

“WE DON’T LIKE TO CALL IT LYING, IT’S JUST THERAPEUTIC COMMUNICATION”:
UNDERSTANDING THE INFLUENCE OF SOCIAL SUPPORT ON COPING WITH
ILLNESS UNCERTAINTY

BY

ANNE MARGARET STONE

DISSERTATION

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Doctoral Committee:

Associate Professor John Patrick Caughlin, Chair
Assistant Professor Marian Huhman
Associate Professor Leanne Knobloch
Associate Professor John Charles Lammers

ABSTRACT

Nursing training stresses the importance of communication in providing care to patients; however, research on communication in particular nursing contexts has trailed behind training programs implemented to improve communication efforts. Training interventions are often limited by a cursory understanding of what makes interactions successful versus unsuccessful and often highlight nonverbal communication as being more important than what is actually said. This investigation explored the role of uncertainty for nurses and care assistants communicating support to patients and family members coping with Alzheimer's disease. Using Goldsmith's (2004) normative approach to frame this study, I conducted semi-structured interviews with 32 nurses and care assistants about the role of communication in the context of Alzheimer's nursing. Each interview was transcribed verbatim and analyzed using constant comparative techniques of grounded theory. To determine the role of communication in nurses' interactions with Alzheimer's patients and their families, my analysis focused on five areas: (a) sources of uncertainty for nurses and care assistants, (b) communicative management of uncertainty, (c) ways of communicating support to family members, (d) dilemmas of communicating support, and (e) strategies for managing communicative dilemmas perceived as effective in nursing care. The sources of uncertainty participants reported experiencing become implicated in the complex communication situations that that nurses and care assistants deal with in their work. For example, communicating various types of informational support is a strategy for managing family member's uncertainty about the illness itself as well as relational questions about how to relate to their loved one in a nursing care facility. The findings from this study highlight the importance of enacted support through communication in the context of Alzheimer's care nursing. Practical implications of these findings for Alzheimer's care nurses as well as nurses in

other specialties are described. Theoretical implications for literature on communicating social support and uncertainty management are discussed with reference to these findings, and limitations and directions for future research are outlined.

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CHAPTER 1: INTRODUCTION

When asked how her mother responded to her diagnosis of lung cancer, Joan remembered her commenting that “at least it isn’t Alzheimer’sⁱ.” This comment reinforces reports that Alzheimer’s disease is one of the most feared diseases among senior citizens (Aging No More, 2009). Fear of Alzheimer’s disease stems from the acknowledgement that cognitive function will decline over time until a person becomes incapable of remembering family and friends as well as how to complete tasks of daily living (Mace & Rabins, 1999). This type of dementia begins mildly with diagnosis of the disease based solely on symptoms exhibited (Kumar, Roland, & Burbiedge, 2006)ⁱⁱ. Despite advances in medications (e.g., donepezil hydrochloride – Aricept) that slow the progress of Alzheimer’s disease and delay nursing home placement (Geldmacher, Provenzano, McRae, Mastey, & Ieni, 2003), the efficacy of the drugs over time has been questioned (Adams & Page, 2000).

As the population grows older, fears of dementia-related illnesses such as Alzheimer’s have increased. The National Institute on Aging reported that the population aged 65 and older is growing at a rate of 800,000 people per month (Kinsella & Verhoff, 2001). As the population ages, the number of cases of Alzheimer’s disease will inevitably increase because age is a significant predictor of people developing the disease (Alzheimer’s Association, 2009). Research has suggested that Alzheimer’s disease will affect an estimated 106 million people in the world by 2050 (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). With no cure for Alzheimer’s disease, the impact that this disease has on patients, family members, and health care providers is great. Therefore, understanding the ways in which patients, families, and health care providers (e.g., nurses and care assistants) cope with Alzheimer’s disease is important.

Background and Significance

Nurses are the largest group of professionals to provide mental health care (International Council of Nurses, 2008) and have close contact with patients and their families (Caplan, 1976). Care for Alzheimer's patients is typically delivered by nursing staff. It is important to note that nursing care is delivered by persons with different levels of training, specializations, and unique responsibilities for patient care. For example, certified nursing assistants (CNA) perform basic patient care under the supervision of a registered nurse (RN) or a licensed practical nurse (LPN). Registered nurses and/or licensed practical nurses have more training than nursing assistants and are often responsible for patient advocacy (American Nurses Credentialing Center, 2006).

Given that nurses and care assistants have described the necessity of exerting power in interactions with patients (Hewiston, 1995; Johnson & Webb, 1995), it is not surprising that Johnson and Webb reported that nurses often experienced conflict with patients in medical interactions. Further, in her review of literature on nurse-patient interaction, Shattell (2004) noted that little research has examined how patients communicate with nurses and even fewer studies have been concerned with communication between patients, families, and nurses.

In addition to considering nurses' training and responsibilities, it is important to differentiate between the different types of care provided in nursing homes: skilled care and long-term care. Skilled care typically follows a hospital stay and is defined by specific services only a doctor, licensed nurse (RN or LPN), physical therapist, or social worker can provide. Long-term care, on the other hand, is appropriate for people who need everyday care, including such basics of day-to-day living as eating and hygienic care. Persons with Alzheimer's disease entering a long-term care facility pay for care from their savings until they have exhausted those funds. Although Medicare does not cover long-term care for Alzheimer's disease, Medicaid

supplements the cost of care when the individual's financial resources are depleted. One problem some families may face, however, is that most nursing homes have waiting lists for people who need state funding to enter the care facility.

Research has begun to address the importance of staff involvement in the context of Alzheimer's disease. In particular, Coons (1991) argued that the importance of interactions between nurses, families, and patients warrants specific training in "communication skills and the development of an understanding of the dementia victim" (p. 4). In a recent study of caregiving and Alzheimer's disease, adult children reported that nurses played an important role in managing their uncertainty related to treatment and decision making (Stone, 2008).

Given that interactions in care facilities have implications for the well-being of patients and families coping with illness, as well as for health care providers, research should examine the important role that nurses and care assistants play in Alzheimer's disease care. Thus, this study examines the role of communication in coping with Alzheimer's disease for health care providers (e.g., nurses and care assistants) providing social support to families. Understanding how nurses cope with the uncertainties and related communication challenges they experience is important because nursing is known to be a profession that is stressful, leads to frequent burnout, and is increasingly necessary as the population ages (Iacovides, Fountoulakis, Moysidou, & Ierodiakonou, 1999). Although much research has examined the benefits and dilemmas of social support in close personal relationships (Goldsmith, 2004), less research has examined the efforts of formal health care providers (e.g., nurses and care assistants) to communicate social support and to help families manage uncertainty. Because a goal of this research is to study the care provided for patients and families coping with Alzheimer's disease, this project is well situated to impact scholarship in health, interpersonal, and organizational communication.

Theoretical Perspective

This study is guided by normative perspectives on communication. Communication scholars have developed this perspective on communication in the context of communicating social support and managing uncertainty (Brashers, Neidig, & Goldsmith, 2004; Goldsmith, 2001, 2004). Goldsmith (2004) argued that a normative approach to the study of support is “characterized by a focus on how different ways of carrying out the same task (i.e., coping assistance) may be better or worse at adapting to these multiple purposes as they arise in particular situations” (p. 47).

Normative theories provide a framework to help explain differences between what people actually do and what people should do to successfully manage the challenges and dilemmas associated with providing and receiving support (Goldsmith & Fitch, 1997). A normative approach allows the researcher to provide “a theoretical account to predict and explain the meanings and evaluations of communicative responses” (Goldsmith, 2001, p. 515) and further questions how people are evaluated when they behave in a particular way. To achieve these goals, Goldsmith argued that several factors must be considered to examine communicative phenomena. In particular, researchers should account for (a) the social context, (b) the competing goals with which individuals cope as well as the ways in which individuals are able to manage those goals, and (c) the standards by which people evaluate communication as effective and appropriate (Goldsmith, 2001).

With a normative approach to communicating about Alzheimer’s disease, this study builds upon a growing body of research that examines dilemmas of support (Albrecht & Adelman, 1987; Goldsmith, 1992). These dilemmas of support often become salient because of the multiple purposes that communication can serve (Berger, 2005). Communication scholars

have described how communication springs from a person's goal negotiation (Brown & Levinson, 1978; Clark & Delia, 1979; Craig & Tracy, 1983). Much of this work has been dedicated to the study of compliance-gaining messages (Burgoon et al., 1990; Tracy & Coupland, 1990). Although the particular goals involved in typical compliance-gaining scenarios are different from those likely to be present when people are trying to cope with Alzheimer's disease, the general lessons from this compliance-gaining research are relevant. For example, Clark and Delia described three general classes of communicative goals: instrumental, identity and relational. These types of goals are widely relevant. Also, compliance is relevant to this context. A health care provider often wants to gain the patient's compliance. Based on Dillard, Segrin, and Harden's (1989) conception of primary goals, in such situations a health care provider's main goal would be compliance gaining. In Dillard et al.'s framework, goals such as information sharing, emotional (or arousal) management, and social support are secondary, and a health care provider must evaluate how the accomplishment of these goals constrains the efficacy of the primary goal.

A normative approach maintains that people pursue multiple goals or purposes in communicative interactions. Scholars have argued that these goals are, for the most part, communicated unconsciously (Kellerman, 1992; Moskowitz, Li, & Kirk, 2004). For example, the task component of the interaction (i.e., facilitating coping) might be accomplished by trying to help the family make decisions about treatment and care or manage emotional reactions to these decisions. The identity component includes features of the interaction that reflect on who the nurse is as she or he facilitates coping (e.g., identities such as care assistant or registered nurse). The relational component refers to the nurses' role relative to the role of the patient,

families, and other health care providers (which might be categorized as having a good patient-nurse relationship and in some cases friend and advocate).

Further, Goldsmith (2004) argued that features of messages are designed to achieve specific purposes. For example, an attempt to communicate support from a health care provider (e.g., care assistant or nurse) to a patient's family without an explicit request for support may be perceived as more or less effective in accomplishing the task given the identity and relational goals that are met or not met. Support that is communicated only after an explicit request may, because of similar goal negotiation processes, impact the perceived helpfulness of the support attempt.

Scholars also have described the reciprocal relationship between features of the situation and talk. One important feature of the situation in the context of communicating about Alzheimer's disease is nurses' level of training. A nurses' level of training may influence whether a supportive message succeeds in providing effective and appropriate support for a patient or a family member. For example, Goldsmith argued that "specific features of the person speaking, recipient of the message, the type of problem, and so on may make some kinds of messages and some ways of saying a message more plausible or appropriate than others (p. 49). A care assistant may have less professional credibility than a registered nurse but may have more interpersonal influence on a patient's family because of the time spent with the patient. Further, families who are attentive to patients may influence the necessity of health care providers communicating support in these interactions.

Because the way support is communicated may influence the outcomes of support attempts (Goldsmith & Fitch, 1997), it is important to develop explanatory models to address the questions of how and why some attempts at social support are beneficial and others are not.

Scholars have argued that these models help account for the differences between goals of support attempts and the outcomes of those attempts (Goldsmith, 2001). Developing normative models in communication scholarship has important practical implications (Goldsmith & Brashers, 2008). Practically, scholars will be better able to offer advice about providing social support when coping with uncertainty in the context of caring for Alzheimer's patients and their families. To develop an explanatory model of communicating about Alzheimer's disease, this study identifies the dilemmas of support and begins to examine the features of messages that nurses and care assistants use to respond to those dilemmas when communicating with patients, their families, and other nursing staff.

A normative theory is well suited to drive the questions for the current investigation for several reasons. First, although much has been written about how family caregivers cope with Alzheimer's disease (for a review see Kramer & Vitaliano, 1994), less research has examined how caregivers actively transition to caring for a loved one in a nursing care facility (Aggarwal et al., 2003; Ryan, 2002; Skinner, 2009). This transition, some research has suggested, is often characterized by learning how to communicate with nursing staff (Stone & Jones, 2009). Second, research typically has focused on problems that caregivers (e.g., family caregivers and nurses) face without attention to what methods work when providing care for an Alzheimer's patient (Aggarwal et al., 2003; McCarty, 1996; Sanders, 2005; Williamson & Schulz, 1993). Finally, although research has examined communication in the context of Alzheimer's disease (Hamilton, 1994; Orange & Colton-Hudson, 1998; Smith & Beattie, 2001; Tappen, Williams-Burgess, Touthy, & Fishman, 1997), little, if any, research has explicitly examined the process of communication (e.g., how social support is communicated) among multiple parties including the patient, family members, and health care providers (e.g., nurses and care assistants) involved in

coping with Alzheimer's disease. The following describes relevant research that examines the role of communication and coping.

Communication and Coping

Coping has been defined by scholars as “an individual's efforts to master demands (conditions of harm, threat, or challenge) that are appraised (or perceived) as exceeding or taxing his or her resources” (Monat & Lazarus, 1991, p. 5). Drawing from theories of stress, appraisal, and coping (Lazarus & Folkman, 1984), communication scholars have conceptualized the role of communication in coping. Research from Lazarus and Folkman's program is summarized to provide a foundation for understanding the role of communication in coping. I also describe relevant scholarship from nursing, psychology, and social work literature to demonstrate that an interdisciplinary approach to the study of communication and coping has implications for translating research findings into practical guidelines to produce beneficial outcomes for patients, families, and health care providers.

Coping as a Process

To understand the process of coping, Lazarus, Folkman, and colleagues argued that the way in which people appraise a stressful situation plays a role in how coping works. That is, the process of coping requires thoughtful consideration of the context and the experience of coping. Folkman, Lazarus, Gruen, and DeLongis (1986) described cognitive appraisal as “a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being, and, if so, in what way” (p. 572). The authors also explicated two types of cognitive appraisal. Primary appraisals, Folkman and colleagues (1986) argued, allow the person to determine “whether he or she has anything at stake in this encounter” (p. 572). Secondary appraisals refer to the person's evaluation of “what, if anything, can be done to

overcome or prevent harm or to improve the prospects for benefit” (p. 572). For example, a nurse may be coping with stress due to having to assist a resident and a family member at the same time. The primary appraisal would be how this situation is relevant to him or her as a health care professional and the secondary appraisal would be what the nurse might do to try to address this stress (e.g., reaching out to a peer).

Given the importance of appraisals in coping, Folkman and Lazarus (1988) examined “the extent to which coping mediated emotions during stressful encounters” in two samples to develop a transactional theory of emotion and coping. They argued that scholars often do not clearly investigate the “complexity of emotion and coping processes” (p. 466) and thus provided a rationale for their program of research based on three main arguments. First, the authors argued that, as a person experiences a stressful event (e.g., managing multiple tasks at once) the way that he or she copes is “associated with changes in a wide range of ongoing emotions” (p. 474). Therefore, a theory of coping must consider the range of emotions that are experienced. Second, the authors noted that scholars must consider the ways in which problem-focused coping and emotion-focused coping are related to emotions. Third, the authors pointed out that different forms of coping may have different emotional responses. For example, they noted that “planful problem solving, may have a salubrious effect on the emotion response, whereas other forms, such as confrontive coping and distancing, may make things worse, at least in some populations and in some contexts” (p. 474). These three arguments lay the foundation for work that details and clarifies the experience of coping by examining the processes of coping in addition to the emotional responses integral to understanding those processes.

In more recent work, Morano (2003) sought to clarify the type of relationship (moderating, mediating, or direct) between appraisals and coping by focusing on caregiver

responses to stress (e.g., emotion-focused coping, problem-focused coping, appraisal of burden, and appraisal of satisfaction) on caregiver well-being in the context of Alzheimer's disease.

Caregiver well-being was measured with depression scales. A moderator variable impacts the relationship between two variables whereas a mediator variable is the middle variable in a causal sequence (Tabachnick & Fidell, 2007). Morano found that appraised burden had a mediating effect on depression. Further, emotion-focused coping demonstrated moderating effects on depression for caregivers and problem-focused coping showed neither a moderating nor a mediating effect but a direct effect on two caregiver outcomes – personal gain and mastery. Morano provided evidence that different forms of coping have implications for caregiver outcomes. Further, she argued that interventions and future research should account for the different relationships responses to stress has with outcomes.

Scholars from various fields (e.g., communication, psychology, nursing) have noted the importance of examining coping for individuals confronted with a stressor and have suggested that communication influences this process (Bodenmann, 1997; Lazarus & Folkman, 1984, 1987). Still, little research has addressed specific communication concepts. Some nursing scholarship seems to privilege nonverbal elements of communication. For example, Morse (1992) suggested that touch is an important part of nursing care because it is often used to relieve physical pain. She also discussed verbal efforts to help people cope:

By “talking” we hush cries of distress. It is the sound, the vocalization that is significant, that makes contact with the other; it is not the spoken words. The words may be meaningless, insignificant, but the sound, the tone is distinctive: a long monotone, such as “hush” or “there.” (p. 98)

Although nursing literature seems to highlight nonverbal communication as being an important component to helping people cope, communication literature suggests that features of messages, particularly supportive messages (e.g., person-centeredness, attempt to legitimize feelings) are important. In particular, Burleson and Goldsmith (1998) argued that verbal and nonverbal attempts to offer social support are significant. To better understand coping in specific contexts, it seems that researchers must more actively address the specific role of communication (e.g., how support is communicated).

Coping as Relational

Much research has explicated the concept of coping as an individual experience (Lazarus, 1999) based on changing cognitive and behavioral orientations to demands or stressors, which are appraised by the person experiencing the stressor (Lazarus & Folkman, 1984). Recently, though, scholars in psychology and communication have added a relational component to the study of coping with theories of dyadic coping (Bodenmann, Pihet, Shantinath, Cina, & Widmer, 2006) and communal coping (Lyons, Mickelson, Sullivan, & Coyne, 1998).

Because health interactions are clearly social contexts, it is important to examine research that looks at coping in a social way rather than simply an individual process. Theories of dyadic coping and communal coping were developed in different disciplines but share many similarities. An examination of these concepts and their definition is important and has the potential to lead to better understanding of coping. Dyadic coping and communal coping are defined primarily in terms of the relational nature of coping. A primary difference is in the ways that these constructs have been applied. Dyadic coping has been explicated in the context of romantic couples and communal coping has been examined in multiple relational contexts (e.g., sisters, romantic partners).

Although dyadic coping likely occurs alongside individual coping efforts (Bodenmann, 1997), Bodenmann, Pihet, Shantinath, Cina, and Widmer (2006) explicated dyadic coping in terms of “the efforts of one or both partners to engage in a stress management process aimed at either creating or restoring prior physical, psychological, or social homeostasis within both of the partners, individually, and within the couple as a unit” (p. 572). Stress, defined as either something experienced by one partner that impacts the relationship (e.g., problems at work) or as something experienced by both members of the couple (e.g., a child’s illness) is a key feature of the definition. Bodenmann et al. argued that different types of stress can prompt different types of dyadic coping. For example, common dyadic coping occurs if both partners are impacted directly by a stressful event and cope together. Supportive dyadic coping occurs when one partner is impacted by the stressor but is assisted by the other partner in coping. A third orientation to dyadic coping is delegated dyadic coping where the partner impacted by the stressful event asks the other partner to help by delegating tasks to lower his or her stress level.

Like dyadic coping, communal coping perspectives suggest that coping occurs between two or more people, that the stressor is shared, and that therefore the coping is shared (Lyons, Mickelson, Sullivan, & Coyne, 1998). Lyons et al. argued that communal coping requires “the pooling of resources and efforts of several individuals (e.g., couples, families, or communities) to confront adversity” (p. 580). Because dyadic coping focuses solely on committed relationships (e.g., married couples) and the scope of the current project extends beyond this particular interpersonal relationship, the construct of communal coping is adopted.

Lyons, Mickelson, Sullivan, and Coyne (1998) argued that the concept of coping in scholarship must be reconceptualized to focus on the relational component of coping as well as the emotional stress component. They reviewed individual and social perspectives on coping to

develop the concept of communal coping into a framework for future scholarship. The concept of communal coping is clearly distinguished from Lazarus and Folkman's (1987) definition of coping because it takes a relational perspective. They argued that coping has been operationalized as an individual's activity starting with the appraisal and moving to the decision to organize resources to deal with the stressor. More than simply changing the emotional state of an individual, Lyons et al. suggested that relational maintenance may be an important factor affecting coping attempts.

Theories of communal coping argue that people make decisions about how to cope with a stressor based, at least in part, on the relationships that are important to them. Lyons, Mickelson, Sullivan, and Coyne (1998) highlighted a shared appraisal component and suggested that coping examined in terms of a simple provider-recipient model of social support does not account for the coping process that they are concerned with elaborating. Instead, communal coping occurs when people in a close relationship think about a stressor jointly and deal with it together. The authors further explicated three mechanisms that account for the process of communal coping. First, "at least one person in the social unit must hold a communal coping orientation" (pp. 583-584). This means that one member of the unit believes that dealing with the problem together will be most advantageous. In the context of Alzheimer's disease, an adult child might react to a parent's diagnosis of Alzheimer's disease with "We will handle it together." In this example, the adult child would hold a communal coping orientation. Second, the people who share the communal coping orientation must communicate about the stressor in order to share the significance of the situation. Communicating about the stressor, like holding a communal coping orientation, requires the knowledge that after discussing the details of the situation, "we" will cope with the stressor. Finally, individuals must engage in cooperative action. Engaging in

cooperative action requires that individuals reduce the negative impact of the stressor and figure out how activities of daily living will be impacted. For example, for a family coping with Alzheimer's disease, the decision to take the car keys away from the person diagnosed with probable Alzheimer's disease may require cooperative action. For the purposes of the current project, the concept of communal coping extends beyond the family to include health care providers, particularly nurses who communicate with and help the family cope with the stressor.

To further clarify how communal coping is different from individual and other social perspectives of coping, Lyons, Mickelson, Sullivan, and Coyne (1998) developed a framework of communal coping. In their model, "an appraisal dimension runs vertically that represents variations in the degrees to which problems will be construed as shared or individually owned" (p. 586). The appraisal dimension spans from a communal orientation to an individualistic orientation. A second dimension described as the action dimension runs horizontally to "reflect variations in the degree to which coping strategies will be mobilized by involved partners or by the individual" (pp. 586-587). The action orientation spans from believing the stressor is an individual problem to believing the stressor is a shared problem. Communicating social support, for example, may be one coping strategy characteristic of the action dimension. Given these two dimensions, each of the four quadrants represents a degree of appraisal and action orientation. For example, the upper right quadrant represents the concept of communal coping as shared appraisal and shared action while the lower left quadrant represents an individualistic orientation to the stressor with individual appraisal and individual action orientation.

Lyons, Mickelson, Sullivan, and Coyne (1998) ended their discussion of communal coping by examining the positive and negative aspects of the concept. They argued that there is a problem in evaluating communal coping in terms of a simple benefit versus cost analysis.

Instead, that analysis must account for the complexity of the concept and the situations in which it plays out. That is, the process of communal coping with both its benefits and costs must be examined. They proposed that four factors may influence the use of communal coping, including the situation, the cultural context, characteristics of relationships, and sex of participants. Accounting for these factors in an analysis may further elucidate the process of communal coping.

Scholars have demonstrated that communal coping is a part of illness experiences (Koehly et al., 2008; Lewis et al., 2006; Monnier & Hobfoll, 1997). Drawing from Lyons, Mickelson, Sullivan, and Coyne (1998), Afifi, Hutchinson, and Krouse (2006) proposed a theoretical model of communal coping in the specific relational context of post divorce families. The authors argued that this model is also applicable to other naturally occurring groups like stepfamilies. The theoretical model of communal coping proposed incorporates the important dimensions of appraisal and action. However, the model differs and thereby extends previous theories of communal coping in significant ways. First, this model (a) provides a more nuanced understanding of how coping is interdependent, (b) furthers scholars' understanding of coping as a process, (c) examines the role of responsibility within group for the stressor, (d) argues that group dynamics affect the coping process, and (e) shows that the type of stressor and the context in which the stressor is faced are factors in the coping process (Afifi et al., 2006).

Social Support as Coping

Scholars have long acknowledged the importance of social support for coping with life's stressors (Cassel, 1976; Cobb, 1976) and have articulated a theory of social support that highlights the important role of communication in the receipt and provision of support (Albrecht & Adelman, 1987; Goldsmith, 2004). Social support has been defined as "an interpersonal

transaction involving one or more of the following: emotional concerns, instrumental aid, information, or appraisal” (Cutrona, Suhr, & MacFarlane, 1990). In addition, it has been described as “an umbrella construct used to refer to several related yet conceptually distinct social phenomena and processes” (Goldsmith, 2004, p. 3) associated with the ways in which people cope with a stressor (e.g., giving advice, preparing a meal).

Research in the area of social support is motivated by several important factors. Burleson, Albrecht, Goldsmith, and Sarason (1994) described pragmatic, theoretical, and ethical reasons for the study of social support as a construct. Pragmatic reasons, they argued, related to the empirical link that researchers have found between social support and health outcomes. Research that indicates that social support has both positive and negative outcomes provides one motive for pursuing this topic. Scholars have also demonstrated that communication research is particularly well suited to developing interventions aimed at improving outcomes through social support (Goldsmith & Brashers, 2008). Theoretically, Burleson et al. (1994) concluded that, because social support is a basic function of communication in relationships, research should continue to highlight the criteria that are factors in acquiring and maintaining supportive relationships (e.g., person centeredness). Finally, Burleson et al. suggested that “social support is moral (or morally relevant) conduct, and by studying it we better acquaint ourselves with the nature and practices of virtue” (p. xv). Given the importance of this area of research practically, theoretically, and morally, as well as the breadth and depth of social support literature, the following outlines three approaches to the study of social support: social network approaches, psychological approaches, and communicative approaches (Burleson et al., 1994). Examining different approaches to the study of social support enables the researcher to better integrate research findings.

