. In Sarah's case, the ability to be alone, either briefly or for longer periods of time, is one way coping and adjusting are performed. In Rouel's case, teamwork is supportive because he and Sarah work together when they need to, such as when John has an anxiety attack, but they also know when they do not need one another's help.

As also noted at the outset of this chapter, my second research question--How is what primary and hired caregivers identify as support negotiated in talk?--was answered by interviewing Sarah and Rouel and by analyzing the interview transcript. This analysis demonstrated that the episodes described in

the diaries were not inherently supportive, but were constructed as support in the context of a larger process. This process consisted of four elements: 1) the hired caregiver is there when the primary caregiver needs him, 2) the hired caregiver is part of the family, 3) the hired caregiver goes beyond the call of duty, and 4) the primary caregiver is able to cope and adjust. The episodes Sarah and Rouel identified in their diaries serve to create the support process and the support process enables Sarah and Rouel to construct the episodes as support.

Chapter 4

Implications, Limitations, and Conclusion

This research has theoretical, methodological, and practical implications. In this chapter, I will discuss these implications as well as the limitations to this research project and suggestions for future research.

Implications

This research has theoretical implications for the study of support because the social constructionist framework provides information which no other perspective can provide. Reflexivity is central to the constructionist perspective. Reflexivity refers to the inextricable nature of speech acts and context. Speech acts create contexts and contexts determine what speech acts may be performed and how speech acts are to be interpreted (Pearce, 1994). This research demonstrates that support is not tied to the presence of others, it is not a mental representation, and it is not ostensibly linked to messages; it is constructed between people in a reflexive communication process.

In their diaries, Sarah and Rouel identified specific episodes they found supportive, but in the interview they discussed *how* they construct the themes I identified in their diaries as support. For example, teamwork was a theme in Rouel's diary. Teamwork is constructed as support for Rouel because communication processes create a sense of family; thus, he and Sarah are working together to take care of someone they both care about. Teamwork is a specific action and a sense of family is a context. This action and context are reflexive; a sense of family is made by teamwork and the meaning of teamwork is derived from a sense of family. The episodes Sarah and Rouel reported in their diaries, such as incidents of teamwork, are not inherently supportive; they

are constructed as support in a reflexive process.

The support process (See Appendix D) as a whole is reflexive; speech acts create the process and the process creates the opportunity for certain speech acts to occur and for certain speech acts to be interpreted as support. Each individual part of the support process is also reflexive and this reflexivity is transformative.

The first part of the support process is the hired caregiver being there when the primary caregiver needs him. Sarah and Rouel have negotiated, via speech acts, when Rouel needs to assist John alone, when Sarah and Rouel need to work together, and when Rouel does not need to be with John; speech acts create the nature of Rouel's caregiving assistance. The nature of the caregiving assistance Rouel provides leads to speech acts which identify his being there when he is needed as supportive. These speech acts cycle back and recreate the nature of his assistance. This reflexive loop transforms the social context in which Sarah and Rouel live.

The social context has been transformed because Rouel is now a part of Sarah's household. Sarah's decision to maintain live-in caregiving assistance is a result of reflexivity within the first part of the support process. Prior to hiring Rouel, Sarah did not think she would like an extra person in her home. Reflexive communication processes have created a system where Rouel is there when he is needed, but not intrusive. This transformed Sarah's apprehension regarding live-in caregiving assistance. With her apprehension eased, Sarah has continued to employ Rouel. Rouel's addition to the household transforms the social context within Sarah's home and this transformation is achieved through reflexive communication processes.

The second part of the support process is the hired caregiver being a part of the family. Again, there is reflexivity within this part of the support process. Speech acts create a sense of family and a sense of family enables speech acts which recreate the sense of family. This reflexive loop has transformed the primary/hired caregiver relationship in that Sarah does not view Rouel as merely an employee in her home and Rouel does not feel like an employee. Transformation of the primary/hired caregiver relationship means the definition of a hired caregiver is transformed. Rouel is not an employee who carries out orders; he and Sarah work together to determine what will benefit John. Beyond transforming the primary/hired caregiver relationship, the reflexive sense of family has transformed the caregiver/patient relationship. Rouel and John's relationship has been transformed from care provider and care recipient into friendship. Rouel is taking care of someone he cares about; he is not providing care solely to earn a paycheck. Reflexivity within this part of the process has also extended relationships in that Rouel and Sarah have established relationships with one another's families.