Social Network Approaches

Social network approaches to the study of social support examine the ways in which social network members (e.g., family, friends, priests, and coworkers) provide support to individuals and to large groups. Conceptualizations of a social network approach can be explored with an examination of Granovetter's (1973) seminal analysis of the "strength of weak ties." Although Granovetter described the importance of weak ties in ego-networks (i.e., networks that are structured around an individual) in a work place setting, this approach can be applied to social network approaches to the study of social support. Adelman, Parks, and Albrecht (1987) described four special functions of weak ties: (a) extending access to information, goods, and services; (b) promoting social comparison with dissimilar others; (c) facilitating low-risk discussion of high-risk topics; and (d) fostering a sense of community. For example, one function of social support from a social network approach is to provide information to help alleviate a stressor. Promoting social comparisons with others who are not doing as well as the person experiencing stress or providing an example of a person who was in a similar situation but was able to work through it might also be useful in a supportive interaction. Third, Adelman et al. (1987) suggested that, "Weak ties, as we have noted, tend to be bounded relationships. They must be bounded by their role expectations, by their comparative lack of connection to the rest of the individual's network, or by restricted physical and temporal contexts" (p. 135). This type of bounded relationship clearly helps to ease potentially difficult conversations. Finally, having an extended network seems to suggest that the person experiencing a stressor has support available even if the person does not call on that support.

Further, scholars have provided insights into the link between access to a social network and health outcomes. Cohen, Gottlieb, and Underwood (2000) described social network

approaches to studying social support as stemming from a sociological tradition beginning with Durkheim's (1951) work on social ties. Given the use of social network approaches to examine social support, it is important to examine the measurement tools available to the researcher. Because social network approaches are designed to understand the impact of how much support is available in relationships, these measures ask participants to report on the availability of support if it were needed (Lakey & Cohen, 2000). Perceived available support refers to the support that people think they may have and enacted support is the support that is received by or communicated to an individual. For example, the Arizona Social Support Interview Schedule (ASSIS) is a measure that is commonly used in studies of social support (Barrera, Sandler, & Ramsay, 1981). The ASSIS is a network-based survey that measures emotional, instrumental, informational, companionship, and validation support. Although the ASSIS measures different categories of support depending on the study, it is useful for scholars interested in determining perceived available support. Other measures that are useful for measuring social networks include the Involvement in Community Organizations measure (Wayment, Silver, & Kemeny, 1995) and the Multidimensional Perceived Support Scale (Zimet, Powell, Farley, Werkman, & Berkoff, 1990).

Psychological Approaches

Burleson, Albrecht, Goldsmith, and Sarason (1994) cited research that drew from psychological approaches to examining social support that has focused on personality traits (Sarason, Pierce, & Sarason, 1990; Sarason, Sarason, & Shearin, 1986). From this perspective, scholars have described the potential for attachment theory (Bowlby, 1980) to support a working model of, or "cognitive representation of self," that would illustrate some of the ways people appraise supportive interactions (Sarason et al., 1990, p. 500). Much research has examined

social support using attachment theory (Collins & Feeney, 2000; Cutrona, Cole, Conlangelo, Assouline, & Russell, 1994; Nelson & Quick, 1991). Scholars who examine social support from a psychological perspective might use the Social Provisions Scale (Cutrona & Russell, 1987), which measures attachment style and social integration. One major limitation of psychological approaches to the study of social support, Burlison et al. (1994) noted, is that it focuses on the relationship itself, which is not inherently supportive or unsupportive. Rather, interactions within the relationship can be seen as supportive or unsupportive.

Communicative Approaches

The weaknesses of the social network and psychological approaches to the study of social support are addressed by communicative approaches to social support. Communication scholars have distinguished between enacted social support and perceived social support. Goldsmith (2004) described enacted support as communication (e.g., giving advice, providing information, listening to feelings expressed). She argued that enacted support be viewed as “meaningful social action, situated within particular contexts, and undertaken for purposes by which its success may be evaluated” (p. 50). Perceived social support, on the other hand, emphasizes cognition or the thought that, if support were needed, it would be available.

The distinction between perceived and enacted support is important in light of research that suggests that there are dilemmas and challenges associated with enacted social support (Brashers, Neidig, & Goldsmith, 2004; Goldsmith, 2004). That is, research suggests that examining enacted social support allows scholars to highlight the communicative processes that occur, including the benefits of social support as well as the costs and complications associated with enacted support. Such benefits and costs are not present in measures of perceived social

support. Although the benefits of social support have positive associations, the costs associated with social support have been shown to have a negative influence on relational maintenance.

Types of social support. Communication scholars have usefully distinguished between several types of social support that may be communicated through interaction including tangible support, informational support, and emotional support (Goldsmith, 2004). Other conceptualizations may include discussions of esteem support and appraisal support (Goldsmith). Tangible support is defined as what people actually do to provide support. For example, a person might offer to drive a friend to the doctor or bring food to a friend who has been in the hospital so that the person does not have to worry about cooking. Informational support may be described as the things that people say to equip a person with some level of knowledge. Giving advice is a clear example of providing informational support (Goldsmith, 2000, 2004). A third type of social support, emotional support, is defined in terms of the things that people do or say to make a person feel better. Comforting models of support are often cited in communication literature as a particular category of emotional support. Burleson and Samter (1985) and Burleson and Goldsmith (1998) argued that to study comforting within social support requires a focus on message construction. Specifically, Burleson and Samter reported on two studies that used naïve coders to evaluate the functionality of comforting messages against the formal evaluations of the constructivist hierarchy that Burleson and colleagues developed. The researchers found that messages that were considered formally better were also considered functionally better. Furthermore, Burleson and Goldsmith suggested that theories of appraisal and emotion might offer interesting insights into the comforting process.

Main effects model of social support. Researchers have discussed two main models for studying social support: the main effects model and the stress buffering hypothesis. The main

effects model posits that regardless of stressor, social support can have positive effects for a person's health, whereas the stress buffering model suggests, that in the presence of a stressor, having social support buffers the individual from the aversive effects of the stress (Greenglass, Fiskensbaum, & Burke, 1996; Penninx et al., 1997a, 1997b). Literature has examined the role that various factors play in mediating between stress and adjustment to stress. Atienza, Collins, and King (2001), for example, looked at control as a mediator between perceptions of social support and psychological well-being, whereas Terry, Rawle, and Callan (1995) examined the mediating role of coping. Terry et al. (1995) used a longitudinal design to study couple's coping and tested the proposal that coping acts as a mediator in the relationship between social support and stress. They found support for the hypothesis that coping would act as a mediator between social support and adjustment; however, the support was evident with regard to the participant's partner more so than with other family members who had a direct effect on outcomes.

Other studies have examined the role that talking about stress can have on adjustment to stress. In a study that examined mental health for men coping with prostate cancer, Lepore and Helgeson (1998) found that men who perceived constraints in talking did not necessarily have more intrusive thoughts than did men who are able to talk. The intrusive thoughts, however, were associated with distress when men could not talk. That is, the study found that men who had the option to talk to others about their stress may still have intrusive thoughts, but it appears that they were able to process and work through those thoughts so that they did not experience distress.

These findings suggest that social support should be examined in stressful contexts because of the potential positive benefits that may exist. Health care providers may be an outlet for patients and families coping with Alzheimer's disease to communicate uncertainty. The

ability to communicate with a health care professional (e.g., nurse or care assistant) may impact the coping process.

Relational models of social support. Some research has highlighted the role of relationships in communicating support (Koehly et al., 2008; Lewis et al., 2006; Monnier & Hobfoll, 1997; Untas, Quintard, Borteyrou, & Azencot, 2009). Relational models of social support provide a conceptual link to the notion of communal coping; indeed, Goldsmith (2004) suggested that theories of communal coping and studies of routine talk might offer a more nuanced perspective of what occurs in social support interactions. Goldsmith noted that although much literature conceives of social support in terms of provider to a recipient, theories of communal coping (Lyons, Mickelson, Sullivan, & Coyne, 1998) offered a more relational model that might better account for what actually occurs in interactions. Professional relationships between health care providers and families have not been studied as an opportunity for relational level coping to occur. Depending on the particular relationship of the health care provider with the family, however, it seems that communal coping may occur. This may in part depend on the quantity (e.g., length of time the nurse has worked with the family) and quality (e.g., types of communication that occurs) of the interactions that health care providers have with families.

Impact of uncertainty on social support. Scholars have noted that social support is one of the ways that uncertainty can be managed (Albrecht & Adelman, 1987). Uncertainty is defined in terms of the experience of questioning and is inherent in illness experiences (Clayton et al., 2006; Johnson et al., 2006; Jurgens, 2006). For example, people may have questions about medical aspects of an illness, how illness impacts the person, and how illness impacts relationships (Brashers et al., 2003; Stone & Jones, 2009). Social support has been associated with uncertainty management in various illness contexts including cancer (Bailey, Wallace, &

Mishel, 2007; Sammarco, 2001; Sammarco & Konecny, 2008; Thompson & O'Hair, 2008), fibromyalgia (Reich, Olmsted, & van Puymbroeck, 2006), HIV/AIDS (Brashers, Neidig, & Goldsmith, 2004), multiple sclerosis (Wineman, 1990), and organ transplantation (Scott, Martin, Stone, & Brashers, 2009).

There are several ways that social support can manage uncertainty. Research on the role of social support in managing uncertainty suggests that the appraisal process is an important factor in how people cope with illness (Brashers, Neidig, & Goldsmith, 2004). A situation may be appraised as harmful, threatening, or challenging (Lazarus & Folkman, 1984). Research has demonstrated the importance of appraisals in managing stresses (Folkman & Moskowitz, 2004). Brashers, Neidig, and Goldsmith found that, for people living with HIV/AIDS, social support aided them in managing their uncertainty through information seeking and avoiding, providing instrumental assistance, giving emotional acceptance, allowing cathartic ventilation, and encouraging perspective shifts.

Contributions of the Current Study

The growing number of cases and the widespread influence of Alzheimer's disease have drawn considerable attention from the medical community (Brookmeyer et al., 2007), with research ranging from genetic susceptibility testing (Cupples et al., 2004) to potential avenues for treatment after diagnosis (Zhou & Fukushima, 2007). In particular, research has focused on issues of caregiving (Rabinowitz et al., 2006), with some attention to the role of support in managing the disease. Thus far, though, research has not examined in much detail the role of communication in health care providers' experiences working in Alzheimer's care facilities. The lack of research is troublesome given the important role that communication plays for health care professionals in interacting with patients and families.

Examining communication processes lays a foundation for theory and research that addresses how to improve patient and nursing outcomes. For example, research has examined the experience of burnout for employees in helping professions like nursing (Ellis & Miller, 1994; Gillespie & Melby, 2003; Iacovides, Fountoulakis, Moysidou, & Ierodiakonou, 1999; Tselbis, Aikaterini, & Ioannis, 2001). Ellis and Miller suggested that there is “a significant relationship between support and burnout” (p. 91). They argued that improved instrumental and informational support had the potential to prevent burnout and thereby improve patient care. More attention to how uncertainty is experienced and how support is communicated may suggest theory-based avenues for improved working environments.

An examination of the communicative interactions from health care providers’ perspective addresses several gaps identified in the nursing literature. First, scholars have called for more attention to be paid to nurses’ and patients’ perceptions of the role of communication in coping, particularly through providing comfort (Morse, 1983, 1992). Second, research that examines the interactions, including the specific strategies for coping, should be identified and documented (Morse, 1992). Although some literature has highlighted emotional support as a primary goal of nursing care (McIlveen & Morse, 1995), a broader conceptualization of coping that includes identity issues and information-based support may better highlight the communication processes occurring between patients’ families and nurses. For example, Langford, Bowsher, Maloney, and Lillis (1997) argued that defining particular attributes of social support (i.e., emotional support, instrumental support, informational support, and appraisal support) is warranted. This seems particularly relevant in the context of Alzheimer’s disease, which often includes caring for the patient’s family as well as attending to the needs of the patient. That is, what the family experiences (e.g., perception of adequate or inadequate care)

may impact the ways in which nurses cope with daily stressors. For example, families may be skeptical of the value of Alzheimer's treatments. Research has provided a framework for nursing home physicians to discuss treatment options (Bright-Long, 2006). Nurses, however, are often in the precarious position of explaining treatment decisions made by physicians. The challenges faced by nurses are further complicated by the fact that people with Alzheimer's disease often experience an accelerated rate of cognitive decline shortly after entering a nursing facility (Wilson et al., 2007), which may heighten any concerns the family might have about whether the course of treatment is optimal. These areas of research suggest that the communication between patients, families, and nurses is influenced by a complex set of factors.

This project also has important implications for better patient care. Although some scholars have called for more research that examines the patient's perspective (Hawley, 2000), a focus on the interaction between health care providers and patient's families also is warranted in the context of Alzheimer's disease because of (a) the implications the disease has for the family, (b) the influence of the family on the care of the person with Alzheimer's disease, and (c) rates of burnout for nursing staff. Research has demonstrated that caring for a family member with Alzheimer's disease is frustrating (Dupuis, 2002). Details of the interactions from the health care provider's perspective, alongside research that has examined the family's perspective, may provide important insights into the experience of communicating about Alzheimer's disease and managing psychosocial challenges. A better understanding of the experiences of uncertainty and the provision of support in the context of nurses and care assistants communicating with families about Alzheimer's disease can promote quality of life for people living with the disease (Karlavish, Casarett, Klocinski, & Clark, 2001), help to facilitate more effective decision-making for families (Brodie & Gadling-Cole, 2003), reduce the risk of burnout for nursing staff

(Ellis & Miller, 1994), and contribute to training programs for nurses in this specialized area of nursing.

Given the potential for experiences of uncertainty to influence the provision and receipt of social support (Brashers, Neidig, & Goldsmith, 2004) and for support to have both positive and negative effects (Goldsmith, 2001), this project attends to the specific circumstances under which support is provided and received in health and illness contexts. Using a normative approach to guide this study foregrounds the importance of gaining theoretical and practical knowledge in the context of communicating about Alzheimer's disease. This investigation helps explain the process of communicating social support to (a) help families cope with caring for a loved one with Alzheimer's disease and (b) improve experiences of caring for health care providers. This approach further highlights (a) situations under which social support is helpful, unhelpful, or harmful and (b) processes through which helpful, unhelpful, and harmful effects come about. Moreover, this approach to understanding social support in various illness contexts builds upon a growing body of research that examines dilemmas of support (Albrecht & Adelman, 1987; Goldsmith, 1992, 2004). Because the ways in which support is communicated may influence the outcomes of support attempts (Goldsmith & Fitch, 1997), it is important to clearly attend to the process inherent in communicating to address the questions of how and why some attempts at social support are beneficial and others are not.

Practically, based on the results of this study, scholars will be better able to offer advice about providing social support when coping with uncertainty in the context of caring for Alzheimer's patients and their families. In order to develop an understanding of communicating about Alzheimer's disease, this study identified dilemmas of support and the means used to address those dilemmas when communicating with patients and their families.

This investigation was designed to explore the role of communication in coping for health care providers working with Alzheimer's patients and their families to address a gap in nursing and communication literature. As the number of people impacted by Alzheimer's disease grows, understanding how support for families is communicated becomes increasingly important. Using a normative approach to study nurses working with Alzheimer's patients and their families can help health care providers develop more effective interventions and services which may increase the psychological quality of life for families coping with Alzheimer's disease. Furthermore, this approach may allow for better training programs to be implemented for Alzheimer's care nurses.

Finally, this study adds valuable information to the ways that researchers study communication and Alzheimer's disease. Research has addressed the importance of taking a relational perspective to the study of coping; however, little research, if any, has explicitly examined the ways in which formal health care providers engage in coping efforts through communication. This kind of attention may broaden the scope of communal coping theories to include network members outside of the typical social network.

CHAPTER 2: LITERATURE REVIEW

Knowledge of extant literature is essential when developing a research project aimed at providing practical suggestions for improving communication and thereby illness experiences for patients, families, and health care providers coping with Alzheimer's disease. The following chapter discusses literature that has examined the role of communication in Alzheimer's care. Throughout this chapter, I articulate research questions for the current investigation with reference to literature on communication and Alzheimer's disease.

Communication and Alzheimer's Disease

Scholars have examined the role of communication in the context of coping with Alzheimer's disease. Key findings from literature on communication and caregiving highlight two important communication constructs central to the present investigation: experiences of uncertainty and the communication of social support.

Caregiving

Much research on caregiving draws from Lazarus and Folkman's program of research on coping (Kramer & Vitaliano, 1994). The nature of Alzheimer's disease, including loss of memory and thereby loss of ability to complete tasks of everyday living, makes caring for a person with Alzheimer's disease a frustrating experience (Mace & Rabins, 1999). Research has addressed the complex nature of communicating with a person coping with Alzheimer's disease (Bute, Donovan-Kicken, & Martins, 2007; Sanders, 2005; Small & Perry, 2005). Again, difficulty communicating in the context of Alzheimer's disease is evident for both informal caregiving done by family and friends and for formal care providers (Majerovitz, Mollott, & Rudder, 2009; McCarty, 1996; Train, Nurock, Manela, Kitchen, & Livingston, 2005). For example, Train et al. (2005) interviewed people who had been "living in, working in, or had a

relative in the setting (nursing home) for at least three months” (p. 120). They identified several themes related to participants’ experiences with nursing home care including (a) privacy, dignity, and choice; (b) relationships to care environment; (c) activities; (d) the physical environment; and (e) expectations of care environment. The authors concluded that residents, family members, and staff would like to see improvements in communication. They argued that better communication would allow for complaints to be acted upon and care to improve. The authors did not, however, describe specific ways that improved communication might occur.

Building on the idea that communication can enhance care, Majerowitz, Mollot, and Rudder (2009) examined institutional barriers, psychosocial factors, and communication problems among nursing home staff and families to provide information to improve communication. They argued, “good communication between families and nursing home staff must allow each person to be an active participant in the decision-making process” (p. 13). In study 1, Majerowitz et al. (2009) interviewed 103 caregivers from 26 nursing homes to discover (a) what the most difficult aspect of placing a loved one in a nursing home was, (b) what problems caregivers had with nursing home staff, (c) what, if anything, someone had said or done to help the caregiver adjust to nursing home placement for their loved one, and (d) what if anything, someone had said or done that made the situation worse. The authors described themes related to problems communicating with the nursing staff. For example, participants felt that nursing staff were criticizing them for their level of involvement. They also noted that caregivers reported experiences in which nursing staff made them feel guilty for placing their loved one in a care facility. Participants also described how staff rotated so often that it was difficult to know who to speak to about their loved one. Other barriers to good communication included receiving inadequate information from the nursing care facility and supervisors being

unwilling to hear negative feedback from families. In study 2, the authors conducted focus groups and presented surveys to staff of six nursing homes. Majerowitz et al. found that nursing home staff had similar responses to participants in study 1 as to what hinders good communication. For example, they noted that good communication was hindered by not having enough information prior to decision making.

Other studies have focused more on the experience of familial caregivers, often spouses (Brodarty, Thomson, Thompson, & Fine, 2005; Caron & Bowers, 2003; Di Bartolo & Soeken, 2003; Small, Gutman, Makela, & Hillhouse, 2003; Small & Perry, 2005). In a recent study, James, Andershed, and Ternstedt (2009) interviewed family caregivers about their experiences of hospital care at end-of-life for a loved one. James et al. found evidence that family caregivers often felt that health care professionals “did not care about their loved one and that they were alone in their struggles” (p. 261). The authors also found that health care professionals in the hospital setting did not communicate with much empathy when a loved one was near death. A third theme related to how family caregivers partnered with health care professionals to provide appropriate care for their loved one. In particular, James et al. (2009) highlighted how family caregivers were able to share their experiences and information about the patient (their loved one) with health care professionals. The authors described how family caregivers characterized themselves as an expert in providing care for their loved one. Given that family caregivers had a strong belief that they were experts, conflict often arose between the family and the health care professional. These data suggest that negotiating the relationship between family caregivers and health care professionals is difficult. Further examination of the relationship between family caregivers and health care providers (e.g., care assistants and nurses) is warranted to more clearly describe the role of communication in these interactions.

Experiences of Uncertainty

Uncertainty is associated with many illness experiences (Babrow, Kasch, & Ford, 1998; Brashers et al., 2003; Mishel, 1988, 1990). Much scholarship on uncertainty and illness (Clayton, Mishel, & Belyea, 2006; Johnson, Zautra, & Davis, 2006; Jurgens, 2006; Madar & Bar Tal, 2009) has provided support for a theory of uncertainty for chronic illness (Mishel, 1999). Drawing from the experiences of people coping with chronic illness, Brashers (2001) articulated a theory of uncertainty management which states that, depending on an individual's appraisal of uncertainty, a person may want to reduce, maintain, or increase his or her uncertainty. Appraisals, then, are an important part of the management process.

Other research has examined the sources of uncertainty for people coping with a chronic illness (Brashers et al., 2003). Stone and Jones (2009) recently described several themes relating to medical, personal, and social sources of uncertainty for adult children coping with a parent's diagnosis of Alzheimer's disease. Medical sources of uncertainty included insufficient information about the prognosis, ambiguous symptom patterns, and complexity of caregiving responsibilities. Participants also reported experiencing uncertainty related to personal sources, which include complex or conflicting roles and concern for finances. The social sources of uncertainty experienced by families coping with Alzheimer's disease included the unpredictability of social reactions and unclear relational implications. Issues involving unpredictable social experiences, interactions among siblings related to the responsibility of caregiving, and the relationship between the well parent and the sick parent were particularly salient due to these uncertainties.

Stone and Jones' (2009) analysis supported and extended previous research in several ways. First, the study supported the Brashers' et al. (2003) findings that there are medical,

personal, and social sources of uncertainty related to illness. The authors noted that there were similarities across illness contexts. For example, participants in both studies reported that they experienced uncertainty related to the information they received about the diagnosis.

Participants in both studies also discussed the conflicting roles that they experienced. Finally, participants in both studies noted that they experienced some stigma related to the illness.

Although there was consistent overlap in the sources of uncertainty across illness contexts, focusing on Alzheimer's disease and on the experiences of a close family member rather than the individual with illness highlighted areas of uncertainty not discussed previously. There were several findings that warrant further investigation. For example, Stone and Jones (2009) suggested that a parent's diagnosis of probable Alzheimer's disease made participants uncertain about their own future (i.e., the possibility of developing Alzheimer's disease) and those of other members of their family who may be susceptible.

Scholars also have described ways in which problems inherent in communicating with a person with Alzheimer's disease may create uncertainty for social network members (Donovan-Kicken & Bute, 2008). In particular, Donovan-Kicken and Bute found that uncertainty often related to the social network member's perception that they were not able to effectively communicate with their loved one. Other research has demonstrated that social network members create strategies for communicating with a person with a communication-debilitating illness (Bute, Donovan-Kicken, & Marins, 2007). Stone (2008) interviewed adult children with a parent who was diagnosed with probable Alzheimer's disease and discovered that for many participants learning how to communicate with their parent was important for their provision of care.

Uncertainty can also be experienced by health care providers and this uncertainty may impact the experiences of the patients and families they work with (Cranley, Doran, Tourangeau, Kushniruk, & Nagle, 2009). Knowing what forms of uncertainty health care providers experience provides a foundation for contextualizing the role of appraisals in experiences of uncertainty.

RQ1: What are the sources of uncertainty for health care providers working in Alzheimer's disease care facilities?

Experiences of uncertainty may contribute to how health care providers and families perceive their caregiving experiences. It is important, then, to examine the ways in which health care providers manage the uncertainty they experience. Information seeking (and avoiding) has been described in interpersonal (Knobloch & Solomon, 2002), organizational (Morrison, 2002), and health contexts (Brashers, Goldsmith, & Hsieh, 2002) as a communicative means for coping with illness. Individuals may assess and utilize multiple sources of information over the course of an illness. For instance, Brashers, Haas, Neidig, and Rintamaki (2002) found that people coping with illness turned to health care providers (e.g., physicians and nurses), friends, family, the internet, or health-related pamphlets for information. Although seeking out or avoiding these sources is one way that people manage their illness-related uncertainty, there are challenges and dilemmas associated with these information management behaviors. Brashers, Goldsmith, and Hsieh suggested that the collaborative nature (i.e., goals must be coordinated among individuals) and contextual features (e.g., culture and channel of communication) of information management present significant challenges for individuals.

In the context of Alzheimer's disease, Stone (2008) found evidence to suggest that information management is an important part of coping with a parent's probable diagnosis of

Alzheimer's disease. Participants described seeking information about their parent's illness (e.g., how long each stage typically is) as well as information about the potential likelihood of developing Alzheimer's disease later in life. For adult children whose parent has been diagnosed with probable Alzheimer's disease, the risk for developing the illness was a common worry (Stone, 2008). Despite concerns that genetic testing may cause unnecessary tension in families, Lock, Freeman, Chilibeck, Beveridge, and Padolsky (2007) suggested that the results of genetic testing are unlikely to change the relationships among family members and, for some, the information helped them cope with their loved one's diagnosis. More recently, scholars have noted that there is more to the study of information management than seeking and avoiding behaviors and thus research should focus more on information handling and information use (Hogan & Brashers, 2009).