The third part of the support process is the hired caregiver going beyond the call of duty. Speech acts contributing to the sense of family shared by Rouel and Sarah leads to Rouel doing extra tasks. Rouel going beyond the call of duty leads to speech acts which reinforce the feeling that Rouel is not just a caregiver for John, but part of Sarah and John's family and home. This reflexivity transforms the hired caregiver's duties as well as what counts as a supportive act in this relationship.

Sarah hired Rouel to help John with his ADL's, to stay with him when she went out, and to help her when John has an anxiety attack. Rouel went beyond

these duties; he took on household chores and did things to take care of Sarah. Sarah responded positively to Rouel when he did these things; therefore, he has continued to go beyond the call of duty. Rouel's job has been informally transformed via this reflexivity. For example, Sarah did not formally tell Rouel to have her coffee ready when she gets up in the morning; reflexive communication processes added this chore to Rouel's repertoire of responsibilities.

Going beyond the call of duty has also transformed support in Rouel's relationship with Sarah. Rouel providing care for John is supportive to Sarah; her need for this type of assistance is what led her to hire Rouel initially. Now that Rouel's duties have been transformed, the things Rouel does which are not directly related to helping John are also supportive to Sarah. Those acts which count as support have been extended and transformed through reflexive communication processes.

The fourth part of the support process is coping and adjustment. The first three parts of the process all lead to coping and adjustment, but coping and adjustment cycles back into the process and reconstructs the individual parts. This final reflexive part of the support process represents individual transformation. Sarah is a different person now than she was before Rouel joined her household and the support process began. Prior to hiring Rouel, Sarah was helping John with his ADL's; this wore her down physically and emotionally. Sarah worried when she went out by herself because the woman she employed to stay with John could not handle him alone. This state of affairs has been transformed by the support process. Sarah is no longer physically drained or emotionally upset and she can leave the house alone

without worrying. Sarah used to be a person who cried; Sarah is now a person who laughs and smiles rather than crying.

Sarah is not the only person who has been transformed. Sarah's children and grandchildren used to be worried about Sarah and John, but now they are not worried. John is healthier; he is having more good days, is stronger, and has regained his sense of humor. Rouel used to be a caregiver; he made good money and could support his family. Now Rouel works to support his family, but is also happy; he is a family member, not just a caregiver. Reflexivity within and across the support process is not just enabling Sarah and Rouel to feel supported; it is transforming them and the people around them.

Prior social support research was guided by sociological, psychological, and message-centered perspectives. Each of these perspectives evolved from criticism lodged against the preceding paradigm. The social constructionist perspective of support represents yet another evolution. Message-centered research can not account for origins; it can not tell us how the categories of supportive and unsupportive come into being. The social constructionist perspective moves past this criticism because it does not stop at identifying what counts as support; it focuses on how messages are constructed as support.

Continuing to investigate support from the social constructionist perspective allows communication scholars to make a unique contribution. An example can illustrate this contribution. Many people probably view a hired caregiver helping an Alzheimer's patient with his or her ADL's as automatically supportive to a primary caregiver because he or she is relieved of those duties. The social constructionist perspective allows us to see that helping an

Alzheimer's patient with ADL's is not automatically supportive. If a hired caregiver were rough with the patient while giving this assistance, the primary caregiver would not find this supportive and would not respond to the hired caregiver in a way that communicated he or she viewed it as support. The social constructionist perspective allows us to see that support is a product of reflexive communication. Communication scholars can make a unique contribution to the study of support by focusing on this reflexivity.

Beyond implications for support research, this case study illustrates the viability of the social constructionist perspective. The basic premise of social constructionism is that meaning is not tied to the ostensive definitions of words; meaning is in use. From this perspective, speech is action. As Pearce (1994) explains, we coordinate with others to create meaning in specific contexts. Meaning was not tied to Sarah sitting with John during his anxiety attack while Rouel got a wash cloth. This episode was constructed as support for Rouel because there is an historical precedent for Rouel and Sarah working together in these situations and Sarah responds to Rouel in a way that tells him he is doing a good job and she appreciates his help. This episode could just have easily been constructed as unsupportive. If Sarah had rolled her eyes or in some other way communicated displeasure because Rouel could not handle John's anxiety attack alone, her sitting with John while Rouel tended to other tasks would not have been supportive to Rouel.