RQ2: How do health care providers manage the uncertainty they experience?

Communicating Social Support

There are several areas of research within the social support literature that are relevant to the current project. In an analysis of qualitative research on social support for persons living with HIV, Goldsmith, Brashers, Kosenko, and O'Keefe (2007) described research that engaged the need of support, functions and processes of support, sources of support, positive and negative support attempts, managing relationships, influences on support, support interventions, and evidence of support providers. Other research has identified puzzles and dilemmas of support as overarching categories within social support literature (Goldsmith, 2004). The following sections review the major findings in the social support literature by examining the puzzles and dilemmas of communicating social support as well as the positive and negative outcomes associated with enacted support.

Puzzles of enacted support. Goldsmith (2004) described “puzzles” of enacted support. Because “enacted support is communication” and should be studied as such, Goldsmith argued that inattention to the communicative processes inherent in supportive interactions is problematic (p. 50). Using a hypothetical example of a conversation, Goldsmith demonstrated the potential avenues of discovery for researchers interested in understanding why and how social support works in interaction. Using actual conversations, then, gives researchers the opportunity to make suggestions for how offers of support should be given in order to achieve specific goals. The content of talk can be analyzed to define message features that are involved when enacted support is perceived as effective.

Successful support attempts are likely impacted by the ways in which talk accounts for the valued identities of various parties involved in the interaction. Tracy (2007) argued that person-referencing practices and speech acts do identity-work. Person-referencing practices refer to terms of address or the importance of references to illustrate identity. In the context of the current study, these person-referencing practices have important implications for the relationship between health care providers and family members. For example, health care providers must consider what form of address is most appropriate when providing support to a patient and his or her family. Tracy summarizes research that has provided evidence that “the terms people use to refer to self and others do strategic work” (p. 25). This strategic work should be examined to better understand the specific features of communication that may influence health outcomes (e.g., compliance with treatment suggestions). Tracy also argued that relationships are likely to change over time depending on the types of communication exchanged in interaction. For example, a health care provider may begin a relationship with a patient and his or her family when the family makes the difficult decision to place their loved one in a

nursing care facility. Although the health care provider is, for the most part, a stranger, interactions with the health care provider likely change relationships among family members. Changes in the relationship depend on a variety of situational factors related to the perception of the care received by the person with Alzheimer's disease and how care is communicated to families.

Puzzles of support, in part, refer to the fact that while perceived availability of support is seen as enhancing health, sometimes the receipt of that support can have negative effects. Helgeson (1993) examined the effects of different kinds of social support (e.g., tangible, informational, and emotional) on patient and spouse's adjustment to a first cardiac event. Helgeson found that the negative aspects of social relationships are strong indicators of health outcomes. Consistent with previous research, perceptions of support were a stronger predictor of adjustment than received support. Given such puzzles of support, the present study investigates types of social support communicated in the context of Alzheimer's disease to better understand the role of enacted support.

RQ3: What types of social support do health care providers (e.g., nurses and care assistants) communicate to families coping with Alzheimer's disease?

Furthermore, Bolger, Zuckerman, and Kessler (2000) examined a puzzle of enacted support with couples, one of whom was studying for the Bar Exam. The researchers were interested in levels of anxiety and depression for both support provider and support receiver. Bolger et al. found that the most benefit for both parties occurred when the support was invisible. Invisible support is support that the provider reports giving despite the recipient reporting not receiving it.

Building on Helgeson's (1993) work, Bolger, Zuckerman, and Kessler's (2000) study is particularly interesting because it begins to uncover some of the puzzle of why receiving the support that people perceive is available to them leads to negative health outcomes. If receiving informational support suggests that the person receiving the support is in some way incompetent, the result may be lower self-esteem and negative health outcomes overall. In such cases, invisible support would lead to more positive outcomes than would visible support.

As Reis and Collins (2000) argued, "social support necessarily depends on the behavior of two persons" (p. 166). From this perspective, Collins and Feeney (2000) used attachment theory to examine support seeking and caregiving behaviors among couples. The researchers noted that "when support seekers described their problems as more stressful, they sought more emotional support from their partner during the interaction" as opposed to informational or tangible support (p. 1060). Collins and Feeney also found evidence to suggest that the perception of stress level influenced the way that support is sought. Specifically, Collins and Feeney found that participants who perceived their problem was stressful sought support in a more direct way, which allowed the caregiver to respond accordingly. In addition to improving our understanding of puzzles of social support, Collins and Feeney highlighted the potential for research to examine multiple members involved in the supportive interaction. Although the present project does not interview multiple parties involved in supportive interactions, I designed the interview guide to address multiple relationships involved in communicating support.

Dilemmas of enacted support. In addition to the puzzles of social support, dilemmas of enacted support should be considered by those interested in the study of communicating social support. Dilemmas reveal the difficult nature of social support from the perspective of the support provider and the support recipient. Dilemmas seem to exist in a variety of situations

where enacted support may be appropriate, especially in health care contexts. Despite the various stressors that have been examined in literature on social support (e.g., living with HIV/AIDS, coping with cancer, or coping with a myocardial infarction), the concept of dilemmas of enacted support are present. Brashers, Neidig, and Goldsmith (2004) discussed social support for persons with HIV/AIDS in terms of “costs” and “complications” that exist within supportive interactions. Using a focus group of people living with HIV/AIDS, Brashers et al. suggested that support from others helps persons living with HIV/AIDS enhance processes of information seeking and avoiding, providing instrumental support, facilitating skill development, and giving acceptance and validation. Brashers et al.’s research pointed to the important idea that relationships and communication within relationships are negotiated.

In addition, Silver, Wortman, and Crofton (1990) examined self-presentational dilemmas that exist for someone with a stigmatizing illness (e.g., cancer). Silver et al. examined the relationship between support and self-presentational strategies. The researchers found that the participants reacted to the various targets in distinct ways depending on whether or not the target presented him/herself as a good copier, balanced copier, poor copier, or provided no information about coping. Further, Goldsmith, Lindholm, and Bute (2006) looked at the dilemmas among couples in which one partner has experienced a cardiac event. The authors found that partners experienced support as an effort to exert control (“I don’t want to nag but”), creating a dilemma of the well partner infringing on patient autonomy or allowing the ill partner to continue to engage in unhealthy behaviors.

One problem inherent in offering social support relates to the helpfulness of the support attempt. Several studies have demonstrated that not all attempts at offering social support are considered helpful (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Cramer, 1990;

Ingram, Jones, Fass, Neidig, & Song, 1999; Lehman, Ellard, & Wortman, 1986; Lehman & Hemphill, 1990; Pearlmin & McCall, 1990; Picard, Lee, & Hunsley, 1997; Servaty-Seib & Burleson, 2007). Lehman et al. (1986) compared perceptions of helpful and unhelpful behavior between a control group and bereaved persons who had lost a child. Members of the control group were matched to bereaved persons on age, sex, income, education, and number and ages of children. The authors identified the supportive and unsupportive behaviors and the sources of these behaviors from the recipient's perspective. The ability of the control group to produce helpful messages presented compelling evidence that it is not that people are unable to communicate effective social support. In fact, this study suggested that, although people know what is appropriate to communicate in situations in which support should be offered, the anxiety of providing support may influence the potential effectiveness of the message. The authors argued that the support provider's attempt to control the emotions that he or she is experiencing as well as addressing the support recipient's vulnerability may contribute to the discomfort of the situation. Other research has demonstrated that people are often motivated to alleviate their own stress in situations rather than focus on the needs of the other person (Burleson & Goldsmith, 1998).

Another area of research that suggests dilemmas exist is research on advice giving (Goldsmith, 2004; Goldsmith & Fitch, 1997). In an observational study of everyday talk, Goldsmith and Fitch described three dilemmas associated with seeking, giving, and receiving advice. Specifically, people may face the dilemma of being supportive versus honest, appearing caring/helping versus butting in when giving advice, and being seen as autonomous and competent versus ungrateful when receiving advice. Goldsmith (2004) explained how each of these dilemmas operates in everyday talk. For example, because giving advice suggests

relational caring and has implications for the identity of the person receiving the advice, Goldsmith noted that participants in her studies made a distinction between advice that was solicited and advice that was not solicited. Advice that was solicited was perceived as helpful, whereas advice that was unsolicited was perceived as butting in. These dilemmas suggest that providers and recipients of support must negotiate multiple goals when engaging in supportive interactions. That is, although giving advice may on the surface seem a task inherent in helpful communication, scholars have noted that communicating support through advice is a complicated task.

In a more recent study, Arora, Finney Rutten, Gustafson, Moser, and Hawkins (2007) examined the helpfulness of social support (e.g., informational, emotional, and decision-making support), from family, friends, and health care providers for women coping with a diagnosis of breast cancer. Using a longitudinal design, the authors noted that women received social support close to the time that they were diagnosed but received less helpful support as time passed. This study added the important element of time to our understanding of how helpful support is conceptualized and suggested that social support may be readily available at the onset of a stressor only to dwindle as time passes.

With an understanding of what is perceived as helpful in actual attempts at communicating social support, it is important to continue to develop an understanding of what constrains communication efforts. Working with the same patients and families on a consistent basis may cloud health care provider's perceptions of the types and sophistication of the support messages they communicate with patients and families. Given previous literature that has documented that support attempts decrease over the course of a relationship, this study examined

dilemmas of support that may be related to the quality of relationships between providers and patients' families as they develop over time.

RQ4: What are the dilemmas, if any, for health care providers communicating social support to families coping with Alzheimer's disease?

Outcomes of enacted support. Scholars have described the impact that communicating social support has for those who provide and receive social support. Goldsmith (2004) described the importance of this type of research because social support can have either a positive or a negative influence on a person's physical and mental health. Goldsmith and Brashers (2008) argued that intervention efforts must be guided by communication research because of the potential effect social support has on outcomes. In a summary of findings on how social support impacts individuals under extreme stress, Hobfoll and Stephens (1990) argued that support has mixed effects. Studies have provided evidence for the positive impact that social support has on people coping with stress (Albrecht & Hall, 1991; Coker et al., 2002; Goldsmith & Albrecht, 1993; Hudson, Lee, Miramontes, & Portillo, 2001). Other studies have suggested that social support can have a negative impact (Ingram, Jones, Fass, Neidig, & Song, 1999; Swann & Brown, 1990), especially if people report being dissatisfied with the support they receive (Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006).

For those who are in need of social support, the receipt of or lack of social support has an impact on their physical and mental health. In an investigation of stress, social support, and health status among elderly adults, Weinberger, Hiner, and Tierney (1987) used objective (e.g., measures that assessed network size) and subjective measures (e.g., measures that asked participants to assess tangible, informational, and emotional support) but found no evidence to support the buffering model of social support. Uchino, Cacioppo, and Kiecolt-Glaser (1996)

used meta-analytic procedures to review 81 studies that provided evidence that social support “was reliably related to beneficial effects on aspects of the cardiovascular, endocrine, and immune systems” (p. 488); however, they argued that the studies that examined associations between social support and blood pressure did not consider the multi dimensionality of social support and instead measured social integration and perceptions of support. They noted that examining the particular aspects of social support is important for future research that deals with how social support impacts health.

Following Krause’s (1997) study of social support in elderly populations, LeFrancois, Leclerc, Hamel, and Gaulin (2000) found that for the elderly, receiving social support may have a negative impact on their health and well-being, perhaps because of a desire to remain self-reliant. LeFrancois et al. (2000) argued that interacting with relatives and friends often indicated that there was something wrong, which led to experiences of distress. The authors found no evidence of a buffering effect of social support in this population adding to a growing body of research that examines the impact of social support for elderly populations. These findings may, however, be an artifact of an elderly population with cognitive abilities that allowed them to perceive support in a positive or negative way. For people with Alzheimer’s disease, receiving support may not have the same negative identity implications because of their diminished cognitive capacity.

Research has also described the benefits that social support can have for the provider (Brown, Nesse, Vinokur, & Smith, 2003; Liang, Krause, & Bennett, 2001). For example, Brown et al. (2003) grounded their study of providing social support in older married adults in theories of kin-selection (Hamilton, 1964a, 1964b) and reciprocal-altruism theory (Trivers, 1971) to suggest that helping is an important area of study theoretically and practically. The researchers

were interested in how “the benefits of providing social support account for some or all of the benefits of social contact that are traditionally interpreted as due to support received from others” and if “receiving support influence(s) mortality once giving support and dependence are controlled” (pp. 320-321). The authors examined how instrumental and emotional support influenced health outcomes. Brown et al. found evidence to suggest that older adults who provided support to a partner had a reduced risk of mortality.

Given research that has suggested that providing support is a complex communicative phenomenon, it is also important to examine the intricacies of communicating support from the perspective of those who provide the support. Other studies have described the specific role of advice giving in providing support that manages uncertainty. For example, Thompson and O’Hair (2008) described the role of advice giving and uncertainty for cancer survivors. Similar to findings from the Brashers, Neidig, and Goldsmith’s (2004) study, Thompson and O’Hair found evidence that highly optimistic advice may help survivors manage their uncertainty in an adaptive, rather than maladaptive, way. In the context of fibromyalgia, Reich et al. (2006) found that given the illness related uncertainty associated with diagnosis, treatment, and outcome, “partners reported being less supportive when they felt more burdened” (p. 91). They suggested that high levels of uncertainty burdened partners and thereby impacted the level of support that was accessible in that relationship. Because illness experiences are fraught with uncertainty, and research has demonstrated that families coping with Alzheimer’s disease experience uncertainty (Stone & Jones, 2009), the current study further investigated how health care providers communicate to families experiencing this uncertainty.

RQ5: What strategies do health care providers use to respond to family members uncertainty?

Research has examined caregiving, uncertainty, and social support in the context of Alzheimer's disease; however, most research has examined one of these constructs without attention to the ways in which the variables intersect with one another to impact communication and coping. This study adds to an understanding of coping in at least two ways. First, the design for this study allowed me to identify relationships among communication constructs to better understand the role of uncertainty in communicating social support in the relationship between health care professionals (e.g., nurses and care assistants) and families caring for a loved one with Alzheimer's disease. Communication constructs related to caregiving, identity, and information management have clear implications for the current study and therefore served as sensitizing concepts for constructing the interview guide. Second, previous research does not provide practical guidelines for how health care providers (e.g., nurses and care assistants) and health care organizations (e.g., nursing homes) can meaningfully improve patient care and outcomes for the patient, the family, or the health care provider. These studies focus almost exclusively on the problems that participants experienced concerning care. Using a normative approach to frame the design of this study adds to a scholarly understanding of coping and the role of communication by examining the challenges and positive elements of care. This orientation also provides a framework for making practical recommendations to improve the quality of experiences with nursing care through a comprehensive examination of communication processes.

In sum, the aims of this dissertation were to examine (a) the experiences of uncertainty for nurses and care assistants, (b) ways nurses and care assistants managed their uncertainty, (c) types of social support communicated in the more formal relationship between health care providers (e.g., nurses and care assistants) and families, (d) potential dilemmas that health care

providers face in communicating social support to families, and (e) strategies for responding to family members' uncertainty. The chapters that follow describe (a) the methods used to collect and analyze interview data, (b) findings from participant's narratives, and (c) theoretical and practical implications of this project.

CHAPTER 3: METHODS

Given the specific aims of this study, I examined the experiences of health care providers in uncertain situations using a grounded theory approach. Rather than focusing on the particular language use of participants as a discourse analyst might or subscribing to strict guidelines for what constitutes a proper interview format as a phenomenologist might, a grounded theorist is interested in discovering themes salient to the experience of participants (Bryant & Charmaz, 2007; Corbin & Strauss, 2008). Grounded theory approaches to scholarship have several strengths that should be recognized by researchers. In particular, grounded theory offers a systematic way of analyzing qualitative data. Corbin and Strauss (2008) argued that grounded theorists should be guided by their questions to articulate a theory that explains the process of interest. Using this conceptualization of grounded theory allows for scholars to more clearly attend to research questions of interest.

Moreover, a qualitative method was consistent with the normative perspective used here. Goldsmith (2001) argued that qualitative research is “one important component of a normative approach because it provides a description of meaningful practices and attention to how communication practices are related to broader cultural themes” (p. 519). Taking a normative approach to this study led me to conduct semi-structured interviews to examine the experience of communication and coping with Alzheimer’s disease for nurses and care assistants.

Participant Recruitment

Recruitment Materials

Before beginning the project I secured IRB approval from the University of Illinois (Appendix A). With permission from various nursing organizations in California, Florida, Illinois, and Missouri (see Appendix B), flyers with contact information and a description of the

study were posted in nurses' lounges or common areas. An effort was made to recruit a balanced sample (e.g., similar numbers of nurses and care assistants). Snowball sampling was also employed. Snowball sampling allows for study participants to aid in recruitment by passing on information about the study to other eligible nursing staff (Babbie, 2004).

Participant Characteristics

Data were collected from individual, semi-structured interviews with 3 men and 29 women nursing staff (e.g., nurses and care assistants) working in Alzheimer's care facilities dedicated to caring for patients and families who are coping with Alzheimer's disease. Participants ranged in age from 20 to 80 years ($M = 46$, $SD = 15.36$). Participants included registered nurses ($n = 15$), care assistants ($n = 13$), and licensed practical nurses ($n = 4$). Participants reported working in the nursing profession for an average of 15 years (range 1 to 40 years) and working in Alzheimer's care for an average of 13 years (range 1 to 49 years). The participant who reported care for Alzheimer's patients and their families for longer than the longest time spent working in the nursing profession was a participant who had personal experience as a child caring for a grandparent with Alzheimer's disease. Twenty-one participants self-identified as White (not of Hispanic origin), five participants self-identified as Black (not of Hispanic origin), four participants self-identified as Hispanic (or Spanish surname), and one participant self-identified as Asian/Pacific Islander. One participant declined to report his/her ethnicity. Pseudonyms are used to refer to study participants throughout the manuscript. Participant's level of nursing is reported in the results section when it is useful for understanding the quotation. Inclusion criteria were (a) self-identified health care provider in an Alzheimer's care facility, (b) age over 18, and (c) able to speak/read English. These requirements were needed because of the theoretical domain of the study (i.e., the challenges health care providers

face communicating with families coping with Alzheimer's disease) and the nature of the research method (i.e., an interview that requires ability to understand the interviewer and written documents).

Contextual Considerations

To better understand the communication that occurs between nurses and residents, nurses and family members, and nurses and coworkers, it is important to examine the context in which interactions take place. Nussbaum and Robinson (1990) suggested that this was “especially true with nursing homes that exert so much dominance over those who live, work, and visit within the walls of the facility” (p. 353). Participants were recruited from assisted living facilities and facilities with skilled nursing care. An important difference between the context within which nurses and care assistants interacted with patients and families is the difference in care that is required in each environment. Residents of assisted living facilities are typically in the early stages of Alzheimer's disease and are more independent. Individuals in such facilities do not require much medical care (e.g., may need reminders to take medications) and are able to complete daily tasks like bathing, dressing, and preparing meals. Individuals living in a skilled nursing setting require more care than those in assisted living facilities, even though this care is often given in the same facility by the same nursing staff. For example, although a skilled nursing facility provides a great deal of care beyond assisting individuals in tasks of daily living, both skilled nursing facilities and assisted living facilities often have a specific Alzheimer's or dementia wing of the organization. The dementia wing is typically a locked unit that requires staff and visitors to enter a four digit code before entering. This code changes weekly to ensure the safety of the residents. Dementia wings have their own dining and recreation areas for residents.

A second important consideration concerns how residents and their family members finance the care they receive. Medicare does not cover the long term care necessary for Alzheimer's residents in assisted living or nursing homes. Medicaid covers long term care stays for Alzheimer's residents, but many assisted living facilities and nursing homes have a limited number of spaces for residents who are not able to personally finance their care, which places a great amount of stress on family members, particularly the power of attorney, who is charged with decision making and providing care for their loved one. This impacts communication between all of those involved in caring for someone with Alzheimer's disease including nurses and family members.

Data Collection

Procedures

This study utilized a qualitative grounded theory approach using a one-on-one semi-structured interview format (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Before each interview, the study was fully explained and participants were asked to sign an informed consent form (Appendix C). The informed consent form began with a description of the purposes of the study and possible risks and benefits of participation. I also highlighted (a) the voluntary nature of the study, (b) the \$25 incentive for participating, and (c) contact information for the researcher and the Institutional Review Board. Interviews were conducted at a location that the participant chose (e.g., office space at the University of Illinois or other private location). For interviews conducted in other states, I invited participants to choose a convenient location for the interview. A list of resources was also provided to the participant in case s/he experienced any discomfort because of the interview experience (Appendix D). When I followed up with participants to

thank them for their participation, they often noted that they enjoyed the experience; thus, I am not concerned that the interview process was psychologically damaging.

After having read and signed an informed consent form, participants completed a short survey of basic demographic data, including number of years in nursing profession, previous nursing related positions, and level of nursing training (Appendix E). Each questionnaire was assigned a numeric label to match the participant's digitally recorded interview. Questionnaires provide background information to better contextualize the experiences of participants.

A semi-structured interview schedule (Appendix F) was developed based on a review of the literature (Brashers et al., 2003; Goldsmith, 2004), the pilot study (Stone, 2009), and studies that have used a normative approach to research (Scott, Martin, Stone, & Brashers, 2009). The first section of the interview schedule was designed to facilitate rapport-building and to orient the interviewee to the purpose of the interview and each question set. The second section of the interview schedule was structured to invite participants to describe experiences of uncertainty. The third section probed into uncertainty management strategies by asking about (a) typical scenarios in which nurses have communicated social support, (b) the types of social support (e.g., informational, emotional, instrumental) nurses communicate to families coping with Alzheimer's disease, (c) the dilemmas nurses face when communicating social support to families, and (d) the specific message features that nurses use to communicate social support to families. I conducted all of the interviews, which lasted an average of 41 minutes.

Data Analysis

The research process followed five basic steps: (a) collecting rich data, (b) coding with detail, (c) writing memos to develop conceptual analysis, (d) theoretical sampling to refine emerging ideas, and (e) explaining findings and implications in writing (Charmaz, 2000). Using

a normative approach as the guiding framework for this project, grounded theory provided a systematic method for analyzing qualitative data.

Digitally recorded interviews were transcribed verbatim, with any identifying information removed from the transcripts. After the transcripts were completed and checked for accuracy, I stored all materials in a locked filing cabinet to protect participant's confidentiality. I also uploaded all transcripts to a qualitative data analysis software program (MAXQDA) on a password protected computer. Following Corbin and Strauss' (2008) suggestion, the software program allowed me to organize and store data and memos in addition to providing flexibility in the way I open coded segments of transcripts in the first stage of analysis. The following describes specific steps I followed to analyze my data.

Theoretical sampling. Theoretical sampling, allows the researcher to collect, code, and analyze data in order to determine what concepts are salient to participants and therefore what should be explored further as the theory is defined. I followed this procedure so that data collection and analysis were done simultaneously. As Charmaz (2008) outlined in her discussion of theoretical sampling, coding and analyzing data as I conducted interviews allowed me to determine which constructs were salient for participants and allowed me to further develop my questions to better understand participants' experiences. This process also allowed me to collect data that further developed my analysis of the process of communicating support that I describe in the next chapter.

Negative cases. Throughout my analysis I looked for negative cases or "alternative hypotheses" (Glaser & Strauss, 1967, p. 230) in participants' experiences. Although not a prominent feature in the analysis, memos were developed to discuss alternative explanations for

the themes developed. This further strengthens the validity of my claims by addressing questions readers may have about alternative explanations for the data.

Memo writing. Memo writing and informal note taking also helped me develop a systematic way of recording theoretical relationships between variables that emerge from the data. “Memo-writing,” Charmaz (2008) argued, “is the pivotal intermediate step between data collection and writing drafts of papers” (p. 72). She suggested that memos are a record of the researchers’ thoughts throughout the research process. Keeping these ideas gives the scholar a concrete way of organizing his or her data. Furthermore, it allows other researchers to have confidence in the results that the grounded theorist presents. I followed five steps when compiling my memos: (a) dated memos and diagrams, (b) created a heading for each memo and diagram, (c) included short quotes or phrases of raw data in the memo, (d) regularly updated memos, and (e) kept a list of concepts and sub-concepts available for reference.

Coding. Qualitative data is analyzed using a series of coding procedures. Coding allows the researcher to name “segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data” (Charmaz, 2008, p. 43). Corbin and Strauss (2008) suggested that there are several ways for the analyst to engage in open coding of his or her data. An analyst might, for example, choose to analyze the data using line-by-line coding. Line-by-line coding allows the researcher to understand the data at micro level of analysis. Often, the data are analyzed by word or short phrase. This type of analysis, however, does not always provide the analyst with a meaningful understanding of the data. For some analysts, it is more beneficial to engage in sentence level coding or paragraph level coding; still other analysts might code larger excerpts of the transcript. I began my analysis of the data with line-by-line

coding and moved to code larger excerpts of text to gain a better understanding of key constructs elaborated in the data.

First, I labeled concepts or phenomena that emerged from the data. As I coded, I engaged in constant comparative analysis (Corbin & Strauss, 2008; Lincoln & Guba, 1985). Constant comparative analysis allows researchers to distinguish patterns and themes in the data. Categories are then refined over the course of data collection. Because of the often large number of codes an analyst may discover in his or her data, describing more abstract categories allows the analyst to more clearly identify and describe the theoretical links between concepts. For example, I began with 768 codes as I read through the initial transcripts. After further examination I developed more abstract categories that better illustrated the experiences of participants. In the end, the refined categories or themes provided an explanatory framework for understanding the relationships between the concepts under investigation.

In addition to open coding of the data, I utilized axial coding, or “the process of relating categories to their subcategories” (Strauss & Corbin, 1998, p. 123). From the 768 codes that used the language of the participants to describe categories, the second level of analysis provided a theoretical conceptualization of categories.

In summary, I used a grounded theory approach (Corbin & Strauss, 2008) which involved preliminary analyses of prominent themes that emerged from the data. As a first step, I independently coded a subset of the transcripts. The procedure of open coding allowed me to begin to label concepts that are evident in the data using the language of the participants. The process of axial coding then allowed me to identify major emergent themes among the participants’ responses related to experiences of uncertainty and management strategies. Next, a colleague was trained to code the data in a series of meetings. I created detailed coding

directions and coded sample transcripts to be sure that the instructions were clear. My colleague and I discussed the themes as we coded the remainder of the interview transcripts. These substantive codes (Glaser, 1992) clearly described the participant's experiences.

Throughout the data analysis, my colleague and I met to discuss emerging relationships among the concepts and keep informal notes and memos. Having multiple coders on the research team can enhance the richness of the description based on having multiple, complementary perspectives. We coded for one research question at a time. First, we coded all interview data related to the types of social support (e.g., emotional, informational, tangible). Then, we coded interview data related to dilemmas that nurses face in communicating social support to families. Then the research team transitioned to code the remainder of the research questions related to the sources of uncertainty for nurses and how nurses respond to uncertainty communicated by families. We also identified several recommendations for improving communication in the context of Alzheimer's care.

After findings were organized into categories I conducted follow-up interviews with 3 participants to serve as a member check of the data. Nursing staff who participated in these interviews were asked if my interpretations fit with their experiences. Member checks like these follow-up interviews are useful for establishing reliability of the findings and guard against researcher bias (Lincoln & Guba, 1985).

CHAPTER 4: FINDINGS

Newspaper articles and popular books encourage people to do more crossword puzzles, to take vitamin E supplements, to eat more curry, all in an effort to stave off a disease without a cure. Still, science and medicine promote the idea that there *is* a cure – something to hope for. Researchers have looked at the benefits of red wine, green tea, and blueberries. Scientists have done tests on genetically engineered mice with cognitive decline like that seen in Alzheimer’s patients, which have led to several breakthroughs that, when tested in clinical trials on humans, have been halted because of side effects or inefficacy. It is no wonder that patients, families, and health care providers express frustration at the lack of treatment for Alzheimer’s disease. In the absence of a cure, it is important to examine the experiences of those coping with Alzheimer’s disease to determine the best ways of improving outcomes. Communication is one way that outcomes can be improved. Goldsmith (2001, 2004) outlines several foci for a normative approach to studying uncertainty and communication. First, scholars must shift their focus from measuring levels of uncertainty to considering the multiple and often conflicting meanings that uncertainty may have for members of the speech community. Further, normative approaches evaluate communication behaviors and seek to explain the effectiveness and appropriateness of communicative responses to uncertainty.

The current project takes a normative approach to the study of uncertainty and communication. To determine the role of communication in nurses’ interactions with patients and their families coping with Alzheimer’s disease, this analysis focused on six areas: (a) the socio-cultural context, (b) sources of uncertainty for nurses and care assistants, (c) communicative management of uncertainty, (d) ways of communicating support to family members, (e) dilemmas of communicating support, and (f) strategies for managing

communicative dilemmas perceived as effective in nursing care. The sources of uncertainty participants reported experiencing become implicated in the complex communication situations that that nurses and care assistants deal with in their work.

The Socio-Cultural Context

Although some important aspects of the socio-cultural context can be understood by considering structural factors like the type of care facility and the service of payment arrangements, participants provided some important insights about the particular nature of working in Alzheimer's care facilities. These insights are important for understanding the context in which they experience uncertainty.

Participants reported several aspects of their experiences providing care that influenced the ways in which they communicated and developed relationships with residents, family members, and coworkers. First, participants working in assisted living and skilled nursing care facilities reported that caring for Alzheimer's patients is "not for everyone." Because of the specific challenges that nurses and care assistants must cope with in the context of Alzheimer's care, participants described specific characteristics that make a "good" Alzheimer's nurse. For many nurses and care assistants, one of the features that made a good Alzheimer's nurse rested on what drew them into nursing. Participants described how they felt called to geriatric nursing because of uncertainty they experienced related to their own relationships with their grandparents or elderly family members. For some participants like Kathy, "missing out on" relationships with grandparents drew them to Alzheimer's care.

In addition to those participants who reported that they became an Alzheimer's care nurse out of a love for the elderly, participants also noted that they had a desire to provide care for our aging population because of the necessity of the position. Elizabeth, for example, commented

that “dementia is just where it’s (nursing) going.” Although the participants in the current study provided ample evidence of their commitment to their work and their residents, they also described situations where nurses and care assistants they work with do not belong in Alzheimer’s care because they do not exhibit the qualities of this type of nurse.

Another socio-cultural challenge that nurses and care assistants cope with concerned economic barriers to facilitating proper care. One challenge nurses described concerned the amount of pay they received for providing care in an Alzheimer’s care facility. For some, despite working over 20 years, the facility was not able to compete with pay scales of other nursing specialties. For example, Mary has worked in the same nursing facility for 25 years and has held administrative positions as Director of Nursing and Care Plan Coordinator. She described how she felt trapped in her position saying, “it is really hard for me to leave even though the pay is terrible.” Mary felt like she could not leave because of the patients she cared for despite the fact that she had not received a raise in the last several years and was only earning \$25 per hour. She continued, “it doesn’t matter, whether you do a good job or not. We didn’t get raises last year. That was, frustrating to a lot of our staff here. Myself included.” Pay in some facilities was below the typical rate for registered nurses who have worked approximately twenty years and earn between \$26 and \$35 an hour (Payscale, 2010). Certified nursing assistants, on the other hand, earn between nine and twelve dollars per hour (PayScale). This is just over minimum wage in most states.

Related to economic concerns over how much nurses and care assistants earn when providing care is the challenge of training enough people to become nurses and care assistants. A nursing shortage has been widely acknowledged as a challenge that the United States faces currently and will continue to deal with unless more resources are allocated to nursing schools.

Mary and other nurses in administrative roles feared that the lack of permanent staffing in nursing care facilities would limit the quality of care that Alzheimer's patients will receive.

Mary said:

Permanent staffing. It is so important to have the same person day after day because they get to identifying that person, they do identify with that caregiver. Seeing that face, day after day multiple times a day, they know the person and when you switch that person to a different group they do not do well. Or when that patient's regular caregiver is a day off, or on vacation you can tell, difference in those patients almost immediately. So, trying to keep a regular caregiver is very important, for demented people

This was echoed by Nicole, an RN who works the night shift. As the charge nurse on the night shift she described the challenges she faces working with temporary or part-time staff. The night shift is a time when Alzheimer's patients require specific medications and do not have activities to occupy their time. Often this means that the nursing staff has the opportunity to engage in more psychosocial care (e.g., communicating with the patient). Mark, a full time CNA working in a nursing care facility, described the joy he experiences taking extra time to communicate with and acknowledge the unique experiences of his residents on the night shift. He said that during the night residents often experience greater levels of confusion than they do during the day, which sometimes leads to fear and aggressive behaviors. If, however, the staff knows the resident well, efforts can be made to calm and care for the resident before challenging incidences occur.

There is a lady who is musician and I am a musician so we start to talk about that every night about 2 or 3 o'clock in the morning, she wakes up and she is hungry and is sitting on the edge of her bed. Now she is half sleep all day and hardly anybody has time to talk

to her, but it would be ridiculous and sad if I just went in and said “okay well you need to go to the restroom” then I hurry off to do somebody else. If I did not sit and talk to her...and she tells me the same stuff every time. It’s not like she is talking about the history of the world, she is talking about whether or not she is hungry and what she used to eat, what her mom said to her. That is about as far as she can think, but that is the only time she has expressed a thought all day. It would be wrong of me on a human level to not be tender to her when she feels like talking and expressing herself because it may be the last time she can do it. I just think it would be a travesty if I did not pay attention to what she was saying. I think that is the main thing, you have to patient because when you speak to them, depending on their level of function, there is a gap of 3 to 5 seconds sometimes when you can ask them a question.

As Nicole said, part time staff did not have the same knowledge that full time staff had and were less likely to engage residents in talk as they are working through the tasks that were in the job description.

Participants suggested that the socio-cultural context in which they work influenced their experiences of stress and uncertainty. In particular, pay differences between nursing care facilities and other nursing specialties (e.g., intensive care nurses, medical-surgical nurses, etc.) contributed to experiences of burnout because of their perceptions about their value in the health care system. Meredith, for example, said that she gave up her career as an Alzheimer’s care nurse because she experienced burnout. Her stress and decision to change specialties was influenced in part by economic circumstances and was further exacerbated by the difficulties experienced working with Alzheimer’s patients and their families. Concerns about their value in the organization and in the wider health care system as well as questions about how to best

communicate with patients and families contributed to feelings of burnout described by nurses and care assistants.

Sources of Uncertainty for Nurses and Care Assistants

Brashers and colleagues have argued that understanding the different forms of uncertainty people experience “enhances our ability to describe and explain its influence on behavior and to develop strategies for improving people’s lives” (Brashers, 2001, p. 479). Beginning this study with a focus on the different types of uncertainty participants report provides a foundation for later sections that explain the communication processes that assist and hinder uncertainty management. As previous scholars have demonstrated, various forms of uncertainty are experienced by individuals with illness (Babrow, Kasch, & Ford, 1998; Brashers, Neidig, Reynolds, & Haas, 1998; Martin, Stone, Scott, & Brashers, 2010; Mishel, 1988, 1990, 1999) and those coping with another’s illness (Donovan-Kicken & Bute, 2008; Goldsmith, 2010; Stone & Jones, 2009).

In addition to exploring uncertainty in illness experiences, scholars have examined the role of uncertainty in organizational contexts (Kramer, 1993, 1996; McPhee & Zaug, 2001). Knowing what to expect at work and how to manage relationships with coworkers are common forms of uncertainty in organizations (Teboul, 1994). Although researchers have examined experiences of uncertainty at specific organizational transitions like entering an organization (Mignerey, Rubin, & Gorden, 1995) and job security when organizations are firing employees (Casey, Miller, & Johnson, 1997), researchers have not explored in much detail the experience of uncertainty for health care providers who work in assisted living and nursing home environments.

All of the nurses and care assistants who participated in this study described the role of uncertainty in their lives. For some, uncertainty was localized to a specific question they had about medical interventions. For others, like John, uncertainty was experienced every day. Examining sources of uncertainty in specific socio-cultural contexts highlights the multiple meanings that uncertainty has for members of the speech community. Nurses and care assistants described four main sources of uncertainty: (a) Alzheimer's disease itself, (b) communication with the patient, (c) communication with family members, and (d) communication with other health care providers. Uncertainty about Alzheimer's disease focused on medical questions and concerns about behavioral changes. Uncertainty about communication with the patient, family members, and other health care providers was rooted in questions about what counts as adequate care for the resident, how much others (e.g., resident and family members) understand about various aspects of Alzheimer's disease, and why coworkers choose to behave and communicate in specific ways.

Uncertainty about Alzheimer's Disease

Many nurses and care assistants described how difficult it was to make decisions about what care to provide because of the *varied reactions to treatment* people with Alzheimer's disease may have. Laura, for example, described how there "is no such thing as a right and a wrong and you make the best judgment and then sometimes retrospectively is the only way, and you don't always know for sure that was the decision you should have made." She continued with an example of a resident who exhibited "behaviors" (e.g., yelling, hitting) and how the decision to intervene to correct those behaviors often exacerbates the problem by making residents more upset. Still, Laura noted that, despite the uncertainty that she experienced concerning what to do to manage the behaviors the patient exhibited, she had to try to help. She

continued, “You wonder at times if that was even the right decision. Should we have really have tried that psychotropic or not?” Because human beings are unique in how they react to medications and treatments, nurses and care assistants like Laura noted that “it takes a lot of judgment and sometimes you only know afterwards.”

Even participants with many years of experience expressed that despite working with Alzheimer’s patients and their families, the specific *characteristics of the disease* (e.g., variable symptom patterns) contributed to the uncertainty they felt. Erica, a director of nursing and founder of an Alzheimer’s unit, described her uncertainty across her career when she said, “I do have uncertainty, and when we opened our doors I had a lot of uncertainty and I often said to myself ‘I wish I were six years into this so I’d had the experience to know what to expect’ and now that I’m ten years into it I still have uncertainty.” Acknowledging that Alzheimer’s disease creates uncertainty because of the specific nature of the disease was a common theme in participant’s narratives.

Uncertainty Communicating with Residents

Participants described how communicating with a person who has Alzheimer’s disease induces uncertainty. When asked about their experiences working with people who have Alzheimer’s disease, participants reported that they had a lot of questions about how to communicate with someone with limited cognitive abilities. Nancy and many others described how they wondered “about how much they’re understanding. Some of them you ask them to do something and they look at you and you just sit there and wonder, ‘okay, are you really understanding what I’m saying?’” Samantha reported “We have a number of patients who are not able to communicate. They don’t talk at all or they have word salad or that sort of thing and they can get very distressed.”

The distress that residents experienced contributed to the uncertainty nursing staff described. Participants suggested that they would like to be able to do more. After describing the distress that some residents without the ability to communicate anymore exhibit, Samantha continued, “I’d like to be able to help soothe more than just what I do.” Melissa further summarized what many other nurses and care assistants described saying, “there are some things that I could’ve done differently or I was like ‘what should I do?’” Questions like “what should I do?” highlight the pervasiveness of uncertainty in the experiences of nurses and care assistants working with Alzheimer’s patients.

Nicole described how not being able to ask a question and trust the response of a patient is a constant source of uncertainty. She said, “when you’re dealing with an Alzheimer’s patient and you tried the normal techniques that have worked in the past and you’re not able to get it, and you’re not able to really understand where they’re coming from, then you’re uncertain.” The “normal techniques” that Nicole referred to include strategies that nurses and care assistants developed with particular residents to communicate with them. Despite developing techniques, participants like Erica continued to explain how “no one day is the same as the next. You never know what’s going to trigger a behavior. You can kind of see it coming. And usually you try and ward it off but a lot of times you can’t see it coming. It’s different, it’s different every day. Every day is different.”

Another source of uncertainty for nurses and care assistants communicating with residents concerned policies aimed at regulating interactions between nursing staff and residents. Nurses and care assistants described how some of their training had impressed upon them the importance of “redirecting” residents. Redirecting occurs when a resident gets confused about a situation. For example, if a resident meets a member of the staff in the hallway and believes that

the staff member is their son or daughter, a nurse or care assistant would be instructed to tell the resident that their son or daughter is not here and that the person they think is their son or daughter is a member of the staff. Ruth described how a resident would constantly ask her for her brother or where her children were. Ruth noted that she had to monitor her communication with other staff members because “our housekeeper has the same name as her son and when I talk to him I can’t say ‘hey [name of housekeeper],’ she might think her son is there.” Instead of prompting a situation where Ruth would have to redirect, she tried to avoid the situation. For others, instead of avoiding situations where redirecting would be necessary, several participants including Michelle and John reported that “communicating in their own world” became a more appropriate strategy. Most participants noted that redirecting is no longer an advisable principle to follow. Michelle summarized this saying, “It doesn’t always work to redirect. If they don’t want to be redirected it’s hard.” She continued by describing how

Sometimes you have to go along with the story. You know, but you can go on with the story and they’ll change it on you so fast so it’s like okay we were talking about this but now we’re talking about a dog or we’re talking about outside or something or anything.

But most of the time it is kind of hard to redirect them. We were told to redirect them but they don’t want to be redirected.

Not being able to redirect in the way that their training suggested often required participants to pretend to be a resident’s daughter, son, mother, father, sister, or brother or to make up stories about how the resident’s car was still in the repair shop. Further, participants described uncertainty rooted in communicating with residents the way that they were taught to (e.g., to redirect) or to communicate with the residents the way they knew would be more successful. Similar to the challenges faced by medical interpreters due to role expectations placed on them

by others (Hsieh, 2006), participants in the current study faced challenges because of the role expectations placed on them members of the medical team and family members. Role conflict, which was described by Hullett, McMillan, and Rogan (2000) as occurring “when a person is playing more than one role but the expectations for those roles conflict,” is evident in participant’s experiences of residents often regarding them as surrogate family members (Hullett, McMillan, & Rogan). Hullett et al. further suggested that although caregivers communicate emotional support, it is not an official part of their job description at some facilities, which sometimes go so far as to discourage becoming “too friendly” with the residents and their family members.

Implicitly, participants reported that what counts as a good way to interact with patients does not match the training they receive in nursing school. Such contradictions require nurses to negotiate between what they were taught in school and what their experiences suggest are best practices. Scholars have noted that this type of negotiating occurs in other contexts. For example, Hsieh (2004) described how medical interpreters often go against their training to maintain cultural appropriateness by altering the message instead of communicating the exact translation. Instead of cultural appropriateness, participants in the current study were concerned with how they could best communicate with persons who are experiencing often dramatic cognitive decline. Samantha suggested that nurses and care assistants go against their nursing training because they recognize that the training that they received in nursing school was not specific to Alzheimer’s care. Because this disease has specific characteristics that make communication challenging, nursing training that is not Alzheimer’s specific is difficult to apply. The directive in nursing training appears to be aimed at treating patients with the dignity they deserve. For patients who may be experiencing momentary confusion associated with any

number of diseases, this recommendation to explain that the situation is different from that which the patient believes is understandable. The confusion associated with Alzheimer's and other forms of dementia, however, cannot be treated with the same communication strategies without facing challenges. Not all participants recognized this distinction between nursing training and the necessity of having specific protocol for Alzheimer's care. Even for participants like Samantha, who clearly acknowledged the necessity of going against her training, uncertainty about how much to redirect patients was still a prominent part of the experience.

Finally, participants reported that not knowing whether a resident was having "a good day or a bad day" was a prominent source of uncertainty when communicating with Alzheimer's patients. As Rau (1993) noted, "the person with dementia will typically show an inconsistent pattern in his ability to complete tasks or to understand and communicate" (p. 25). Participants in the current study noted that communication strategies were in large part determined by whether the resident was having a good day or a bad day. Good days were described as days when the resident was lucid and able to communicate needs and desires more clearly than they otherwise had been. Bad days, on the other hand, are characterized in terms of the difficulties the resident has with all of the activities of daily living that the nurse or care assistant is tasked to complete. When a resident was having a good day, nurses and care assistants could accomplish more and with greater ease than if the resident was having a bad day. John described how uncertainty typified his experiences of caring with residences and how the good day, bad day categories influenced the experience of uncertainty.

I kind of respond to what their behavior is. If they're having a good day you kind of push them, elevate the positive feeling. And if they're having a bad day, I usually tell them, "You know I'm having a bad day too. Let's have a bad day together." That type of thing.

“It happens to all of us.” Like I said like the little things like brushing teeth and having breakfast and stuff like that. I kind of just see how they’re doing that day and if they’re willing to do it we do it and if they don’t want to do it at that time we come back later.

John and others experienced uncertainty communicating with residents, especially if they were having a bad day. Uncertainty was described as part of the everyday experiences of nurses and care assistants working with Alzheimer’s patients.

Uncertainty Communicating with Family Members

A third salient source of uncertainty for nurses and care assistants concerns communication with family members. Participants reported that families had a lot of questions about the care their loved one was receiving and that they did not always have answers to these questions. This uncertainty was rooted in the complex challenges they faced as Alzheimer’s care nurses for whom every day was different. Although anticipating questions seemed to come with experience, nurses and care assistants described the uncertainty they experienced when they were unsure about how to answer particular questions in a way that would satisfy or bring peace of mind to the family or if a family member challenged a decision.

Participants reported that one of the most common and difficult questions family members asked related to how nurses and care assistants could ascertain the pain level of their loved one. Melissa described how families ask questions about pain, “‘how are you going to tell they’re having pain?’ then I tell them what we do to look for pain, nursing interventions.” Having a clear protocol for responding to questions about pain helped nurses and care assistants feel confident in their ability to communicate with the family.

Nurses and care assistants reported that a second prominent area of concern for families was whether the medication was working for their loved one. As Stone and Jones (2009) found

in their study of adult caregivers of a loved one with Alzheimer's disease, unclear efficacy of medications contributed to caregivers' overall experience of uncertainty. Variable responses to medications and treatments required nurses and care assistants to come to terms with their uncertainty and to communicate that uncertainty to the patients' families. Melissa described how constant education was necessary to get families to understand why it was necessary to try different types and doses of medication. This was particularly difficult when residents arrived in the care facility with a long list of medications, often seemingly unnecessary. She said "you try to reeducate the family and explain this is probably better for them and to have a little less and they always have these behaviors you just have to see what works for them."

A third area that nurses and care assistants reported contributing to their uncertainty communicating with family members was related to the dynamics of the family. Samantha described how "family issues" induced uncertainty because they often distract from providing care for the resident. Samantha continued by describing a specific situation where she felt uncertain about how to communicate with family members.

I had a patient once who, she has one daughter who lived in town and called her every day and then she has another daughter who lives in [name of place] and calls maybe once a week. And the two sisters don't get along. And I'll get one daughter calling me to talk to me saying, "I'm concerned about mom and I've got this thing with the sister." And then the other sister calls ten minutes later, and will be like, "I can't believe she said that to you" and I'm like, "How do you even know?" kind of thing. But it's a lot of tension outside of the facility and that causes tension within the facility.

This tension often resulted in nurses and care assistants having to acknowledge that they could not help the situation between the family members, often siblings. Instead, relying on other

health care providers like a social worker was a useful solution.

Uncertainty Communicating with Coworkers and other Nursing Staff

In addition to experiencing uncertainty when communicating with residents and family members, participants reported that communication with coworkers was a prominent source of uncertainty. John described how conflict with his coworkers or “not seeing eye to eye” about issues related to caring for residents and communicating with family members caused him to experience uncertainty about how to communicate with his coworkers. He provided an example of his experience of uncertainty when a fellow certified nursing assistant (CNA) addressed a resident rudely. Although he knew that the resident should not be addressed in a rude manner, he expressed sincere concern that discussing the issue with the coworker would “create too much conflict.” Instead of communicating directly with the other CNA he tried approaching an administrator.

I mean a lot of time I just don't know how to [communicate with the other CNA]. I mean I'll tell the nurse and I'll tell the DON (director of nursing) but nothing really happens. And it continues and continues. I mean it's not like physical or verbal abuse. It's just more they'll respond if a resident will be screaming like, “Hello, hello, hello, hello, hello” repeatedly and their reaction is “what do you want?” And I'm like, you don't say that.

Others described how they experienced uncertainty because coworkers did not effectively communicate information across shifts. Nicole, who worked the night shift, described how not knowing the resident's “life story” makes it difficult to tell her coworkers, including other registered nurses (RNs) and CNAs, how best to approach a resident.

Interactions with physicians who do not care for the residents on a consistent basis also contributed to the uncertainty nurses and care assistants experienced. Samantha described uncertainty she experienced because the doctors she worked with “just don’t get it.” She continued:

And I run into this almost daily. I’m trying to explain to them what I’m seeing with my patients. How things are, how things progress or the behaviors I see. I think probably the thing that I laugh at both because it’s just too stupid it’s so funny, doctors want, I’ve had doctors order psych consults and therapy for Alzheimer’s patients. I’m like, “Are you kidding me?”

For nurses and care assistants, ordering tests and therapy that would not help their patients was frustrating and a source of uncertainty because they often described not knowing how to discuss reasons why these treatments would not be useful. For some residents, treatments like this triggered negative behaviors and led to other problems participants had to deal with.

A final form of uncertainty in communicating with coworkers was related to why staff decided to become an Alzheimer’s care nurse. Nicole, a RN in charge of coordinating and training staff on the night shift, described how not knowing “where they’re coming from” contributed to her experience of uncertainty. In this instance, Nicole was particularly concerned with staff who became nurses because of the limited job market in other fields. Participants suggested that working with staff who are more interested in job security than caring for patients created uncertainty for nurses and care assistants related to how best to communicate.

With research that illustrates the pervasive nature of uncertainty, it is important to understand the specific sources of uncertainty that people experience. Although four specific forms of uncertainty were reported by participants, it is important to acknowledge that

uncertainties are interconnected. For example, questions about how to communicate with an Alzheimer's resident can create uncertainty about how to communicate this issue to the resident's family and to other coworkers, who may be experiencing similar problems with the resident. A detailed understanding of the sources of uncertainty is essential when taking a normative approach to a study of uncertainty and communication because it highlights attention to the ways in which potentially conflicting goals are managed in communication as nurses and care assistants who work with Alzheimer's patients struggle with various sources of uncertainty.