I asked Rouel if it would be support no matter who was there to help him when John has an anxiety attack. He said it would not; it has to be Sarah. I asked Sarah if it would be support no matter who she had to take care of John. She also said it would not; it is the way Rouel does his job and is part of her

family that makes his presence supportive. Sarah and Rouel have created a process that goes beyond ostensive meaning. They recognize that the episodes they identified are supportive for a reason. The social constructionist perspective does not try to find this reason in people's minds; it identifies how that reason is constructed in talk. It is the way the participants talk to one another that influences how they think about their relationship and how they behave in the relationship.

In addition to theoretical implications, this research has methodological implications for the study of support. Past research has provided a variety of methodological models appropriate to sociological, psychological, and message-centered perspectives of support. There are, however, no models for exploring support from a social constructionist perspective. While the diary/diary interview method is not new, using this method to get at the social construction of support is new. What made this method ideal for investigating the social construction of support was interviewing the participants together. The interview served as a context for caregivers to socially construct support in talk. I do not claim this methodology is the ideal way to investigate support from this perspective, but this research can serve as a starting point for a dialogue concerning methodological means of conducting social constructionist support research.

Opening a dialogue pertaining to social constructionist support research is important because this perspective can explain research findings which are anomalous under different perspectives. Previous support research has not yielded consistent results. These inconsistencies are apparent in both the caregiving and non-caregiving support literature. Researchers have sought to

illustrate that support leads to positive mental and physical well-being. While some studies do indicate a positive relationship between support and well-being, others have shown no relationship or a negative relationship between these variables.

These anomalous findings can not be explained under the sociological, psychological, and message-centered perspectives. For example, if a researcher is guided by the sociological model, an individual's social network is equated with support and support is believed to have positive health effects. A researcher can not explain how two caregivers with similar social networks can have vastly different levels of depression. One caregiver may indeed have low levels of depression as measured by a depression instrument, but the second caregiver may rate much higher on the same depression measurement scale. From the psychological perspective, if an individual's general sense of support leads to positive health outcomes, researchers can not explain how a caregiver who rates himself or herself as generally supported can have the same level of depression as someone who rates himself or herself as lacking support. Finally, from the message-centered perspective, researchers can not explain why some caregivers could find certain messages supportive while other caregivers do not.

Inconsistencies seem to arise in research because what counts as support is assumed at the outset. For example, respite services are assumed to count as support and, therefore, are expected to benefit caregivers. This was the case in the Quayhagen and Quayhagen (1988) research, which found respite benefited daughters caring for impaired parents, but had no effect on wives and a negative effect on husbands. This finding is consistent with social

constructionism because support is not expected to be an automatic byproduct of respite. The primary caregiver's past respite experiences, his or her relationship with the respite provider(s), the Alzheimer's patient's reaction to respite care, and the reaction of others to the respite program all may impinge on whether respite is or is not constructed as support.

From the social constructionist perspective, Quayhagen and Quayhagen's (1988) findings are not inconsistencies; people are simply constructing different realities. Perhaps an adult daughter who is a primary caregiver takes an Alzheimer's patient to an adult day care center. The primary caregiver's friends all say how happy they are that she is taking a break. In addition, the Alzheimer's patient seems to enjoy the center and the day care employees are pleasant to the caregiver. In this case, speech acts create a context within which respite may be constructed as support; thus, respite may have positive effects for the caregiver. In another case, friends of a man who is a primary caregiver for his wife may ask if she is scared when she is left alone with strangers at the day care center. The Alzheimer's patient may resist being left alone or the day care staff may burden the caregiver by reporting every instance of the Alzheimer's patient's anxiety. In this case, speech acts create a context within which respite may not be constructed as support for the caregiver; thus, respite may have negative effects.

Social constructionist researchers expect people in social systems to construct support differently. For this reason, social constructionist research would focus on how respite is or is not constructed as support rather than assuming it counts as support for all caregivers. While social constructionist research should not replace all other forms of research, it does fill a gap by

describing the construction of support, or lack thereof, before describing its effects. If this description is to occur, researchers must develop methodologies which illuminate the construction of support in talk.