Management of Uncertainty

Participants described the various ways they used communication to respond to their experiences of uncertainty. Goldsmith (2001) argued that a normative approach accounts for how some communicative responses to uncertainty are evaluated as functionally better than other responses in managing uncertainty. Three prominent uncertainty management strategies, (a) information use, (b) the provision and receipt of peer support, and (c) appraising uncertainty as a part of everyday life, were reported as being particularly important in terms of managing uncertainty about Alzheimer's disease generally and uncertainty about communication with residents, family members, and coworkers in particular. As Goldsmith noted, accounting for the ways in which conflicting goals are "associated with experiencing, reducing, maintaining, or increasing uncertainty through communicative means" is an essential step in building a normative theory of uncertainty and communication. The following describes each of these uncertainty management strategies with examples from interview transcripts.

Using Information to Manage Uncertainty

Drawing from Wilson's (2000) definition of information behavior and literature from communication, social, and behavioral sciences, Hogan and Brashers (2009) proposed that

information behavior should be conceptualized in terms of information acquisition, information handling, and information use. Information acquisition relates to the sources that an individual uses to obtain materials, as well as information seeking and avoiding behaviors. Hogan and Rintamaki (2006) also found evidence to suggest that people have a system for handling the information they acquire, including strategies as simple as memorizing information that they think is important to more complex strategies for organizing information with a physical presence (e.g., pamphlets, notes, prescription inserts), including filing. Information use refers to the ways that people process information and how they communicate about that information with others.

Information acquisition. Participants reported a number of ways in which they acquired information for managing their uncertainty, including (a) selecting sources of information and (b) seeking information. Unlike other studies of information management, participants in the current study did not report avoiding information. One potential explanation for participants not avoiding information may be that nurses and care assistants often characterized information seeking as part of what makes a good health care provider. Avoiding information, by implication, would suggest that they were not meeting their potential. In other words, nurses cannot be harmed by having more information.

Participants described the different *information sources* they consulted to manage their uncertainty about Alzheimer's disease generally and communication related uncertainty in particular, including ways to communicate with other health care providers (e.g., RNs, LPNs, CNAs). Typically, nurses and care assistants reported seeking out peers as sources of information first. Participants valued the opinions of others they worked with because of a common understanding that nursing in the context of Alzheimer's disease is challenging. The

experience of Alzheimer's care provides credibility to the advice that others without the experience would not have. Samantha described how her peers working in Alzheimer's care had "been nurses for a long time," which made her comfortable using them as a credible source of information. This was described in opposition to other sources of information like books and internet, which were described as only being useful for very specific questions that participants had time to prepare answers for. For the most part, participants did not have a lot of time to seek information in books and on the internet because the challenges they faced that prompted them to select a source of information needed to be dealt with immediately.

In addition, the nursing context involves a hierarchy that allows for nurses and care assistants to use each other as sources of information. Often described as a "team" approach, nursing staff tried to cultivate an environment in which uncertainty was accepted. Doctors, however, were rarely mentioned as a source of information. Instead, participants reported that interactions with doctors often produced rather than reduced uncertainty because of the lack of respect many physicians showed to nurses and care assistants working with Alzheimer's patients and their families. For example, Erica, a director of nursing who did use doctors as a source of information, noted that although there were some situations where doctors were a useful source of information, for the most part, the challenge of negotiating the relationship with physicians was considered unnecessary given the expertise of peers.

In addition to choosing peers as an important source of information, participants also discussed the importance of continuing education classes for learning what they considered to be the up-to-date information about treatments and medications. Erin described how she "always read everything. I have nursing journals that I read. I'm always interested in news things." For many participants, like John, continuing education classes were available online.

After selecting particular sources of information, participants reported that *seeking information* was a common strategy for managing their uncertainty. Participants described seeking information on a variety of topics including the disease process and how to work with Alzheimer's patients. Erica in particular described how important it was for her to learn as much as she could about the people she was working with because she had no prior experience with Alzheimer's in her clinical rotations. Participants also noted that nursing education typically glosses over specific illness contexts because of the expectation that much learning occurs once a nurse has chosen a specialty. Erica also described how advances in the medical field have increased her uncertainty about Alzheimer's disease and prompted her desire to learn more. Michelle reported that she managed her uncertainty about how to communicate with residents by taking a class on "how you care for your residents. How the residents come first, your number one goal when you come here is for the residents because that's actually our customer."

Information handling. Managing information has typically been conceptualized as an individual process (Lansdale, 1988). Hogan and Brashers (2009), however, suggested that research should be sensitized to contexts in which information management is not an individual process. The nursing care context is one area in which information management requires careful coordination among members of the medical team (e.g., nurses and care assistants) and family members. Nurses and care assistants handled information by (a) committing it to memory and (b) documenting it in the resident's chart.

Participants reported that handling information is a key for managing the uncertainty that nurses and care assistants experience. Participants evaluated information and, if it was useful, typically worked to remember the information so that they could then use it in similar situations that they may encounter. In addition to remembering information, it is crucial for nurses and

care assistants to document all information pertinent to a resident's care plan in the resident's chart. This is particularly important as nurses and care assistants must share information between shifts. With little time for conversation, having the written documentation of incidents (e.g., falls, rashes) as well as strategies for communicating with residents is essential. Some nurses and care assistants like Nancy suggested writing down personal stories they learned from residents and resident's families in a separate document that could be used to help Alzheimer's patients feel comfortable and build a relationship with the nursing staff. These "my life stories" were described as documents that included "family things, memories of things. Stuff that they're (the residents) trying to remember that they want to remember about."

Challenges of information use. Although selecting particular sources of information and seeking specific types of information may facilitate uncertainty management, participants highlighted challenges that they faced concerning how the information would be used. Specifically, participants reported barriers to communicating with others including the resident, family members, and coworkers.

Nurses and care assistants reported two key challenges of communicating information to *residents*. Although scholars have suggested that infantilizing communication may actually increase the symptoms of dementia (Kitwood, 1990), informal caregivers have noted that the experience of caring for an aging parent was similar to their experiences of caring for a child (Stone & Jones, 2009). Participants in the current study described a challenge that they faced with the choice between using more formal language that communicated respect to residents versus talking with residents as if they were children. Secondary babytalk is defined in comparison to "normal adult speech" as "simplified, more redundant, and less complex" with "the hallmark of babytalk its high pitch and exaggerated intonation contour" (Caporael,

Lukazewski, & Cullbertson, 1983, p. 746). Many participants noted that using secondary babytalk was completely inappropriate because, as Ruth said, “they are not babies, they are adults.” She later continued, though, that it is difficult to always communicate with Alzheimer’s patients as if they are adults because “they forget things.” The person is an adult, who deserves the respect given to all adults but often the situation makes it difficult to communicate that respect. Others, like Leslie and Tina reported that they use babytalk with residents “because there’s a lot who act like children” and “it’s more comforting because they’re going back to being a child.” Nancy, however, felt very strongly that those who used babytalk in her facility had to be corrected:

We have had some and we had to let them know that’s not appropriate at all. They are adults still. You still owe them respect to talk to them like a regular person. They’re not a child. Even though like they’ve lost a lot of their memory function and they go back to some of them result back to where they were children. We feel like it’s not appropriate to treat them like that.

Participants also reported challenges of working with *family members*, which centered around (a) the type of language, formal medical terminology or lay language, that was most appropriate and (b) with whom to share information. Nurses and care assistants noted that a family member’s educational background was an important characteristic determining the type of communication that participants felt was appropriate. More formal medical terminology was used when describing treatments and care plans with family members who were considered well educated. With family members who appeared less educated, using lay language or “simple, calm, simple common language; nothing technical” as Derek suggested were often considered useful tools. Nancy reported that with less educated family members it was important

to not use so much of any type of medical terms or use anything that they would not understand. We try to just talk to them on a regular level like you're communicating with just a regular, a family member of your own. Just being yourself with it. But being respectful at the same time.

Although participants reported that multiple family members were often concerned about the residents' health, only the powers of attorney were supposed to have information about the patients. Nurses and care assistants reported feeling conflicted about having to only communicate information to the power of attorney because of the frustration that family and friends often experienced. Michelle, for example, said "I tell them a little information. That they're having a bad day, they're having a good day." Others like Lily echoed this challenge saying, "We are careful about what we say to anybody if they are not the power of attorney. Just reassurance mostly."

Finally, both nurses and care assistants reported experiencing a challenge in communicating with their *coworkers*. At the beginning and end of each shift the nurses and care assistants on duty give a report to the nurses and care assistants who are starting their shift. This is an opportunity to share the information that participants gained while they were working with the residents and communicating with families. Jill noted at the beginning of our interview that she had a lot to report to the next shift's nursing staff because of several incidents that occurred during her shift including a male resident who fell, a female resident who had developed a rash, and a second male resident who had started drooling. Each of these incidents required Jill to first provide care to the resident and then to use the information she gained from providing that care to communicate it to each resident's family as well as staff who would be responsible for these residents' care on the next shift. One key challenge that nurses and care assistants faced was

exemplified in the situation that Jill and others similarly described. Given that each shift is between 8 and 10 hours long, often there is not enough time to complete all of the tasks they are responsible for. This challenge often creates conflict between staff on different shifts. Because patient care is the number one goal of nursing care, it may seem obvious that information use in the forms of filling out the appropriate paperwork and communicating that information to the incoming staff would be less important. However, without proper information use participants generally reported that quality of care was compromised.

This difficulty often led to a second communication challenge as coworkers were faced with the dilemmas of correcting or teaching a coworker versus letting something go. Samantha described how being one year out of nursing school made her a target for other nurses to give her advice. She reported that other nurses she worked with told her to “stand up for yourself, realize you are doing the best you can do.” This sometimes resulted in conflict situations with other nurses, particularly when nurses corrected care assistants. For example, Nicole described her frustration with coworkers who did not take things as seriously she did. Instead of focusing on quality of care for the residents, some nurses, she said, “blow off residents.” Her dilemma as the charge nurse was to either communicate that her coworkers’ style of communication was not acceptable, which would risk creating conflict within the staff, or to ignore the situation to keep peace.

John, a CNA, also described the often embarrassing situation care assistants deal with when a resident does not make it to a bathroom before they relieve themselves. Instead of highlighting that the resident had an accident, he described how he would tell her a story to distract her from the uncomfortable situation she was experiencing.

She would have a lot of accidents. She had to use the bathroom a lot, a lot of the CNAs and nurses “Come on, you had an accident, let’s go. Come on.” She would just get bright red, embarrassed even though she had moderate Alzheimer’s. I mean you don’t, what I would do is create a story like, I knew she loved cats, you’ve got to find out what they love. She loved cats so I would tell her that I had seven cats and I would tell her all their names, and I would tell her all their adventures and I would get her walker and say “Come with me. Did I ever tell you about my cat? What she did this morning?” And then I would tell her the story all the way to the bathroom. I would open the door and continue the story all the way until it was done.

As he notes, most other nursing staff would not be so creative in the way that they handled the situation. However, because John believed that he had found a way to communicate with residents that allowed the resident to maintain dignity as an adult and receive the care they needed, he reported wanting to direct other nursing staff to do the same. Again, John faced a dilemma of challenging coworkers to change or ignore others actions to avoid conflict.

Participant’s narratives demonstrate that uncertainty characterizes many aspects of nursing care in the context of Alzheimer’s disease. Information management is one mechanism by which nurses and care assistants communicatively manage this uncertainty. Participants also described information seeking behaviors and strategies for handling the information they acquired. Finally, participants illustrated several challenges that they faced in using information to manage uncertainty.

Provision and Receipt of Support

The participants from this study demonstrated that nurses and care assistants seek the majority of support they need from their peers. There are two prominent reasons for seeking

support. First, participants reported that they felt like peers were an excellent source of advice because of the credibility experience with Alzheimer's nursing brings. Second, participants also felt that they were able to vent about their frustrations to peers. John, and others who reported not experiencing peer support, described feeling like they did not have much support, often because it was difficult to talk about work related topics with loved ones at home. Participants suggested attempts at offering support can at times facilitate uncertainty management and at other times hinder uncertainty management. This section highlights some of the complexities of communicating social support in an organizational context by examining the important distinctions between peer support that is perceived as (a) assisting the process of uncertainty management and (b) hindering the process of uncertainty management.

Assisting uncertainty management. Kathy and other participants reported that informal efforts at providing support greatly assisted in managing uncertainty for the nurses and care assistants she works with because it is important to "talk about it." For many participants, like Nicole, peers assisted uncertainty management because they were able to understand what she experienced and communicated support based on their previous experiences. Nicole reported,

For one thing they understand. So you can get that and then again especially when you asked before about not being sure of some things it also helps you to kind of brainstorm and learn certain techniques to talk to someone else about it and say "hey what about this?"

Participant's narratives demonstrate that, in addition to have a cathartic effect in expressing the need for support by telling one's story, the act of communicating support to someone with similar experiences may also be examined as a common and important part of interactions that also help individuals make sense of their experiences. Meredith continued that peers were essential

support providers because

it is very hard for somebody to understand the situation unless you actually lived with or been in it. I think that applies to a lot of things in life, but definitely something that can be such an emotional rollercoaster; dealing with someone who doesn't know what they are doing that puts you in very unique situation. I think that the people that have been there, done that, are the people that probably understand it the best.

Overall, participants felt that having someone to talk to about questions they had working with the residents, families, and coworkers assisted management of uncertainty and thereby allowed participants like Kathy and Meredith to communicate more effectively with those key members with whom participants experienced uncertainty. These situations may have been perceived as assisting uncertainty management because they provided participants an opportunity to have their actions and communication strategies validated by others with similar experiences.

Hindering uncertainty management. Participants also reported that there were times when communicating with peers hindered their ability to manage their uncertainty. For example, participants described times when communicating with others at work led to feeling incompetent. Derek described how others would try to “take the bossy role” and tell others what to do rather than offer advice in a way that was less face threatening. Many scholars have examined the role of advice giving in relationships and suggested that disclosing a stress or a problem typically triggers an advice giving response (Cutrona, 1986; Cutrona & Suhr, 1994; Goldsmith, 2001; Goldsmith & Fitch, 1997). Additionally, scholars have argued that situations where advice would be perceived by the advice giver as helpful are not always evaluated as such by those receiving the advice (Cutrona & Suhr, 1994; Pistrang, Piccioto, & Barker, 2001). Participants in the current study strengthen these claims through reports of feeling that the advice

given was not appropriate because of the situation within which it was given. As Cutrona and Russell (1990) suggested, different types of problems should be dealt with different forms of support. Derek, for example, continued that his peers “get like an ego or attitude where they might sound like they’re better than you.” When Derek sought advice from coworkers about how to communicate with a resident who is becoming aggressive, providing advice as if the problem is controllable may be perceived as unhelpful whereas advice that acknowledges that the issue is uncontrollable would allow the advice recipient to feel confident that his question was appropriate. These types of interactions hindered the process of uncertainty management for participants by adding an additional layer of complexity to the situation. Clearly there are risks in asking questions about how to do one’s job. These risks could, however, be mitigated by a more appropriate response from coworkers.

A second example of support attempts hindering uncertainty management efforts is illustrated through participants who described fear of communicating with coworkers because some people might use what they say against them. Meredith said, “You got be careful what you say. People tend to like to use your words against you, and so you have to be careful that you don’t say anything out of turn that could be misconstrued.” Erin continued that receiving support from peers may hinder uncertainty management “because somebody may know you’re weak, may perceive you as weak. If you’re saying something that happened to you, that you’re upset about or you know that you’re not perfect, they may take that as a sign of weakness on your part.” These comments further suggest that uncertainty management efforts are complicated by involving others. Instead of feeling at ease in communicating with coworkers about issues that are relevant to providing care for Alzheimer’s residents and their families, participants consistently reported that receiving support from peers is not always helpful and may in fact

challenge the abilities of the advice seeker.

Goldsmith (2001) elaborated a model of communicating advice that “suggests effective support is adapted to the situation and to the multiple purposes of assisted coping” (p. 56). She further explained that advice that meets three conditions will be likely to be perceived as more helpful than other attempts at communicating advice. These conditions include: (a) advice is an appropriate form of support for the problem, (b) the content of the advice is useful, and (c) advice attends to the multiple purposes at hand in the situation such that “the advice communicated is responsive not only to the task of assisting with problem solving but also to the identity and relational implications of directing another person’s behavior” (p. 56).

For Derek, and other nurses and care assistants in the current study, seeking support from peers served multiple purposes. Although there were instances when participants reported seeking support to solve a specific problem they were coping with (e.g., getting a resident to eat), often participants reported that communicating with other staff about problems was seen as an opportunity to vent frustrations, and therefore validating actions that the nurse or care assistant may be uncertain about or encouraging discussion of various options would be more appropriate than providing advice aimed at problem solving.

The specific content of advice communicated by peers was typically constrained by the context of the situation. For example, Derek described how a nursing assistant attempted to provide tangible assistance by providing an oxygen tank that his resident needed. The nursing assistant did not, however, check to ensure that the tank had been properly maintained since the last time it was used. Derek reported that he received advice from others on how to deal with situations where someone seems apathetic to the specifics of the job and the care of residents. When advice was communicated that specifically addressed the communicative challenge

participants faced, advice was perceived as more helpful than harmful. If, however, the advice did not pertain to the challenge the participant was coping with, nurses and care assistants noted that these attempts to communicate advice hindered uncertainty management efforts.

Goldsmith (2004) described the important distinction between solicited and unsolicited support as a criterion with which to understand why some attempts at communicating advice are perceived as helpful and others are not. Yet, participants in the present investigation reported that the distinction between what makes advice helpful versus not helpful is not based on whether or not the advice was solicited. Instead, advice was perceived as helpful if it clearly related to a problem at work that the advice giver had previous experience with. For example, nurses and care assistants reported getting along better with some residents than others. If Nurse A is working with Resident C and Nurse B has what appears to be a good relationship with Resident C, Nurse A would likely report that advice from Nurse B about how to communicate with Resident C was helpful regardless of whether Nurse A asked for the advice or not. If, however, Nurse B does not have a good relationship with Resident C and offers Nurse A advice about how to communicate with Resident C, Nurse A may perceive that advice as not as helpful because it is not grounded in concrete experiences.

The dynamic between what is considered helpful support and what is not considered helpful support is also affected by the orientation that the nursing staff has generally with each other. Samantha described how building a team orientation provides a context within which support is generally viewed as helpful:

We are trying to create a network of nurses and caregivers in my facility where we are a team. We all work with each other and help each other. If someone is having difficulties, someone else comes in and gives them a hand or gives them advice or in some cases

takes over because that's just what needs to be done. We work together that way because we need to get it done.

Having a common goal of providing quality care for residents and an agreement that working together as a team is more important than individual needs clearly shaped the distinction participants described between helpful and unhelpful support attempts.

Finally, it is important to consider the third condition of Goldsmith's (2001) model. In a profession where hierarchy structures the responsibilities of each actor in interactions, considering the implications that receiving support has for the identity of the participant and the relationships they are involved in is essential. Goldsmith and others (e.g., Tracy & Coupland, 1990) have conceptualized identity and relational concerns in communicating advice in terms of Goffman's (1967) conception of *face*. Participant's reports suggested that it was important to attend to identity goals when communicating support. Erin, for example, described how a disadvantage of getting support from peers was that some peers may "perceive you as weak. If you're saying something that happened to you, that you're upset about, or that you're not perfect at they may take that as a sign of weakness on your part." Although participants did not report specific examples of managing this identity concern, it seems that offering support in a manner that assures those receiving the support that they are not weak and that support is an integral part of nursing care would attend to identity concerns that participants reported.

In addition to identity goals, participants described the ways in which they attended to relational goals in their interactions with other staff. Kathy, a registered nurse who was in charge of managing the other nurses and care assistants during her shift in the Alzheimer's care facility, described how she attended to relational concerns with her team. Instead of focusing on the different responsibilities that characterize nursing care for different members of the health care

team, Kathy noted that making sure her team members “know that they can come to me with anything” helped her assist others’ uncertainty management. She continued that she is

not afraid to get in there and do it, the actual work that they do and instead of telling somebody to go do something, say if there is like a problem with something and I have to show them or correct them I’d say, “come on, I’ll show you.” And I go with them, say if I’m making my rounds after they say that their work is all done and somebody isn’t really repositioned right at bed I’ll say “come with me and we’ll do it together and I’ll show you how I want it done.” So then we did together and they see.

Participants perceived that this was a useful way of managing relationships with coworkers as it attempted to balance advice giving with the intention of improving care rather than making problems. Examples like this illustrate how attention to relational goals in interaction may impact the perceived helpfulness of the support attempt.

Accepting Uncertainty as Part of Everyday Life

Uncertainty can be experienced as a one-time question or as an ongoing sense of how life is lived. Brashers (2001) noted that ongoing uncertainty “spans the trajectory of a chronic illness, the life cycle of a career, or the duration of a relationship” (p. 481). Participants reported that uncertainty was ongoing throughout their careers as nurses and care assistants. In addition to the temporal element of uncertainty, it is important to note that uncertainty can be appraised in a number of ways (Brashers, 2001; Mishel, 1988). For many participants in this study, uncertainty was commonly appraised as part of everyday life (i.e., something they integrated as routine) as opposed to a danger (i.e., something that worried them) or an opportunity (i.e., a chance to make changes). For participants, reducing uncertainty was often seen as an impossible and not always desirable task. Instead, acknowledging the permanency of uncertainty allowed

them to maintain it in a manner that facilitated coping efforts. For example, Meredith described her experiences of uncertainty as “human nature” saying:

Things do not always work out perfectly, and your plans do not always come to light. In order to be a confident leader you have to be able to be comfortable with your decisions.

You can't second guess yourself and you can't go back and undo what has been done.

Instead of appraising the uncertainty she experienced as she made daily decisions in terms of the dangers she faced in making the wrong choice, Meredith and others were able to come to terms with uncertainty as a part of their professional identity as nurses and care assistants. Erica further acknowledged that “every day, every minute is a new challenge basically.” This helped them communicatively manage their uncertainty by acknowledging that uncertainty is a part of their daily experience. Laura demonstrated how appraising uncertainty as a part of everyday life helped her manage the uncertainty she experienced communicating with families.

They (family members) appreciate knowing that nothing is black and white. They tend to see things as more black and white for example treatment options, this medicine, “I'm sure that it will make it all better for mom and we won't have these behaviors anymore” kind of thing. They appreciate knowing when we know things, rather than being black and white, that we are doing the best we can.

Communicating to families that nurses and care assistants are doing the best they can impacts the emotional responses associated with appraisals of uncertainty. Scholars have noted that emotional responses are related to the appraisal process so that when uncertainty is appraised as a danger people may experience negative emotional responses to uncertainty as opposed to those who appraise uncertainty as beneficial who are more likely to have a positive emotional response (Babrow, 1992; Brashers, 2001; Brashers et al., 2000). For nurses and care assistants in the

current study, emotional reactions to uncertainty were typically positive. In fact, participants seemed to use uncertainty about Alzheimer's disease and treatment to reduce family member's uncertainty about health care provider's motives and goodwill. Focusing on one type of uncertainty to reduce the kind of identity and relationship uncertainty involved in being a nurse who deals with families coping with Alzheimer's disease suggests a complex appraisal process resulting in specific communication strategies that make uncertainty a part of nursing care.

Communicating Social Support to Manage Family Members' Uncertainty

In addition to managing their uncertainty through information management strategies, providing and receiving peer support, and appraising uncertainty as a part of everyday life, participants also reported that they worked to manage family members' uncertainty by providing different types of social support. Examining meanings and dilemmas of support is an essential part of understanding when and how communication can facilitate optimum outcomes. Goldsmith's (2004) model of communicating social support argues that communicative interactions are evaluated as more or less successful depending on whether or not the conversation attends to multiple goals. Families with a loved one who has Alzheimer's disease often find themselves experiencing uncertainty from a variety of sources. Experiences of uncertainty can lead family members to question the efficacy of medications and treatments as well as their decision to place their loved one in a care facility and their own emotions related to the experiences, such as feelings of ambiguous loss (Boss, 1999; Stone & Jones, 2009). Goldsmith's model suggests that providing specific support that attends to the task or need expressed by family members while also accounting for identity and relational implications of the support attempt will be more successful than attempts that simply attend to one goal to the neglect of the others at work in the interaction.

Goldsmith's model is appropriate for understanding support attempts of nurses and care assistants working with families in the context of Alzheimer's disease for several reasons. First, family members are coping with a great deal of uncertainty stemming from medical, personal, and social sources (Stone & Jones, 2009). They may be grappling with feelings of guilt and anger at their decision to place a loved one under professional care as well as coping with the financial burden that professional care often entails. In addition, family members may experience a significant loss of support if other members of the family did not agree with the decision to place a loved one in a facility. For participants in Stone and Jones's study, when to place a loved one in a nursing care facility and how to communicate with staff once a loved one was placed created uncertainty. Participants in that study suggested that the care their loved one received by nurses and care assistants as well as the relationships that they formed with staff helped them to manage the uncertainty they experienced. The current investigation builds on previous research on uncertainty to examine the ways in which nurses and care assistants communicatively managed the uncertainty of family members who had placed a loved one in a care facility. This study sought to examine the particular task, identity, and relational qualities that are salient in the context of coping with Alzheimer's disease. Nurses and care assistants described efforts to communicate informational support, emotional support, and tangible support. Participants also reported that they experienced dilemmas associated with their efforts to communicate support including: (a) providing information versus maintaining policy, (b) providing options versus telling the family what to do, (c) reassuring versus discouraging, (d) providing equal care versus the desire to provide special care to those residents with whom participants felt a connection, and (e) making care visible versus completing tasks.

Different dimensions of support serve important functions in communicative interactions. Describing the functions of support and the dilemmas that participants contended with contributes to a normative theory of uncertainty and communication by further elaborating the communicative behaviors that may be evaluated as better and worse ways of providing support to families coping with Alzheimer's disease. Although I describe the types of support and dilemmas separately, I do not mean to suggest that dilemmas are only faced in those instances categorized as dilemmas. Rather, I separate the categories to clearly illustrate examples of participant's experiences communicating support and then highlight dilemmas to further understand the communicative interactions that define uncertainty management in this context.

Informational Support

Participants described several ways in which they used *information* to manage the uncertainty family members experienced when a loved one was living in an Alzheimer's care facility including: (a) educating the family about disease process, (b) defining expectations of caregiving, (c) discussing day to day activities, (d) informing about changes or specific incidents (e.g., falls), (e) explaining treatment plans, and (f) teaching family how to interact with residents in the care facility.

Educating about disease process. One of the most common questions nurses and care assistants reported family members asking was "Is this normal?" Family members had a hard time judging whether or not the disease was progressing normally in their loved one or if something about moving into the nursing facility had exacerbated the symptoms and hastened the progression of the disease (Gambassi et al., 1999). Melissa described the challenge of educating families about the disease process saying:

Family members don't know about the disease process. Unfortunately, Alzheimer's is a one way progression. They're not going to get better from it. They're going to get worse. It may be a slow progression, they may seem normal, but it's only going to keep going one way.

Samantha also described how she "would explain what they can possibly expect" and that she "would also tell them that every case is different. That some patients only get so far into the disease, that they don't actually get all the way, and others progress quickly."

The challenge, then, for nurses and care assistants becomes how to communicate the disease process to family members. Some participants noted that using analogies or metaphors was useful in educating people. When asked how she talked with families about the disease process Samantha said, "I'll use analogies if I can." She later provided this example.

If I were trying to explain to a family why their memory is going instead of getting into the technical of neurons misfiring or not firing at all and that kind of thing I would say, I would use the string or the line analogy. I would say, "It's like there are strings in their brain but there is a sharp object rolling around in there which is the disease which is cutting the strings." I would use that kind of analogy, "and therefore they cannot make connections because the string is cut."

Laura also described a metaphor she used to explain the disease process to a resident's family:

The body is a telephone; the tangle of the places in the brain or like the telegraph; the message can't get from one to the other because there is a protein plaque into the middle.

Because there is a blockage in the wire.

Participants reported that using analogies and metaphors allowed them to clearly explain a technical process without confusing families with technical terminology. Although participants

described the usefulness of analogies and metaphors in explaining illness, most participants could not recall an example of a specific analogy or metaphor that they commonly use to communicate with families about the disease process. Participants suggested that this lack of recall was associated with the spontaneity with which they decide how to communicate information. That is, because each family is different and therefore has different needs and goals in each communicative interaction, nurses and care assistants have to assess the pertinent goals and decide how best to try to meet those goals in the moment. Communicating using analogies and metaphors was often seen as a way of meeting the family member's goals of wanting information about the disease process without neglecting the identity goals that might have been threatened had the nurse or care assistant used highly technical language to describe the disease process.

Further, nurses and care assistants reported that the process of educating family members about the progression of Alzheimer's occurs over the course of their loved one's life in the nursing care facility. Derek reported that he talked about the disease process with family members "pretty much every day." Typically conversations about disease progression occurred when a resident was experiencing a change (e.g., change in behavior or eating habits). Laura described an experience with a resident who fell. After telling the resident's daughter about the situation, she "needed to explain to her (the daughter) that most dementia patients can't make sense of an experience like that, falling and breaking a hip and this could be the beginning of the end." She continued,

After her mother passed away, the daughter was so glad that she was informed that this could be a possibility. I didn't tell her it was going to happen, but I said sometimes with dementia this is the route it takes because they have trouble making sense of the

experience. She asked a lot of questions about what would happen and again I said I don't know. Sometimes the families ask how long is this going to take. Anytime a resident is declining or is possibly dying, of course we have to say we don't really know. This is what you have to expect, she quit eating she doesn't understand the pain, her mother lost her speech months before. The daughter was asking questions about death and I really think it helped her to have pre knowledge of the stuff that could happen. This example illustrates the uncertainty that family members experience when coping with a loved one's Alzheimer's disease and further highlights the important role that nurses and care assistants play in managing that uncertainty by providing information that educates about the disease process.

Defining expectations of caregiving. Family members seemed uncertain both about what they could expect from their loved one and what they could expect from the nursing staff. Participants reported that a common task in communicating with family members was defining expectations of caregiving. When families begin to consider placing a loved one in an Alzheimer's care facility, they typically begin with a visit to various organizations. On this first visit, an administrator at the facility shows the family the resident's rooms, dining areas, and common spaces. Administrators may also introduce family members to the activity director and other staff on duty. This begins the process of defining expectations by giving family members a sense of what their loved one's life will be like in the facility.

Nurses and care assistants reported that it is difficult to set expectations with families because every family, and every resident, is different. This means that each resident and family has different needs. To cope with this challenge and manage family member's uncertainty, nurses and care assistants described their efforts to make the tasks they do visible to family

members. For example, Laura said she would make sure to show family members visiting their loved one that the resident was being well cared for by communicating that care to the family. Setting expectations, though, often presents a significant challenge to nurses and care assistants because of the limited time they have with residents. Melissa described an interaction with a resident's spouse who complained about the resident drooling. Melissa heard the complaint, but before she was able to discuss the matter with the resident's spouse, the spouse had left. Another CNA on shift described the spouse as being upset about her partner's appearance when she visited him in the care facility. Melissa had violated a family member's expectations and perhaps increased the uncertainty the family member experienced. Instead of continuing with the task she was working on, Melissa said that going to deal with the issue as soon as it came up would help the family member feel more confident about the care her loved one was receiving.

Discussing day-to-day activities. In addition to providing information to family members about the disease process, nurses and care assistants reported that discussing the day-to-day activities of the residents was an important way that they managed family member's uncertainty. Family members were assured, participants reported, that they would be informed of any big changes to the resident's care plan. However, nurses and care assistants noted that many of the questions that family members asked when they came to visit the resident or called the nursing facility were about the resident on the particular day of the visit or the call and not about changes in the care plan. This likely served a relational function. Family members often care for their loved one before entering a nursing facility and become accustomed to knowing their day-to-day activities and routines. After entering the nursing facility, however, it is very difficult to know how the resident is doing unless those providing care in the facility communicate that information. Michelle, a caregiver in an assisted living facility, described how

she can only “tell them a little information” because of the legalities of communicating about the resident to anyone other than the power of attorney. She continued that despite not being able to give a great deal of information to family members she can tell them “they did this, this, that. They’re having a bad day. They’re having a good day or this is what’s going on with them as far as behavior-wise.” Because care assistants are with the residents for longer periods of time than most of the registered nurses and licensed practical nurses on staff, Michelle noted that families come to her for information because she “really pays attention to the residents.” Because care assistants “really pay attention to the residents” family members can ask questions about how much their loved one ate and what they seem to be enjoying in addition to what they watched on television and if they participated in any social activities. This further manages the uncertainty family members may be experiencing by providing information about the quality of life of their loved one.

Informing about changes or specific incidents. Participants in the current study also noted that informing family members about changes in the care plan or specific incidents that occurred (e.g., falls) was an important part of managing family members’ uncertainty. Being honest with family members, particularly after an incident like a fall, is an opportunity to support the family by providing information. Participants suggested that communicating the problem as well as a solution was an important element of managing family member’s uncertainty. Samantha, for example, described

Times where I’ve had to call and say, “I’ve noticed your mom has not been doing as well this past week. She’s not engaging. She’s not making eye contact.” That type of thing. Those are difficult calls to make sometimes but usually I will also include, “but we’re going to try this.”

Communicating to the family that those who are providing care for their loved one are aware of an issue and are actively trying to compensate for the problem allows the family member a space to ask questions and become an active part in the care of their loved one in a positive way. In contrast, participants suggested that when problems are presented without informing family members about what is being done, the family members become agitated and frustrated with the information being provided.

Explaining treatment plans. Participants reported that explaining how medications work, the influences of other diseases (e.g., diabetes) on care, and why a doctor might have prescribed a particular medication or treatment plan for a loved one helped manage the uncertainty family members had about changes in care plans. For some families who, as Samantha described, “are not huge fans of medication” it was especially important to explain the rationale for the choice of medication. Medications like Aricept and Namenda, while not a cure for Alzheimer’s disease, have demonstrated positive effects on Alzheimer’s patients in terms of slowing the progression of memory loss. Although this does not cure Alzheimer’s disease, it does allow Alzheimer’s patients to maintain their current state of memory loss. For some this is extremely important as it allows residents to maintain some autonomy and allows family members more time with their loved one.

When explaining a decision a physician makes, nurses and care assistants described how family members prefer to ask them questions because of the frequency and quality of contact nurses and care assistants have with their loved one. Despite the physician’s status as a medical doctor, family members develop relationships with nursing staff such that family members may privilege the information they receive from nurses and care assistants often over what the doctor suggests. Samantha described some of the questions family members ask her and how she

responds.

They do bring them (questions) to my attention. “Is this really what we need to do?” “Do you think this is going to help?” and I will give them my thinking or if it’s something that came from the doctor “this is why the doctor thought to do this for her” and I’m always open to what they want. There’s one family who their father is in his 90s and they’re like, “Does he really need to be on all these medications?” And I looked at the pills, at what he was taking, and I’m, like, “I’ll ask the doctor” because I was thinking why is he on potassium? The only reason he was put on the potassium to begin with is a few months ago he was on a diuretic but he’s not on that diuretic anymore. But they kept him on the potassium. And that’s two huge pills three times a day. And so I talked to the doctor and I’m like “does he really need to be on this? His family doesn’t think he needs to be on this.”

Advocating for residents and family members and explaining the decisions of all members of the medical team (e.g., their own decisions as nurses and care assistants as well as decisions made by physicians) assisted in managing family members’ uncertainty. In many ways, nurses and care assistants allied themselves with the family, which created a sense of community and eased efforts to communicate.

Teaching family how to interact with residents. The final way that nurses and care assistants reported using information to manage family member’s uncertainty was through teaching families how to interact with residents in the nursing facility. Communicating with someone with a communication debilitating illness like Alzheimer’s disease is an uncertainty inducing situation (Donovan-Kicken & Bute, 2008). This often creates unnecessary tension in interactions between the residents and the family member. For example, Samantha described

how many family members try to get their loved one to remember who they are. Asking questions like “do you know who I am?” often frustrates Alzheimer’s patients, especially those in the early stages who are aware of their diminishing mental capabilities. When residents become frustrated, nurses and care assistants reported that they often engaged in negative behaviors like hitting and yelling or becoming confused, which may lead to crying. Instead of asking that question (“do you know who I am?”), Samantha explained to the family member how this frustrates the resident saying, “I’ve noticed when you come in that you ask your mom who you are. That really frustrates her because she doesn’t remember your name. Say to her, ‘hi, I’m your daughter [name]’.”

Explaining that a mother can no longer recognize her daughter is a difficult task and requires the balancing of multiple goals. Although the primary goal may be the task of communicating the information so that the daughter does not continue to frustrate her mother, the nurse or care assistant must also manage identity and relational goals. For example, participants reported that it is important that nurses and care assistants do not suggest that the daughter is doing something wrong as that might threaten her identity as a dutiful daughter coming to visit her ailing mother. Participants also noted that they did not want family members to perceive that they were suggesting that they understood or knew their mother better than the family member did. Some participants managed these multiple goals by reminding family members of how important spending time with their loved one is for the health of the resident and for their own well-being. Samantha said:

And a lot of time the visits, the more higher functioning residents, they get benefits from the visits from their families but then we have others that are pretty clueless about what is going on because they don’t remember five minutes from now and that’s when I say,

“Your visiting your mom is for you. She gets the warmth and the love from the attention because I can’t pay attention to everybody for the amount of time you can. Come in and sit with your mother and hold her hand but is she going to remember you were here? Probably not. But for those minutes that you sit with her it’s healing, it’s helpful.” And I try to express that to families.

Providing information to families about what the visits can be helps manage the uncertainty they experience when coping with the newness of the situation and the changes they are experiencing with a developing parental relationship.

Emotional Support

Emotional support was also communicated to family members to manage the uncertainty they were experiencing. Although participants predominately described information as the main form of support communicated to family members, emotional support was also described in terms of (a) expressions of concern for family members and (b) efforts to communicate reassurance. The following describes the ways in which emotional support was communicated.

Expressions of concern. Nurses and care assistants expressed concern for family members in a variety of ways. One particularly interesting reflection on communicating emotional support was described by John who noted that he works to give families “their space.” He continued that it is important to choose an appropriate time to provide emotional support saying, “I try to pick my moments where I can give them comfort.” Choosing the appropriate time was often predicated on perspective taking. John continued, “I put myself in their shoes. I see some person hurt or crying, I’m going to do something about it. If I can do something, great.” Participants also reported that to comfort family members sometimes the best they can do is “say something to cheer them up.” Communicating care to family members assists in

managing their uncertainty by expressing concern for the family members' well being.

Communicating reassurance. Participants reported different situations in which they perceived that communicating reassurance was appropriate with family members. First, participants described how they reassured family members that their loved one would be taken care of in the nursing facility. Participants reported that in addition to needing informational support when a resident first enters a nursing facility, nurses and care assistants often communicate emotional support through reassuring statements to the family. Erin, for example, described how family members may feel guilty about leaving their loved one and her response to them if they express that feeling:

I think the most wonderful response that you could have to them (family member) is to say "I'm so sorry that you feel that way. Is there anything I can do to help you?" because they do feel bad. They do walk away and they are very protective. I try to be prompt with them (family members) and give them the reassurance and new patients I try to tell them "okay, you're here, when you leave I'll be here until such and such a time and on the weekend I'm here, there is always someone here if you want to call just to see how he or she is doing" because that kind of a thing relieves fears that there's a way they can find out how their family is. You need to give them that. You need to make them feel secure.

You know. It's important.

Samantha also provided an example of reassuring family members that if a behavior (e.g., crying) continues that she and the other staff would make a special effort to spend time with the resident and, if necessary, seek medical advice from a physician. For one resident, Samantha said:

I was noticing that she was crying more often so I called the doc and asked for an antidepressant and it's helping. You know, it's very mild antidepressant I gave her but we try different things and I'm always grateful for the families because they know their parents before I did and sometimes they notice things that I wouldn't have attributed to a problem. So we work together in that respect and I let them know that they're helping me.

Participants suggested that reassuring the family that they were doing the best they could for their loved one met multiple relevant goals including identity concerns by making the family feel part of the decision making process. Establishing trust with family members through reassurance messages like Nancy's who said that she "lets them know if they need anything they can always call" helps family members know that the person caring for their loved one is available to support them and able to provide quality care.

Participants also described the importance of reassuring family members that their loved one was an important member of the community. Participants often expressed this by discussing how the resident was part of the family and by extension that the nurses and care assistants were also part of the resident's family. John illustrated the importance of communicating emotional support through reassurance that the resident was doing well in the facility. One resident he described had great difficulty communicating with staff and family members because she mixed up the order of words in sentences and spoke, as he said, "kind of a word salad." During an interaction with him, though, she was lucid:

She has severe dementia but for five minutes she was completely lucid. We had a conversation. She asked where her children were and everything and she, she could barely talk, it was kind of like, I just couldn't believe. I was so happy when I told the

family, they were just so elated. Just knowing that her mom that [name of female resident] thought about her children that she's still thinking about them. When the children came, she was completely oblivious, not there. But yeah, just for a few, five, maybe less than five minutes she was so lucid. And asking for her children, making complete sentences, and the children just loved it, just knowing that their mother is still, was there, is there inside still.

Communicating with families that their loved one is still their loved despite their diminished mental capabilities reassured family members and managed their uncertainty stemming from a variety of sources. Participants perceived that knowing that their loved one still thought about them at times helped family members cope with the ambiguous loss (Boss, 1999) that many family members experience when a loved one develops Alzheimer's disease.

Tangible Support

Participants noted that a third way that they were able to manage family member's uncertainty was through *tangible assistance*. Tangible support often was provided by caring for the resident with Alzheimer's disease in a way that showed an appropriate level of care. Making care visible to families was one salient way participants reported communicating tangible support.

Caring for Alzheimer's patients is often done in the absence of others watching, either because family members are not present to visit with their loved one or because the nature of Alzheimer's disease makes daily activities relatively regimented. Some activities, however, such as feeding, can be done in a way that demonstrates to family members that their loved one is being cared for. Participants suggested that being able to see the care that their loved one receives managed some of the uncertainty family members experienced from leaving their loved

one in the care of another.

Dilemmas of Communicating Support

Participants reported that with each form of support they offered (i.e., informational, emotional, and tangible) they faced specific communicative dilemmas. Many of these dilemmas were alluded to in the previous section, but more specific attention is warranted given the potential for improved communication if these dilemmas can be acknowledged and addressed by nurses and care assistants in partnership with family members coping with a loved one's Alzheimer's disease. Because participants identified informational support as the predominant type of support communicated to family members, it is not surprising that the dilemmas nurses and care assistants found most salient were related to (a) providing information versus maintaining institutional policy, (b) providing options versus telling the family what to do, and (c) communicating reassuring information versus information that might be perceived as discouraging. Dilemmas of emotional and tangible support were also reported and will be discussed.

Dilemmas of informational support. Participants described a salient dilemma they faced in *providing information that they perceived met the goals of the family members versus maintaining institutional policies*. In particular, challenges in providing the quantity and quality of information family members requested was described. Participants highlighted that despite being aware of this challenge, they struggled with ways to achieve appropriate information sharing in interactions. This was impacted by institutional policies concerning HIPAA, the Health Information Portability and Accountability Act (1996). Kathy explained that "if it's their power of attorney, they have the right to know everything that's going on." I then asked about the information she communicated if it was not the power of attorney seeking support. She

responded, “Not everyone understands and if it’s someone who has their sister and they’re not the power of attorney, they can get a little cross with you.” In this case, Kathy was guided by particular rules and regulations for how much information to communicate. She described interactions like these as dilemmas of communicating support because she was able to understand the perspective of the family members who wanted and felt like they needed and deserved more information to manage their uncertainty. On the other hand, however, Kathy and other participants were bound by policies meant to maintain the resident’s privacy.

Participants also reported that in their struggle to communicate appropriate information to family members they often had to decide if they were in fact the best person to communicate a particular message. Michelle, a care assistant, noted that her role in the health care system requires that she direct family members to the nurse on duty even if she feels that she has the answers to the questions family members are asking. She said, “because I can’t answer the questions they (the family) want me to, I direct them to the nurse.”

Nurses and care assistants commonly reported a dilemma of *describing options versus telling the family what to do* because of their role as a resource for family members who must make important decisions related to their loved one’s care. Many participants suggested that family members wanted them to be more active in telling the family what decision they would make. Giving their professional opinion was described as a communicative dilemma. Samantha suggested that being seen as “an authority figure” makes family members come to nurses and care assistants for answers.

What becomes difficult is that I’m not allowed to offer, you can’t tell them what they should do. I can offer my opinion as the medical professional but it’s, it comes down to what they want to do. And it becomes difficult for families sometimes to deal with that

because they'd rather just be told what to do.

Participants reported that it was very important to communicate the various options that family members had despite feeling compelled to tell the family what they should do. Providing options allowed nurses and care assistants to attend to the task of providing informational support as well as communicate that the family had autonomy in the situation.

Participants described instances in which they were confronted with the choice of communicating informational support in a manner that honestly depicted the situation the resident was in or framing the information in a way that reassured the family that their loved one had some quality of life. This dilemma was often framed in terms of *being reassuring versus discouraging*. Being reassuring often implied that truths were told selectively. John noted that he was uncomfortable admitting that he struggled with this because he felt like he was lying to the family. He said, "I hate to say this, but I do lie sometimes to them. I'll tell them, 'Oh, they had a great day. We had so much fun.' I'll lie and I'll say that. I don't know, just something to cheer them up." He continued that he perceives that giving family members "that little extra boost" allows them to maintain hope despite the deterioration of their loved one

Dilemma of emotional support. Participants also reported a dilemma of communicating emotional support when nurses and care assistants described wanting to *provide equal care versus providing special care to those residents with whom participants felt a special connection*. Although all residents get the same general quality of care, nurses and care assistants described feeling closer to some residents over others to the point where they considered some residents family. Tina described her relationship with some residents in terms of how they treated her like an "emotional boxing bag." She continued that she saw this as part of her job but that it was easier to cope with depending on the relationship she had with specific residents. Samantha

struggled with this as a new nurse who felt drawn to communicating with and comforting families who were struggling. Although participants overwhelmingly reported that they provided high quality care to each resident, they were also able to tell stories of particular residents and family members they felt like they had a special connection with. Samantha said, “It depends on the situation and what is going on and who you’re talking to and how often you talk to this family” implying that having a “rapport” with a particular family makes conversations and expressions of concern different from interactions with those that she did not have “rapport.”

Dilemma of tangible support. Finally, participants suggested that a dilemma of providing tangible support was evident in interactions where family members were present. Nurses and care assistants were often faced with the choice between *making their work visible to family members versus completing tasks in the most efficient manner possible*. Participants reported that making tasks visible often eased family member’s concerns but also often meant not being able to attend to their tasks efficiently. Attending to tasks efficiently, then, often meant having to complete the request of a family member at a different time. For example, participants like John described the communicative dilemma he faced in involving the family in some of the tasks he completed as a CNA. He described one situation where he asked the family if they would like to help reposition their loved one so that she would be more comfortable. He continued that the way one communicates this tangible support is salient. Starting with a direct request, he reported, helped family members feel like it was appropriate to get involved in the care. He said, “I would ask the family, ‘Come help me. Will you help me reposition her?’ I would have them help me take care of their mother.” This was not always a simple interaction. Rather, participants described how important it is to focus on the family’s cues (i.e., nonverbal communication and language use) when providing tangible support. Although many nurses and

caregivers would ask the family to leave when they were completing caregiving tasks, (e.g., changing a resident's briefs or helping them go to the bathroom), getting the family involved even in the seemingly more difficult tasks of caregiving allowed nurses and care assistants to provide evidence of the tangible support they gave the family's loved one on a daily basis. Participants suggested that this translated into communicating support for the family.

Overall, the nurses and care assistants involved in this study provide an example of a community in which communication behaviors are associated with a desire to manage uncertainty with times that warrant reducing uncertainty and other situations that warrant maintaining or increasing uncertainty. Acknowledging that there is no one-size-fits all solution for managing a family member's uncertainty is an important first step in improving care through communication training efforts. In particular, identifying specific dilemmas that nurses and care assistants face highlights several ways in which communication can be improved and better outcomes can be achieved.

Communication Strategies for Managing Dilemmas of Support

Nurses and care assistants developed various communicative strategies for managing the multiple and often conflicting goals related to support and uncertainty. The strategies for managing challenges communicating with family members were often specific to the particular dilemma they faced. Further, nurses and care assistants reported useful strategies for managing their own uncertainty when communicating with family members as well as ways of communicating despite the uncertainty they experienced with coworkers and staff in nursing and assisted living facilities. Although not all strategies for managing the dilemmas nurses and care assistants face were perceived as effective, participants suggested that there were ways of communicating that ameliorated uncertain interactions. The following describes the strategies

that participants reported were more effective at managing the various communication dilemmas they faced.

Managing Dilemmas of Communicating with Family Members

Multiple family members were often involved in the care and treatment of a loved one with Alzheimer's disease and whether a family member was power of attorney impacted the amount of information that could be disclosed by nursing staff. Participants described how *communicating the reasons* behind organizational policies that limit disclosure were useful for managing the challenges they faced when family members who were not the power of attorney wanted information. The most cited reason for not disclosing information to family members was that the Health Information Portability and Accountability Act (1996) made it illegal to do so. Kathy noted that "everybody knows about HIPAA now" but then corrected that statement saying, "well, they should." Although participants in the current study commonly believed that the family members they were working with would be aware of HIPAA, they also acknowledged that being aware of the policy did not mean that they understood the policy or believed that it applied to them. Describing the reasons behind a nurses' decision to limit the type and amount of information communicated to family members was described as helpful. Kathy said, "you just have to keep your cool and be very sympathetic to how they must feel."

Emphasizing the positive aspects of interactions was a second communicative strategy that helped participants manage the dilemmas of informational support they faced. This was particularly the case in situations where nursing staff felt like they were dealing with a resident who was exhibiting aggressive tendencies. Instead of bringing attention to an issue that participants believed they could not change, Samantha described how she would "focus on things like, 'well today they had French toast for breakfast', you know, pointing out the good things in

the day, ‘they went outside for some sunshine and had popsicles at snack time and she sat with her friends.’ I just have to give them the feeling that mom is feeling okay in the present, or that mom and dad are okay at the present time.”

Managing Uncertainty Communicating with Coworkers

Nurses also developed communicative strategies for managing the challenges and uncertainty they faced communicating with other nursing staff. These strategies included (a) selectively seeking support and (b) framing talk in “team” language.