In addition to theoretical and methodological implications, this research begins to lay a foundation for practical application. More and more primary caregivers for Alzheimer's sufferers are turning to formal care services for assistance, but the relationship between hired and primary caregivers has been neglected in research. The goal of caregiving research should ultimately be to improve the lives of caregivers. As more research focusing on the social construction of support between caregivers is completed, the insights gained by researchers could be used to help other primary and hired caregivers construct supportive relationships. For example, researchers could help caregivers talk about the primary/hired caregiver relationship as a partnership rather than as an employee/employer relationship. When caregivers transform their relationship via speech acts they will act in ways which are consistent with that relationship. It is within this context that speech acts are constructed as support. Practical application of this nature may enable caregivers to transform their lives and form mutually supportive relationships.

In regard to my methodology, having hired and primary caregivers talk about support together may be therapeutic. I believe there must have been some effect when Sarah looked across the table at Rouel and said that she appreciates all he does for her and that he has changed her life. I also believe there must have been some effect when Rouel looked across the table and said Sarah has made him like a part of her family and he loves her and John. Harré and Gillett (1994) argue that our thoughts result from our "interpersonal

discursive processes" (p. 27). It seems logical that Rouel and Sarah's talk would result in thoughts of the relationship being good and the relationship being supportive. Talk and action are also reflexive; therefore, Rouel and Sarah are likely to continue saying and doing what one another identified as supportive. Research is always an intervention which can have positive or negative effects for participants. In the case of this intervention, the research seemed to have a positive effect on people's lives rather than solely contributing to a body of scholarly knowledge.

Limitations

Although this research described what a hired and primary caregiver for an Alzheimer's patient find supportive and how that support is negotiated in talk, there are several limitations to this project. These limitations pertain to the scope of the project and several aspects of the methodology.

The first limitation of this research is that it became a case study. The difficulties which arose in recruiting participants could not be foreseen, but they did limit my ability to identify commonalities among caregiver experiences. The data collected only reveal how one primary/hired caregiver dyad negotiates support. Future research should include multiple dyads in order to determine if similar realities are being negotiated. There were striking similarities between my pilot study results and the actual case which became the focus of my research. For example, both dyads spoke of a sense of family. Despite this similarity, how a sense of family is performed was quite different in each case. Another task for future research is, therefore, to determine not only if caregivers create similar realities, but if there are similarities in how they go about creating that reality. In other words, do caregivers tend to arrive at the same place

through similar means or do they arrive at the same place through a variety of means?

A second issue which relates to including more dyads is the inclusion of more demographic information. In this research I only provided the caregivers' biological sex, ethnic background, and length of time together. Other factors such as age and whether the primary caregiver resides with the Alzheimer's patient should be included in future research. Correlating demographics with other variables is not paramount to the constructionist perspective, but there may be demographic differences related to how caregivers construct support. For example, whether a primary caregiver lives with the Alzheimer's patient or resides elsewhere may impact the negotiation of support. Culture may also be a factor. When I was recruiting participants, the director of the gerontology center told me that I was going to find great differences between what a Filipino hired caregiver and a hired caregiver of Mexican descent identify as support. I did not find this to be the case with the hired caregiver in my pilot study and actual study, but additional research may reveal such differences.

A second limitation of this research is that my methodology does not adequately present the reflexivity within each part of the support process. For example, Rouel and Sarah spoke of teamwork. I do not know how knowing when to work alone and knowing when to work together was originally negotiated or how it continues to be renegotiated in discourse. I know under what circumstances Rouel and Sarah work as a team and I know that it is important to both of them that they do so, but I do not know how teamwork is initiated, performed, and evaluated in talk. If this negotiation is to be documented in future research it would require some form of ethnographic

research in which a researcher could keep detailed field notes.

A third limitation to this research is that support was assumed to be a significant aspect of the primary/hired caregiver relationship. Asking caregivers to write and talk about support privileged my belief that support is a critical part of caregivers' lives. If the goal of future research is to contribute to the support literature, this methodology seems appropriate; however, if the goal of future research is to discover what is important in this relationship the methodology would be inappropriate. Future research should document the talk in primary/hired caregiver relationships more generally and then determine if support is an important aspect of the relationship.

A fourth limitation of this research pertains specifically to data collection. Caregivers were asked to write and talk about those aspects of the primary/hired caregiver relationship which are supportive, but not those things which are unsupportive. Focusing solely on support may inaccurately characterize individual primary/hired caregiver relationships. In fact, the primary caregiver who could not participate because the hired caregiver did not complete her diary told me that everything she wrote in the diary was true, but there are also a lot of things she does not like about the hired caregiver. Requiring participants to write and talk only about support prematurely assumes the relationship is supportive overall.