First, participants reported managing multiple goals in supportive interactions with other nursing staff by selectively seeking assistance from particular staff members. For instance, Erin described how she avoided seeking support from a particular coworker even if she needed advice on how to handle a situation because she could not trust her coworker. She described a coworker who frustrated her “because she’s one of those people who, don’t try to be my boss when you’re my coworker.” Instead, Erin, and other nurses in similar situations, described how seeking assistance from nursing staff with which they had a good relationship helped them manage the uncertainty they experienced.

Second, framing talk in terms of “team” language was useful in managing the uncertainty that participants faced when communicating support to other nursing staff. Participants generally defined a team approach as “everybody on the same page working together, trying to get things accomplished. We’re all working towards the same goal and in this case taking care of the residents and making sure they have what they need.” When this type of communicative approach was used, participants reported that they were less concerned about whether or not a coworker would interpret informational support as not helpful because it impedes a person’s feelings of autonomy. Erin, for example, described how she corrects other nursing staff she

works with by working together.

If I'm making my rounds after they (other nursing staff) say that their work is all done and somebody isn't repositioned right at bed I'll say, "come with me and we'll do it together and I'll show you how I want it done."

Erin suggested that other nursing staff appreciated this direct approach because it demonstrated that she was correcting others because she had high standards for quality of care for residents that they could achieve if the staff worked together. When asked what the advantages to a team approach are, Laura and other participants suggested that "better care more, resident centered care, better communication. It is so important to keep everybody in the loop."

It is important to note that the hierarchy in nursing that is typically clear in situations where nursing staff interact with one another and with residents or family members is lessened when nursing staff take a team approach. Samantha noted:

Even an experienced nurse, there's things they've never seen before, and we work as a team. I'm always consulting with the other nurses. I even consult with my caregivers sometimes. Because while they might not have the training I do, they've been doing this for a while. I remember one, she's been a caregiver/CNA for fifteen years, and you know, for behavioral issues, I could be like "How do you think would be a way to keep this guy from going out the door?" And she may have some ideas. I mean teamwork like that.

Taking a team approach alleviates some of the uncertainty that nurses may experience when trying to decide who to seek for information or who to provide informational support.

Clearly social support is an important aspect of nursing care in the context of Alzheimer's disease. The nurses in this study experienced uncertainty stemming from multiple sources and

faced challenges in providing and seeking/receiving support. Participants described the communication strategies they developed for providing and seeking/receiving support. The support that nurses communicate is an important part of family members' adjustment to their loved one's diagnosis of Alzheimer's disease and plays a role in how nurses and care assistants cope with challenges at work. A summary of the major findings reported in this chapter are illustrated in Table 1 below.

Table 1

Summary of Major Findings

Construct	Description
Sources of Uncertainty for Nurses and Care Assistants	
1. About Alzheimer's disease	Uncertainty about medical issues related to Alzheimer's disease
2. Communicating with the residents	Uncertainty about redirecting versus communicating at the level of the resident
3. Communicating with the family	Uncertainty working with family members who are coping with their own uncertainty
4. Communicating with coworkers	Uncertainty relating to communication and relationships with other staff
Communicatively Managing Uncertainty Experienced by Nurses and Care Assistants	
1. Information management	Information acquisition Information handling Challenges of information use
2. Provision and receipt of support	Assisting uncertainty management Vent and exchange ideas Hindering uncertainty management Implies incompetence or weakness
3. Accepting uncertainty as part of everyday life	Uncertainty becomes associated with daily activities

Table 1

Summary of Major Findings (contd.)

Construct	Description
Communicating Support to Manage Family Member's Uncertainty	
Types of Support	
1. Informational support	Educating the family about the disease process Defining expectations of caregiving Discussing day to day activities Informing about changes or specific incidents (e.g., falls) Explaining treatment plans
2. Emotional support	Teaching family members how to interact Expressing concern Communicating reassurance
3. Tangible support	Making care visible to families
Dilemmas of Communicating Support	
1. Dilemmas of informational support	Providing information vs. maintaining policy Providing options vs. telling the family what to do Reassuring vs. discouraging
2. Dilemma of emotional support	Providing equal care vs. special care to residents
3. Dilemma of tangible support	Making care visible vs. completing tasks
Communication Strategies for Managing Dilemmas	
1. Managing dilemmas of communicating with family members	Communicate the reasons behind institutional policies Emphasize the positive aspects of interactions
Communication Strategies for Managing Challenges with other Nursing Staff	
1. Managing dilemmas of communicating with coworkers	Selectively seek support Frame talk in "team" language

CHAPTER 5: DISCUSSION

The aim of this study was to learn more about how uncertainty and social support impact the experiences of nurses and care assistants working with families and patients who are coping with Alzheimer's disease. Specifically, this research drew from theories of coping, uncertainty management, and communicating social support and used semi-structured interviews informed by grounded theory methods. This research is a first step in developing a normative model of social support for health care providers communicating with families about the uncertainties inherent in the diagnosis of and treatment for Alzheimer's disease. The following sections describe the theoretical and practical implications of this research for patient care, informal familial caregiving, and nurses' training. Limitations and directions for future research are also addressed.

Theoretical Implications

The present investigation extends existing theory and research in several ways and provides further evidence for the role of communicating support, particularly informational support, in managing uncertainty. The following situates the findings from this study with reference to our understanding of (a) the nature of uncertainty, (b) communication as uncertainty management, (c) dilemmas of communicatively managing uncertainty, and (d) the role of communication in experiences of burnout. I also describe implications these findings have for communication scholarship, particularly for communication scholars interested in organizational and family communication.

Nature of Uncertainty

As the findings from this study suggest, experiences of uncertainty and uncertainty management strategies are complex (Brashers et al., 2003). Given the complexity of experiences

of uncertainty, it is interesting to note that the concerns participants voiced about communicating with residents, family members, and coworkers align strongly with research that has examined forms of uncertainty for friends and family members across illness contexts. For example, research on uncertainty for social network members of someone with a communication debilitating illness (Donovan-Kicken, & Bute, 2008) and on adult children coping with a parent's diagnosis of Alzheimer's disease (Stone & Jones, 2009) described how close others experienced uncertainty and what strategies they used to manage uncertainty. Findings from these studies reported that close others were uncertain about how the illness would progress and what ambiguous symptoms meant for their loved one.

Health care providers in the current study described how they managed uncertainty that close others experienced, particularly with regard to providing information, and highlighted the challenges that they faced providing this type of support. These challenges, while unique to the context of communicating about Alzheimer's disease, likely have implications for nurses and care assistants in other specialties. For example, nurses and care assistants working in a hospital setting will likely encounter people with Alzheimer's disease and their families. Tasks as seemingly simple as taking a medical history of an Alzheimer's patient are significantly more difficult, participants noted, if the nurse is not aware of ways to communicate with someone experiencing cognitive decline. Further, these findings demonstrate that family members who may be accompanying a loved one with Alzheimer's to the hospital may also be experiencing uncertainty that the nurse might address by acknowledging the family member's experience and providing informational support to manage that uncertainty. Knowing what challenges Alzheimer's care nurses and assistants face on a daily basis may improve efforts of other nursing staff in hospitals as they work with new patients.

The findings from this research are consistent with previous scholarship suggesting that communication ability be taken into consideration when examining the link between communication and experiences of uncertainty (Donovan-Kicken & Bute, 2008). As these scholars point out, Mishel's (1988) model of uncertainty in illness suggests that cognitive capacity influences experiences of uncertainty. Because Alzheimer's disease compromises people's ability to express themselves effectively with others, health care providers cannot rely on them to communicate with clarity. This means that people with Alzheimer's disease cannot reliably discuss information or concerns with others and that others (i.e., health care providers and family members) have to depend on each other in the absence of a cognitively aware patient to communicate and make decisions. Again, these findings provide support for Donovan-Kicken and Bute's theorizing that "communicative ability can affect how people reduce or maintain uncertainty" (p. 14).

Uncertainty stems from various sources and influences the type of coping that can occur for nurses and care assistants and for family members. Although there is some overlap in the forms of uncertainty across studies, the illness context and the focus on a health care provider rather than the person with illness or a close family member highlights forms of uncertainty not evident in extant research. Conceptualizing interactions in terms of a system of uncertainty as Merry (1995) has suggested highlights the unique role that nurses and care assistants represent in health interactions. Uncertainty is a social experience (Goldsmith, 2010) and nurses and care assistants are both professional (e.g., health care provider) and often considered a member of the family. This study demonstrates that the sources of uncertainty nurses and care assistants experience, and the way communication can manage those sources as well as the uncertainty that

family members experience, may lead the system to develop and change. Uncertainty, then, is shaped by the system, which in turn influences the communication of uncertainty.

Further, experiencing uncertainty related to illness in an organizational context has not been discussed with attention to specific sources of uncertainty. That is, although scholars have examined the role of uncertainty in organizational contexts (McPhee & Zaug, 2001), research has typically focused on the importance of reducing rather than managing uncertainty. For example, findings that knowing what others expect of new employees reduces uncertainty experienced by new staff entering organizations are undoubtedly useful (Teboul, 1994). However, participants in the current study described sources of uncertainty that pervade their experiences of communicating care to patients and family members coping with Alzheimer's disease. As Kramer (1999, 2004) and others have theorized, these findings suggest that uncertainty reduction may not be a productive way of thinking about uncertainty. Instead, this study extends research that has proposed that management is a more productive way of theorizing about communication and uncertainty by examining the organization as a source of uncertainty (Brashers, 2001). Highlighting the organization as a source of uncertainty provides further insight into understanding the complexity of experiences uncertainty.

In addition, this study provides further evidence that appraising uncertainty as part of everyday life rather than an anxiety inducing state is adaptive (Brashers, 2001; Mishel, 1990). As Brashers (2001) noted, "adapting to chronic uncertainty also includes redefining tasks" (p. 484). Participants in the current study demonstrated that they were able to change the ways that they communicated with family members and coworkers to reflect their appraisal of uncertainty as part of their daily experiences. Although research has demonstrated that routines can be valuable for people coping with chronic uncertainty (Brashers, 2001), the findings from the

current study suggest that in the absence of developing a routine, communicating about the pervasiveness of uncertainty can be adaptive. That is, Alzheimer's nurses and care assistants may not be able to create a structure to adapt to chronic uncertainty but they can develop strategies to communicate about their experiences.

Communication as Uncertainty Management

Participants reported that nurses and care assistants use communication to manage the multiple forms of uncertainty they experience. First, the sources of information nurses and care assistants reported using overlap with other research that has examined the sources of information for people with a health concern (Brashers, Haas, Neidig, & Rintamaki, 2002). This study builds on previous literature by examining the sources of uncertainty and the importance of selecting sources of information that are best suited to uncertainty management efforts.

Participants described some information sources as more useful than others because of factors such as the source's position in the hierarchy of the health care system (e.g., peers versus physicians) and accessibility of information (e.g., peers versus continuing education classes). Although participants did not report that one source of information was universally better than other sources, they did illustrate that nurses and care assistants recognize the utility of specific information sources over others depending on the circumstances.

Second, nurses and care assistants reported that they developed strategies for handling information. Scholars have illustrated various reasons that motivate a person's decision to handle information on their own (personal information management) or with others (social information management; see Bruce, 2005; Moen & Flatley Brennan, 2005). For nurses and care assistants who view communication as a team effort, handling information collaboratively may be more appropriate than it would be for health care providers who are not comfortable relying

on the other nurses and care assistants they are working with. Future research should more explicitly examine specific information handling behaviors in organizations that value a team approach. Comparing these behaviors to organizations with staff who do not value a team approach may allow for useful comparisons that suggest better and worse ways of managing information.

The findings from this study also suggest that the role of institutional policies on the ways in which information is handled should be addressed as these policies may be different across organizations. For example, although all health care organizations enforce HIPAA, some nursing care facilities may have unique policies that account for some of the variance researchers may find in approaches to information management. Although participants in the current study did not explicitly describe differences in organizational policies, a more thorough examination is warranted.

Findings related to information management challenges highlight the importance of the appraisal process for people coping with uncertainty (Mishel, 1988). Participants described the ways in which they appraised uncertainty as a part of their everyday life. There are a variety of reasons that scholars would suggest that this type of appraisal may be more adaptive than other appraisals. For example, appraising uncertainty as a danger instead of an opportunity may influence information management behaviors to be less flexible than the information management strategies that participants reported in the current investigation.

The challenges that nurses and care assistants identified warrant further investigation in light of research that has examined direct and indirect methods for seeking information (Miller & Jablin, 1991). Berger and Kellerman (1983) suggested that people should consider the balance between what is considered appropriate and what is effective when seeking information from

others, suggesting that indirect methods might be more appropriate and effective when the information sought is considered sensitive. Although participants in the present study described the importance of information seeking, they also described how determining the correct source of information was a challenge. Given that participants often perceived negative consequences of seeking information from coworkers who would perceive them as weak, more attention to the relative benefits and risks of direct and indirect information seeking strategies may allow for more successful information management attempts. The findings from the current investigation provide insight into the ways in which indirect information seeking strategies may be useful for nurses and care assistants who choose to manage their uncertainty.

Dilemmas Inherent in Communicatively Managing Uncertainty

Although extant literature has demonstrated the importance of providing emotional support to families coping with a loved one's illness, participants in the current study reported that they are called on to provide a great deal of informational support. Nurses and care assistants reported a dilemma of communicating informational support to families in a manner that was honest but did not dishearten. In particular, participants saw the dilemma as communicating information that would reassure families rather than discourage them. Scholars have identified similar experiences in other illness contexts. Most notably, Brashers (2001) suggested that people may communicatively manage their uncertainty in ways that allow them to maintain hope. For example, Brashers found that people may avoid information from specific sources to increase their uncertainty about an issue that would otherwise be defined negatively.

Much research has described experiences of uncertainty as an individual experience. Recently, however, Goldsmith (2010) has argued that managing uncertainty is not a solitary endeavor. Findings from the current investigation further highlight the cooperative nature of

managing uncertainty and the role of health care providers in this process. Family members view nurses and care assistants as credible and responsible for the well being of their loved one (Stone & Jones, 2009). Participants noted that they were aware of their responsibility to communicate key information to family members and that the words they used were important. This dilemma of being honest versus being disheartening suggests that nurses and care assistants working with Alzheimer's patients and their families face unique communication challenges in managing uncertainty that have not been explicated in previous literature. The specific case of Alzheimer's disease highlights an illness context within which there is great uncertainty but not the same hope for recovery that people in other illness contexts may have. Instead, the type of things that people may hope for, or find encouraging, are things that improve the quality of life for the person with Alzheimer's disease (e.g., having a good day). The data from the current study suggests that this is an area in which the theory of uncertainty management may be extended to include communicative attempts that are not meant to maintain hope for recovery but instead are intended to reassure and highlight positive aspects of interactions.

Participants also described that they perceived a dilemma associated with the visibility of their work. Nurses and care assistants are tasked with a variety of responsibilities during the work day. One of the goals they reported trying to meet is communicating support to family members visiting loved ones in the Alzheimer's care facility. Nurses and care assistants suggested that one way of communicating support to family members visiting a loved one was to make their work visible to family members. This, however, was not a simple act. Instead, participants described the dilemma they faced in taking extra time to make care visible versus completing their tasks regardless of the performative value. Scholars have demonstrated the value of tangible support for those coping with illness (e.g., Goldsmith, 2004) and have

suggested that the visibility of the support attempt shapes the degree to which the support attempt is evaluated as helpful (Bolger & Amarel, 2007; Bolger, Zuckerman, & Kessler, 2000). Bolger et al. (2000) examined the helpfulness of support attempts in committed couples and suggested that support attempts that are perceived by the support provider as supportive but that are not reported by the support recipient may be the most beneficial way to communicate support. The authors termed this type of support “invisible” support because the support recipient does not acknowledge its receipt. Nurses and care assistants who provided invisible support perceived their efforts to communicate support as less effective in managing family member’s uncertainty. It seems that the professional nature of the relationship between health care providers and family members coping with a loved one’s Alzheimer’s disease may be an important reason for these disparate findings. Also, one reason why visible support may be harmful in committed couples involves the identity issues in receiving support: Needing support can imply that a person is incompetent or helpless. Because Alzheimer’s patients are manifestly incapable of performing many tasks, the identity implications of visible support may be moot, which would change the meaning of overt support to have a more positive connotation.

Invisible support may, however, be a useful strategy for communicating support in peer relationships because of identity issues that scholars have reported in committed couples. One major reason for not seeking support when nurses and care assistants needed it was fear of appearing weak. Because nurses and care assistants are faced by similar stressors in Alzheimer’s care facilities but often feel like they are responsible for specific care tasks apart from the team, providing invisible support may be an alternative to engaging in communal coping efforts that may not be practical given time constraints in the workplace and changing shifts of nursing staff. Invisible support may be helpful, then, in peer relationships to avoid feelings of incompetence

and to improve overall patient care.

Communication and Burnout

Many of the challenges the nurses and care assistants in this study faced were related to learning how to communicate in difficult conditions. Nurses and care assistants must contend with less than perfect circumstances (e.g., long hours, shortage of staff) and many are experiencing symptoms of burnout. Burnout is defined by three factors including feelings of emotional exhaustion, depersonalization, and lack of personal achievement. Theories of burnout argue that burnout is experienced as a “response to chronic interpersonal stressors on the job” (Maslach, 1981). Participants suggested that the uncertainty they experienced communicating with others (e.g., residents, family members, coworkers) contributed to their sense of burnout. Erin felt “emotionally drained” from her work. Erica noted that she felt “used up at the end of the workday.” These findings are consistent with current articulations of burnout. However, nurses and care assistants also reported that experiences of burnout influenced the ways in which they communicated with residents and their family members and other nursing staff. This is evident in the descriptions of communicative dilemmas participants reported. For example, feelings associated with burnout may impact how nurses and care assistants communicate with families seeking informational support.

Participants also described the importance of providing and receiving peer support as a buffer to experiencing burnout. As scholars have noted, coping with stress is a social process (Lyons, Mickelson, Sullivan, & Coyne, 1998). In the nursing context, communal coping may occur between staff members if nurses and care assistants take responsibility for the stressor as a group. Many participants suggested that communal coping, or taking a team oriented approach to coping with stressors, was ideal but unrealistic given current trends in nursing care towards

too few staff and too little pay.

Understanding how people experiencing burnout communicate and if that contributes to their ability to cope with stressors is an important area of future research. Scholarship may build on existing theory by conceptualizing burnout both in terms of a response to stressors and as a baseline measure for how people are functioning. This type of work is important for several reasons. First, given the current levels of unemployment and the growing need for nurses, there are few jobs as safe as nursing. The growing aging population, number of medical advances, and opportunities for funding contribute to the stability of nursing as a profession. Further, the education required for becoming a nurse is shorter than many other careers within the same pay range. Finally, nursing is a profession that requires a great deal of interpersonal skill and caring and therefore has a high rate of burnout. These factors make burnout an unfortunate but common reality for nurses and therefore should be examined in light of these contextual factors.

Implications for Communication Scholarship Generally

The most direct implications of the current study are for our understanding of communication in health contexts, but the findings from this study also have implications for communication scholars theorizing in the areas such as organizational and family communication. Organizational communication scholars may find this project useful for thinking about how the ways in which health care providers' identification as a professional and as a member of an organization influences the degree of burnout experienced. This project also provides evidence to suggest that a systems approach to examining family communication may benefit from including network members outside of the family. That is, because health care providers, particularly in the context of Alzheimer's disease, play an important role in communicating about and making decisions, family communication theorists may benefit from

considering the multiple parties involved in interactions.

Practical Implications

This investigation further highlights the utility of illness-specific theorizing from a communication perspective. Scholars have found evidence to suggest that examining the particulars of specific illness experiences is important if one of the goals of our research is to provide more effective care (e.g, Kleinman, 1988). For example, although research has suggested that invisible support is useful because it allows participants in the interaction to manage identity and relational goals amidst task goals of communicating support (Bolger, Zuckerman, &Kessler, 2000), findings from the current study suggest that visible attempts at communicating support are more effective in managing multiple goals for nurses communicating support in the context of Alzheimer’s disease.

Given the importance of context-specific theorizing, the findings from this study also have practical implications for caring for people with Alzheimer’s disease and their family members and for future training programs for nurses and care assistants interested in Alzheimer’s care.

Implications for Patient Care

Nurses and care assistants in the current study reported that they experienced a dilemma between communicating care equally to all versus providing special care to those residents with whom they described having a unique relationship. Although participants did not suggest that any of the people they worked with were neglected by nursing staff, nurses and care assistants noted that providing care to another person is an interpersonal process and therefore is influenced by various personal characteristics. Given the evidence from participant’s narratives that nurses

and care assistants view the choice between providing adequate care and special care as a dilemma, there are several issues to address for patient care.

First, participants consistently described the necessity of caring for the individual with Alzheimer's disease as a person with a history rather than simply a person with a disease. Because Alzheimer's disease robs individuals of their memory and other characteristics that define their identity, nurses and care assistants noted that it is easy to forget that the patients were professionals, parents, spouses, and friends before Alzheimer's made it difficult for them to remember their name and whether they ate breakfast that morning.

Findings from the current study also highlight a significant communication challenge related to the aforementioned dilemma for those providing care for someone with Alzheimer's disease. Some nurses and care assistants described wanting to soothe and reassure their patients using language like "sweetheart" and "baby" that may be perceived by others (e.g., nursing staff, family members) as condescending. Although scholars have argued that this type of talk is patronizing (Caporael, Lukazewski, & Cullbertson, 1983), it seems that in the context of Alzheimer's disease it may serve the purpose of communicating emotional support to someone with limited cognitive abilities. Instead of using language alone, tone of voice and touch communicated support. In addition, participants suggested that using secondary babytalk or words like "sweetheart" to address persons with Alzheimer's disease reflected the resident's limited ability to understand other terms. For some nurses and care assistants, using secondary babytalk was one way of managing the dilemma of providing what they considered to be special care to their residents without adding extra tasks that would take more time than they perceived they had.

Participants for the most part, however, would not recommend that secondary babytalk be used universally with Alzheimer's patients. Instead, nurses and care assistants suggested that health care providers need to account for the stage of Alzheimer's the resident is in and the relationship between the health care provider and the resident when making decisions about how to best communicate. As Tracy (2007) noted, person-referencing practices do identity-work and therefore must be used strategically to ensure that relationships between health care providers, residents, and family members are strengthened rather than undermined by communication. Nurses and care assistants also noted that despite the fact that not all personality types easily connect with each other, it is important that all members of the nursing and care team recognize the dilemma of communicating adequate care versus special care to residents so that they can be sure that all residents are maintaining a high quality of life.

Implications for Familial Caregivers

Familial caregivers experience a great deal of uncertainty associated with the decision to place a loved one in a nursing care facility and have identified nurses and care assistants as significant sources of support in managing their uncertainty (Stone & Jones, 2009). As these findings suggest, communicating support is a complex task that requires managing multiple goals in interactions. Not surprisingly, nurses and care assistants in the current study described a number of dilemmas they faced when providing support intended to manage family members' uncertainty. The following reviews the dilemmas that participants reported and further explicates the implications these findings have for familial caregivers.

First, nurses and care assistants were consistently called upon to provide informational support. Specific topics of informational support included educating the family about the disease process, defining expectations of caregiving, discussing day-to-day activities, informing about

specific changes or incidents, explaining treatment plans, and teaching family members how to interact with the loved one in the facility. Participants noted that they were torn between providing information to family members who asked questions about a loved one and following institutional policies dictating that only the power of attorney is privy to private information about residents. Findings from this study suggest that simply not providing any information to family members who are not the power of attorney, as institutional policies often suggest, leaves family members feeling left out and angry.

One strategy for managing uncertainty that was evident in participants' narratives is to communicate what family members can expect from the nursing staff. Having a common set of expectations among familial caregivers and nursing staff may mitigate some of the challenging situations that nurses and care assistants reported experiencing. Expectations may be communicated in the form of pamphlets or brochures given to family members as they make the decision to place a loved one in a care facility. For example, describing the institutional policies behind communicating information to the power of attorney and not other family members when a loved one enters a facility might open lines of communication in a positive way and create a shared understanding for health care providers and family members. Further, pamphlets or brochures might also explain that health care providers are a resource to help family members make informed decisions but that they should not be pressured to make a decision for the family. One participant, Derek, also suggested that he would encourage family members to volunteer in a facility to learn firsthand what the experience of caring for Alzheimer's residents is like in a nursing facility. Having firsthand knowledge may help educate family members so that they better understand the complexity of providing information in a care facility.

Further, nurses and care assistants found that a salient challenge they faced was how to get family members to understand the importance of taking care of themselves. Laura noted that the first thing she would tell someone who had a family member newly diagnosed with symptoms of Alzheimer's disease is "Take care of yourself, this disease is a long process, this will probably be a long term course of illness." Nurses and care assistants perceive that family members, unfortunately, put themselves last, making decisions and care activities more difficult. This also greatly impacts the way that nurses and care assistants communicate with family members. Rather than being able to focus on the resident and what care is necessary to improve a resident's quality of life, participants felt that they are as much "a nurse for the resident as for the family." Participants did not suggest that they did not enjoy working with family members nor did they imply that they did not want family members to come to them with questions or if they needed support. Instead, participants perceived that the care residents receive would be improved exponentially if family members better understood what to expect for their loved one and how they could best manage their experiences as caregivers.