A fifth limitation of this research is that the data analysis privileges my interpretation. I formed the categories and the relationships among categories. Future research should better privilege the participants' interpretations. Two possible methodological modifications could achieve this. One possibility is for individual utterances to be put on cards for the participants to sort. Participants

could sort utterances into categories and determine relationships among categories. A second possibility is for the researcher to check back with participants after categorizing and organizing the data. This check is not necessarily exclusive of the first modification and would allow participants to modify the presentation of findings.

Conclusion

As Alzheimer's disease progresses, its sufferers are robbed of their very being. The loved ones who are left behind must cope with their grief and anger as well as the arduous task of caring for the Alzheimer's patient. Some caregivers find that the only way they can face the challenge of such care is with assistance; thus many primary caregivers hire someone to take on varying levels of care. The primary/hired caregiver relationship is a possible source of support for both individuals. Support is not an automatic byproduct of the primary/hired caregiver relationship, however, and it is not a mental representation. Support is created and recreated in interpersonal discourse.

This research illustrated the centrality of communication to support between primary and hired caregivers for people with Alzheimer's disease. Episodes caregivers identify as support are negotiated in talk. These episodes create a larger support process and the process, in turn, contributes to certain episodes being identified as support. Support is a reflexive communication phenomenon. Reflexivity within and across the process is transformative. Prior to Rouel joining the household, Sarah's home was not a happy place. Sarah was run down, John was weak, their family was worried. Prior to joining Sarah's household, Rouel had a job, but was not happy. All of that has changed. Sarah and Rouel share a sense of family and work as a team, John

and Rouel share a sense of friendship, and everyone involved is able to cope and adjust to their situation.

Reflexivity is the cornerstone of social constructionism, thus identifying support as a reflexive process was not entirely unexpected. What was unexpected was the transformation resulting from this reflexive process. Primary and hired caregivers could create and recreate the same episodes and meanings and never bring about transformation. For example, Rouel and Sarah could have created and recreated an employee/employer relationship, thus never transforming their relationship into friendship or a sense of family. This study illustrates that when primary and hired caregivers negotiate support, they can change their lives. This change brings light to what was once a very dark place.

Notes

1. This is a near-verbatim transcription. Nonfluencies such as “uh” and “um” as well as repetitions such as “I guess, I guess...” were eliminated.
2. All names have been changed to protect the anonymity of participants.

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Appendix A

Diary Instructions and Page

This is the diary in which I would like you document times, when in interaction with [insert name of primary/hired caregiver], you feel supported.

I ask that you observe the following guidelines:

- 1. Answer all questions on the diary entries.**
- 2. Record the incident as soon as possible after it occurs.**
- 3. Be specific regarding what both of you say and do and the order in which things are said and done.**
- 4. Remember, If an incident is notable to you, it is of interest to me. Do not avoid recording an event because it seems mundane.**

Once again, I would like to thank you for agreeing to keep this diary and participate in my research study.

Support Diary

Date: _____

Day of the Week: _____

Approximate time the incident being recorded occurred: _____ a.m. / p.m.

Where were you when this incident occurred? _____

What were you doing when this incident occurred? _____

Who else was present when this incident occurred? _____

What were the other people present doing? _____

In the space below, please describe a time you felt you received support or were supported by [insert name of primary/hired caregiver] this week. Write freely about what happened, be specific about what was said and done, and explain how you felt. Continue writing on the next page if necessary.

Appendix B
Interview Guide

Questions based on the primary caregiver's diary:

1. [To primary caregiver] How does [the hired caregiver] help you cope? How has he helped you adjust to your life? How is helping you cope/adjust performed? How else is it performed?
 - 1a. [To hired caregiver] Do you see yourself as helping [the primary caregiver] to cope or adjust to her life? If so, how do you help her to cope or adjust?
2. [To primary caregiver] How do you know it is support when [the hired caregiver] does something that enables you to be alone (either briefly, like at the market or theater, or longer)?
 - 2a. [To hired caregiver] When you do something that enables [the primary caregiver] to be alone, do you see it as support? How do you see it?
 - 2b. [To hired caregiver] How did/do you come to know to do things that enable [the primary caregiver] to be alone?
3. [To the primary caregiver] How is it that [the hired caregiver] does these things that help you cope and adjust that makes it supportive?
 - 3a. Can you imagine other ways of doing these things that would not be supportive?
 - 3b. You mention in your diary that you thought you would be more miserable with someone living in your home, but you are not. How is it that [the hired caregiver] does his job that makes his being here supportive?
 - 3c. Would it be support no matter who enabled you to be alone? Would this always help you adjust/cope?

4. [To the primary caregiver] How do you let [the hired caregiver] know that what he is doing or the way he is doing it is supportive?
5. [To hired caregiver] How does [the primary caregiver] respond when you've stayed with [the person with Alzheimer's] so she can do what she needs to do? Does she thank you?
 - 5a. How do you know when you are doing something right?
 - 5b. How do you feel when you are thanked or know you did something right? Is this support for you?
 - 5c. How else does [the primary caregiver] communicate that you are doing well or that she appreciates something you have done?
6. [To the primary caregiver] Do you hear stories about other hired caregivers? How do those stories compare to your situation? How does support differ? How is it the same?
7. [To the primary caregiver] How do you define support? How has keeping this diary affected the way you define support?
8. [To the primary caregiver] Specifics from the diary:
 - The hired caregiver took [the person with Alzheimer's] to the car at the market: How was this arranged? How was this "evaluated?"
 - The hired caregiver stayed with [the person with Alzheimer's] while you went to the theater foyer: How was that arranged? How was that "evaluated?"
 - 8a. How are these things supportive?
 - 8b. What is it about the way [the hired caregiver] did these things that makes it supportive?
 - 8c. How did you let [the hired caregiver] know this was supportive?

Questions based on the hired caregiver's diary:

1. [To the hired caregiver] How does [the primary caregiver] help you?
 - 1a. What makes this supportive?
 - 1b. Can you imagine a way that this would not be supportive?
 - 1c. [To the primary caregiver] When you are helping [the person with Alzheimer's] together, do you interpret that as support for [the hired caregiver]? Do you interpret it as support for yourself? One more than the other?
2. [To both] How do you know when to work together as a team? Does [the hired caregiver] ask for help? Does [the primary caregiver] say "Let me help" or "Let's do this?"
 - 2a. [To the hired caregiver] Do you thank [the primary caregiver] for helping you? Does she thank you for helping her?
 - 2b. [To the primary caregiver] How do you know when [the hired caregiver] appreciates your help?
3. [To the hired caregiver] How does [the primary caregiver] let you know (communicate) that you are a team? How is being a team performed? How else?
 - 3a. Would it be support no matter who helped?
 - 3b. Do you often work as a team?
 - 3c. What is it about letting you know you're a team that makes it support?
4. [To the hired caregiver] Take me through some examples from the diary:
 - You both helped coach [the person with Alzheimer's] to his chair for a nap: How was acting as a team arranged, performed, and evaluated?
 - You both stayed with [the person with Alzheimer's] when he was agitated:

How was this arranged, performed and evaluated?

5. [To the hired caregiver] Have you worked in other caregiving contexts or heard others talk about caregiving experiences?

5a. How does support differ?

5b. How is support the same?

6. [To the hired caregiver] How do you define support?

6a. How has keeping this support diary affected the way you define support?

Appendix C

Instructions Sent With Diaries

Dear [insert name of primary and hired caregiver],

I would like to thank you both for agreeing to help me with my research project. As you know, I am interested in how primary and hired caregivers provide one another with support. That is why I am asking you both to tell me about times when something that the other individual says or does is supportive. I have included a diary for each of you (your name is on the diary). I ask that you each record three to five incidents in the diary during the course of this week. When something is said or done that is supportive to you, write about it in the diary as soon as possible so it is fresh in your mind. Two other things are very important: First, do not avoid writing about something you find supportive because it seems too everyday or mundane. If something is supportive to you, I am interested. Second, there are no wrong answers. If you feel supported by something the other person says or does, then it "counts" as support.

I will call you on [insert prearranged day] at [insert prearranged time] to answer any questions you may have. As you know I want to sit down with both of you after you keep your diaries so that I can talk to both of you about support and the incidents you recorded. When I call, I will arrange a date for that interview.

Again, I can not say thank you enough for your willingness to take your time to help me.

Appendix D
The Support Process