Participants also suggested that family members need help understanding the importance of having a support system to take care of themselves. Scholars have described several characteristics of burnout for familial caregivers including role fatigue, frustration, and loneliness (Clark & Rakowski, 1983; Maslach & Jackson, 1981). Rates of burnout for familial caregivers are high because of the challenges they face when managing multiple and conflicting roles as a parent, child, professional, and caregiver. Nurses and care assistants perceived that because family members felt overwhelmed by their emotions and the decisions they had to make, they thought that they did not have the time to take advantage of support groups or other resources available to them. Jamie suggested that working with families as soon as a loved one

enters a nursing care facility to “put a support system into place” is essential. The support system, she continued, could be supplemented by the information that the nursing care facility and nurses could present including “information about the disease process, books, and any support classes, the date and time they could go.” Although not all care facilities that participants worked at had a support group for family members, most participants suggested that having a support group associated with the facility, even if it was held off site, would be helpful for families. This is a great challenge that health communication scholars must attend to if communication is going to be improved in this context. Some scholars have described the utility of online support groups because of the asynchronous nature of communication online. That is, instead of having to find time in an already busy schedule to attend a support group, people can turn to other sources of support.

Findings from the current research offer a starting point for developing questions that may be useful to spark conversations in support groups for social network members, whether they are in-person or online. For example, discussion boards for an online support group may post a question about “why I (family member/friend) cannot learn more information about my loved one when I go to visit?” This would give social network members an opportunity to vent their frustrations in a controlled forum where a knowledgeable facilitator, likely an Alzheimer’s care nurse, can comment on and explain reasons for policies that limit information sharing. Support groups that are open to multiple members of the social network, as opposed to just spouses of people with Alzheimer’s disease, may improve experiences of informal caregivers so that they have a more centralized outlet for voicing concerns and frustrations and for learning about other’s experiences.

Another part of educating the family about how to take care of themselves is getting them to acknowledge that their loved one will not get better, no matter what small moments of lucidity may suggest (Mace & Rabins, 1999). Instead of believing that their loved one is improving, Nicole and other participants suggested that discussing “therapeutic communication techniques” would be useful. Participants described these techniques as strategies for communicating with Alzheimer’s patients that do not aggravate the resident. She further described this by sharing one of her experiences.

We have one family member who comes every night and the mother is looking for her mother. And the daughter goes “mom, you know grandma is dead” or she’s looking for her car and “mom, you don’t have your car here.” You know she kind of, “mom you’ve got to remember,” and you’ve got to learn how to talk with them you’ve got to talk differently. You’ve got to reassure them that everything’s okay. We don’t like to call it lying, it’s just therapeutic communication. But so many families get very frustrated with that, and I think that’s something that that families can benefit from understanding more. How to talk to their loved ones with dementia. So that would be an important topic. Communication.

Nurses and care assistants can work to communicate emotional support that expresses concern and reassures the family members in a way that impacts their perception of what it means to be a good familial caregiver. For example, participants reported that family members often described feeling guilty about not being able to care for their loved one at home. Communicating emotional support was one way that nurses and care assistants tried to alleviate some of the negative feelings they perceived family members felt.

In summary, the dilemmas that participants reported experiencing provide insight into recommendations that can be made to family members coping with a loved one's Alzheimer's disease. Nurses and care assistants are called upon to provide informational, emotional, and tangible support to families. Participants noted, however, that they could not provide family members all of the support they need. Instead, participants suggested that family members "need rest, need vacations. They need to take time when they feel burned out." This advice may be difficult for family members to follow given findings that suggest that caregivers are often too exhausted to receive support from others, which can contribute to their feelings of burnout (Lindgren, Pass, & Sime, 1990). People who feel like they do not have time to be around supportive others are likely to continue to feel lonely and unsupported. Simply being around others, even if their intent is to be supportive, was described as challenging. These findings suggest that professional caregivers may be able to provide support that familial caregivers do not perceive as draining. Instead, professional caregivers like nurses and care assistants may be able to communicate support that improves familial caregiver's experiences. Further, giving familial caregivers the time and permission to care for themselves by caring for their loved one may also contribute to improved outcomes.

Implications for Nurses' Training

Participants overwhelmingly reported that communication is an important and underappreciated part of nursing practice and that efforts to change communicative interactions are necessary if there is hope of improving care in the context of Alzheimer's disease. Although communication skills are described as a salient part of nursing care, many participants reported that communication skills were not a significant part of the training they received. Nurses and care assistants suggested that training designed to make health care providers aware of the

specific aspects of interpersonal exchanges that lead to ineffective communication would greatly improve interactions. This may be achieved through more systematic interpersonal skills training taught in nursing school and continuing education classes. The following section outlines one area of training that may be particularly useful for nurses' training.

The experiences of nurses and care assistants in the current study suggest that being open with family members about the uncertainty that they are experiencing may be one avenue for establishing a trusting relationship. Participants commonly acknowledged that family members expected them to know all of the answers. Working with nurses and care assistants to feel comfortable communicating about the uncertainty they are experiencing may allow them to communicate more effectively.

Although open communication is important, the training must also be careful not to espouse completely unfettered openness. Being open may not be appropriate in all circumstances (Caughlin, 2003). Avoidance in communication often works to protect others from sad or hurtful information (Afifi & Guerrero, 2000; Vangelisti, 1994). Research has found that family members may avoid topics to protect others and their relationship from conflict (Roloff & Ifert, 1998). Participants suggested that they avoided discussing information with family members when that information was not essential to the decision making process or when discussing certain details irritated patients or family members, as in the examples of "therapeutic communication techniques" mentioned by Nicole. Protecting family members from feeling like their loved one was not happy when they exhibited aggressive behaviors may be another reason for avoiding. Future research should continue to examine the reasons and consequences of open and avoidant communication in the unique relationship context of health care providers working with family members.

Given the utility of being open selectively, nursing training should include lessons in how to think through and address particular communicative situations. Incorporating role play activities into training for Alzheimer's nurses and care assistants may be useful in some situations but not others. For example, nursing students could begin the session with a brief discussion of communication theory about open and avoidant communication. After the discussion, a training session might involve nursing students acting out a situation in which the nurse is given a typical Alzheimer's care scenario (e.g., "A resident you care for yelled an obscenity at you when you tried to give him/her his/her medication. His/her family has come in to visit and asked how the day is going. What will you say?). Acting out situations like this may better prepare nurses and care assistants for the kinds of conversations that they are likely to have with patient's families. Different hypothetical scenarios could be developed from participant's narratives to form the basis for this training module. This type of training incorporates the findings from the current study through role play activities.

Strategies for Improving Care through Communication

Normative theories are well positioned to address what makes communication in nursing problematic and may provide recommendations for how communicators can attain desired outcomes. Nurses and care assistants working with patients and families coping with Alzheimer's disease experienced a great deal of uncertainty and found that managing their own and others' (e.g., family members) uncertainty is challenging. With an understanding of participants' experiences, a next step is to develop strategies for improving the context of care in which nurses and care assistants work. The following describes challenges that need to be addressed to improve care through communication. Then, I discuss the psychosocial issues that nurses identified as being salient for families they worked with.

One key stressor contributing to the challenges nurses and care assistants in the current study faced is insufficient nursing staff. A related challenge that participants reported concerned the amount of time that they had to perform their work. These feelings were often due to a shortage of nursing staff. Leslie reported:

I truly wish we had more nurses. I truly do. There are times when it's, it can be very challenging behavior wise. We don't, we don't want our residents to the point where they can't keep their head up at dinner. You know, we're very very cautious about over sedating. And sometimes we get a lot of behaviors because we don't over medicate and that can be real challenging.

Having more nursing staff, participants implied, would help to alleviate some of the stress that they experienced. More nursing staff would provide greater quality care for residents and would allow for nurses and care assistants to have more time to complete the tasks for which they are responsible. Mary highlighted this experience:

I feel really kind of burned out here. Number one, because you know a lot of people, a lot of families call me versus someone else, and, I really don't have the time to get my job done, in here that I need. So that's really frustrating to me to try and get all my paperwork done and work on the floor, and then when I work on the floor I don't get my days off during the week because I can't get my things done so I end up working like nine out of 10, 10 out of 11, sometimes 11 out of 12 days, and I'm exhausted.

Laura commented that "not enough time" characterized the ways that nurses and care assistants rationalized the ways they communicate care to residents and family members. She continued by describing how "it could be better if we could meet more frequently, but families have commitments and we have other things to accomplish." This comment is particularly interesting

because of the way that responsibility is shared among the multiple parties involved in the interaction. Instead of blaming families for the lack of quality communication, participants generally recognized that improved communication required a team approach.

Participants also suggested that training needs to be extended beyond nurses and care assistants who work in long term care facilities to health care providers in hospitals. Nurses and care assistants who work in hospitals are trained to diagnose and treat acute problems (e.g., broken bone, urinary tract infection) and may have a difficult time communicating with people with Alzheimer's disease and their families. Continuing education classes and seminars designed to give health care providers, particularly nurses and care assistants, basic information about the characteristics of Alzheimer's disease, concerns that family members may have, and suggestions for taking the patient's medical history may improve interactions in hospitals.

In order to better communicate with family members, participants noted that having more permanent staffing would likely contribute to improved communication efforts. Given the high turnover of nurses working in high stress occupations like dementia care, attending to the needs of nursing staff to improve the conditions that lead to burnout is essential.

Toward a Normative Model

The suggestions participants made for ways to improve communication in the context of coping with Alzheimer's disease highlight the importance of nurses and care assistants in providing support to family members. Clearly, as is demonstrated by participant's reports described throughout this research, nurses and care assistants are seen as a source of support. They are not, however, typically trained to communicate this support nor are they rewarded for doing it well. Further, nursing textbooks that address communication (e.g., Ellis, Gates, Kenworthy, 2003) do not acknowledge the sources of uncertainty that nurses likely are

influenced by or the uncertainty that family members experience. Another key finding that has practical importance was the complex relationship between providing support and uncertainty. Although receipt of social support was often described as helpful in managing participant's uncertainty, participants reported that there were times when providing support created uncertainty. This is another prominent challenge that nurses and care assistants faced when communicating with family members that is not explicitly addressed in the literature.

The present investigation examined the social support experiences of nurses and care assistants working with families and patients coping with Alzheimer's disease as an initial step toward developing a normative model. Developing a normative model includes an examination of the functions of support, dilemmas of communicating support, and the strategies used to adapt to dilemmas (Brashers, Neidig, & Goldsmith, 2004). Nurses and care assistants in this study cited communication as a major source of uncertainty in providing quality care. Participants were most concerned with improving communication with family members, but they were also interested in exploring innovative ways of communicating with Alzheimer's patients. The uncertainty that participants reported experiencing when they communicated with other coworkers was also challenging. The receipt of social support from peers and the provision of it to family members facilitate working in this nursing context by making it easier to cope with day-to-day challenges and stressors that nurses and care assistants face. The provision and receipt of support, however, was not without its own challenges.

A salient challenge that participants faced when seeking support was related to choosing appropriate sources of support. Participants described having to weigh the advantages of asking for help with the costs of losing independence over the situation and appearing incompetent. Communicating support in this context was described as having the potential to assist the

uncertainty management process by giving nurses and care assistants the opportunity to communicate with one another about challenges they faced. Because peers understand the challenges that nurses and care assistants working with Alzheimer's patients face, peers were able to provide support that reflected specific previous experiences that were relevant to problems participants were coping with. As previous literature has noted, however, support can hinder the process of uncertainty management (Brashers, 2001). This was particularly the case when participants received advice from peers. Some attempts at providing advice were perceived as unhelpful because they threatened the relationship between the support provider and the support recipient. As Goldsmith (2004) argued, the distinction between solicited and unsolicited advice giving is an important criteria for evaluating the helpfulness of support attempts. For participants in the current study, the distinction between helpful and not helpful advice related to whether or not the advice giver had previous experience with problem. A second criterion for judging the perceived helpfulness of the support attempt was whether or not participants communicated with other nursing staff as a team or as individual actors working in the same organization. Participants who viewed their coworkers as part of a team described advice giving attempts as more helpful than those who did not view their coworkers as part of a team. This is a useful finding for future research that examines advice giving in organizational contexts.

To manage these support challenges, participants developed strategies for seeking support. Participants working with others who have a collectivistic orientation to nursing care reported being able to seek support freely. Those who worked in organizations that were more focused on individuals' ability to complete tasks were much more concerned about identity and

relational goals of communicating support because of the potential negative implications that providing support had.

Limitations and Directions for Future Research

One constraint that should be acknowledged is the limited generalizability of the findings. Qualitative grounded theory analysis relies on interviewing techniques, which make large numbers of participants impractical. In addition, recruiting participants for this project was challenging. Organizations I contacted were very concerned about having a researcher speak with their employees. I learned that at one organization someone started a rumor that I was “with the government” which made people uneasy about participating. Although having a sample from organizations who would allow me to recruit nurses and care assistants in their facilities clearly biases my results, there is no evidence to suggest that the challenges participants reported experiencing would be any less salient for nurses and care assistants in more restrictive organizations. It seems, in fact, that nurses and care assistants working in an organization that was more leery of participation in a research project like the one described here may find these challenges to be more salient. The results of this study, therefore, are based on a relatively small sample of nurses and care assistants. Conducting interviews with nursing staff of varied educational backgrounds and in different cities across the United States yielded a sample of participants with diverse backgrounds. Although the findings from this study are the result of a relatively small sample, detailed qualitative studies like this are necessary to uncover relevant challenges and concerns to develop in future research.

Despite the potential limitations of semi-structured, face-to-face interviews, the design situated this project to be successful in a number of ways. Theoretically this study adds to literature on coping with illness generally and on the specific role of communicating social

support as a way of coping with illness. The data illuminated specific circumstances under which social support is perceived as helpful from the perspective of the health care provider (i.e., nursing staff) as well as situations in which support does not facilitate coping efforts. The data also provided insight into the role of multiple goals in communicating support, and this study highlights practical considerations that may benefit health care providers and families committed to providing care to people with Alzheimer's disease.

The exploratory nature of this study provides several directions for future research. First, a more detailed examination of the role of communication in experiences of burnout is warranted. This study provided preliminary evidence that what people actually say and do in interactions influences health care providers' experiences of burnout. Future work should measure the degree of burnout nurses and care assistants experience alongside perceptions of social support to supplement narratives that detail specific conversations in which enacted support was communicated. Second, research should attend to the reasons behind nurses and care assistants' decision to be open with family members or to avoid topics. Although participants reported that there were times where it seemed appropriate to communicate openly and times where it seemed appropriate to avoid topics with family members, nurses and care assistants narratives did not highlight specific reasons for being open or for avoiding. Understanding the reasons for communicating openly about some topics over others may provide information that will be useful for improving nurses and care assistant's perception of readiness for Alzheimer's care. Finally, developing scenarios from participant's narratives to measure the sophistication and specific characteristics of support messages communicated to family members coping with a loved one's illness is a fruitful line of research that deserves attention. This type of scholarship has the potential to add to literature on coping with illness, managing uncertainty, and

communicating social support and has practical implications for how health care providers communicate with families.

Although this study was framed by Goldsmith's (2001) normative approach, several theories may provide an appropriate framework for examining the role of multiple actors involved in communicating support in the context of Alzheimer's disease. For example, systems theory (Checkland, 1999), social network theory (Monge, 2003), and communal coping theory (Lyons, Mickelson, Sullivan, & Coyne, 1998) may be useful for examining these relationships.

Long-term objectives are three-fold. First, this project may be used to develop typical scenarios that nurses encounter to examine the particular message features of social support. With an idea of the types of messages that nurses communicate to families, future studies can examine multiple instantiations of support messages to investigate the efficacy of specific message features in achieving their desired goal. Second, this project provides a framework for studying the impact, if any, that other health care providers (e.g., social workers, physical therapists, occupational therapists, art therapists) working with patients and families coping with Alzheimer's disease have. Third, future studies should also examine similarities and differences across nursing care settings. Although nursing care may be similar across nursing contexts (e.g., Alzheimer's care, Parkinson's care, care for stroke victims), there are also potential differences, and scholarship concerning both the similarities and differences is warranted to provide information to improve patient care and experiences of caregiving.

Conclusion

This study explored the experiences of communicating support for nurses and care assistants working with families and patients coping with Alzheimer's disease. Participants in this study faced numerous challenges communicating support to family members and to other

nursing staff. Examining the challenges nurses and care assistants face, how support functions in nursing interactions, and how support is provided and received demonstrates that communicating support is a prominent feature of nursing care in the context of Alzheimer's disease.

As the number of people with Alzheimer's disease continues to grow, and with research to find a cure still in its preliminary stages, understanding how social support functions and impacts the lives of those affected by the disease is increasingly important. Developing a normative model of social support for nurses and care assistants working in the context of Alzheimer's disease will help training programs to tailor courses that address the specific challenges these health care providers face. Further, materials may be better tailored to prepare families for the type of interactions that nurses report being challenging.

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APPENDIX A: IRB APPROVAL LETTER

UNIVERSITY OF ILLINOIS AT URBANA - CHAMPAIGN

Office of the Vice Chancellor for Research
Institutional Review Board
528 East Green Street
Suite 203
Champaign, IL 61820



January 14, 2009

Dale Brashers
Communication
244 Lincoln Hall
M/C 456

RE: *Communicating about Alzheimer's disease*
IRB Protocol Number: 09363

Dear Dale:

Thank you for submitting the completed IRB Application for Exemption form for your project entitled *Communicating about Alzheimer's disease*. Your project was assigned Institutional Review Board (IRB) Protocol Number 09363 and reviewed. The research activities involving human subjects are exempt from Title 45 – Public Welfare, Part 46 – Protection of Human Subjects, Subpart A – Federal Policy for the Protection of Human Subjects per the following category:

45 CFR 46.101(b)(2): This exemption applies since the study involves demographic surveys and individual interviews with nurses in Alzheimer's care facilities regarding the experiences of uncertainty and communicative strategies associated with providing social support to families of patients with a possible diagnosis of Alzheimer's disease. Although the interviews are video recorded for transcription and analysis purposes, any disclosure of the participants' responses outside of the research context would not reasonably place them at risk of criminal or civil liability or be damaging to their financial standing, employability, or reputation. Therefore, the category 2 exemption may be applied.

Note: Please supply a copy of the approval letters from the following research sites once they are obtained: Carle Arbours; Champaign County Nursing Home; Clark Lindsey Community; Alzheimer's Family Care Center; Leonard Schanfield Research Institute CJE Senior Life; and Beauvais Manor.

This determination of exemption only applies to the research study as submitted. **Exempt protocols are approved for a maximum of three years.** Please note that additional modifications to your project need to be submitted to the IRB for review and exemption determination or approval before the modifications are initiated. To submit modifications to your protocol, please complete the IRB Research Amendment Form (see <http://irb.illinois.edu/?q=forms-and-instructions/initial-application.html>).

We appreciate your conscientious adherence to the requirements of human subject research. If you have any questions about the IRB process, or if you need assistance at any time, please feel free to contact me or the IRB Office, or visit our website at <http://www.irb.illinois.edu>.

Sincerely,

Sue Keehn, Director, Institutional Review Board

c: Anne Stone

telephone 217-333-2670 • fax 217-333-0405 • email IRB@illinois.edu

APPENDIX B: SAMPLE LETTER OF SUPPORT

[REDACTED]

Thu, Feb 12, 2009 at 12:49 PM

To: Anne Stone <amstone2@illinois.edu>

Anne, everyone is on board. We don't post things in the community and so if you can send the document to me for the nurses I can forward to each ED at each of the other 2 communities. Thanks so much for thinking of us. We're excited to be involved.

[REDACTED]

Note. To protect the confidentiality of the centers and participants, the contact information has been removed.

APPENDIX C: INFORMED CONSENT FORM

Dear Participant,

I am Anne Stone, a graduate student in the Department of Communication at the University of Illinois at Urbana-Champaign. I am conducting this research study under the direction of Dr. Dale Brashers, a professor in the Department of Communication. We are inviting you to participate in this study. You must be 18 years or older to participate and be a nurse who works with families coping with Alzheimer's disease.

The purpose of this research is to learn more about nurse's experiences with families coping with Alzheimer's disease (AD). Participation involves engaging in one interview, during which you will be asked to discuss your experiences with a member of the research team and to complete a brief demographic questionnaire. We will ask you questions to guide our discussion. Total participation time will be approximately 1 to 2 hours.

Although you may choose to share private information, your confidentiality will be strictly protected. If you agree to participate, this means that you consent to having your voice recorded. Although your voice is individually identifiable on the digital recordings, we will do our best to make sure that no one can identify you in our publications and presentations. The digital recordings will be transcribed by members of the research team, who will use pseudonyms in the transcription process and in all reporting of data. The digital recordings will be digitally destroyed after five years. Results of this research study may be disseminated via conference presentations, journal articles, or book chapters.

Your participation is completely voluntary. This means that you can decide whether or not you want to be interviewed. You may decline to participate at any point. There is minimal risk to you, but there is always the chance that talking about your experiences may be uncomfortable at times. You are free to withdraw from the study at any time and for any reason. Also, you don't have to answer any questions you don't wish to answer. Once you have completed the entire session, you will receive \$25.00. If you choose to stop the interview before the first set of questions you will not be compensated.

The broad benefit of your participation is that it will help us better understand how nurses communicate with families coping with a possible diagnosis of AD. Our hope is to ultimately utilize the data to make recommendations to others in similar situations that may help improve their experiences. More immediately, we also hope that you may find it interesting and insightful to discuss your experiences.

If you have questions about this project, please do not hesitate to contact us by phone or email. My faculty supervisor for this project is Dr. Dale Brashers (dbrasher@illinois.edu, 217-333-2683), and you may also direct questions about this research to him. Additionally, you may contact the University of Illinois Institutional Review Board (IRB) if you have questions about

your rights as a research participant (irb@illinois.edu; 217-333-2670). You may call collect if you are calling outside of the area.

If you would like to participate, please complete the information below. You will be given a copy of this consent form to keep for your records.

Sincerely,

Anne Stone
818-434-1506
amstone2@illinois.edu



Signature _____ Date _____

Print Name _____

I consent to being recorded during the interview.

This consent form expires January 2011

APPENDIX D: RESOURCES

If you are feeling distressed after discussing your experience, *please contact your health care provider*, who may refer you to a mental health specialist. If, after talking with your provider, you would like more information about mental health services in Illinois, the following resources may be of interest to you:

*Missouri Dept. of Human Services
Mental Health Services
<http://www.dhss.mo.gov>

*Mental Health Association of Missouri
(314) 773-1399
www.mhagstl.org

APPENDIX E: DEMOGRAPHIC QUESTIONNAIRE

Thank you for participating in our study. Before we go, we'd like to know a little more about you:

What is your sex? M F

What is your age (in years)? _____

What is your ethnic group/race? Please check one.

- American Indian/Alaskan
- Asian/Pacific Islander
- Black (not of Hispanic Origin)
- Hispanic (or Spanish surname)
- White (not of Hispanic Origin)
- Other – Specify _____

What type of nurse are you?

- CNA
- LVN
- RN
- Other - Specifcy _____

What is your role in the care of Alzheimer's patients? _____

How long have you been working as a nurse (in years)? _____ years

How long have you been working with Alzheimer's patients and their families (in years)?
_____ years

What other nursing positions (besides working in an Alzheimer's unit) have you held?

APPENDIX F: INTERVIEW SCHEDULE

Thank you for your participation in this study. Before we get started, I want to talk a little bit about what this study is about. I am interested in learning about your experiences with caring for and communicating with Alzheimer's patients and their families. I will ask you some questions to guide our conversation. Please feel free to skip any questions that you do not wish to answer. With your permission, the interview will be digitally recorded. No information, like your name, the names of patients and their families, or the organization you work with, will be associated with the recording. I keep your interview and any other information you share in separate, locked filing cabinets to protect your privacy.

The first set of questions will ask you to talk about your general experiences with nursing care so I can get to know a little bit about you and your history. Then we will go into more specific experiences you've had concerning care and communication.

General Nursing Experience

Can you tell me about your decision to work with Alzheimer's patients and their families?

What type of nursing training have you received?

Do you take continuing education classes?

If so, what classes? Are they useful? If you were to design a class, what would it include?

How and in what capacities do you work with patients and families?

How would you describe yourself as a nurse?

What characteristics does a great Alzheimer's care nurse possess?

How would you describe your job?

Are you guided by specific organizational policies?

Tell me the story of your experience with providing care for patients and families with Alzheimer's disease.

Oftentimes patients and caregivers report having a lot of questions concerning their illness or the care that they or a loved one is receiving. I'd like to talk about interactions that you have had with patients and their families.

Uncertainty

Do you communicate with family members? If so, how?

Face-face? Phone? Email? Combination?

Describe a typical interaction with a patient's family.

Are the tasks that you do visible to patients and their families?

Do you think people notice what you are doing?
Why do you think that they notice (or that they don't notice)?
Do you make an effort to make these behaviors visible or is it part of your routine?

Do families typically have a lot of questions?
How do they feel about asking questions?
Are families open to asking questions?

What kinds of questions do families typically ask?

Do you experience uncertainty (have questions) when working with families?
If so, what types of things are you uncertain about?

How do you think about having questions about the interactions you have with families?

Is there a particular interaction with a patient and family that is memorable because of the questions they asked?

Describe that interaction.
What made that interaction memorable?

One way for patients and families to cope with what they are going through is to look for information.

Information Seeking

What types of information do you offer the family?

Is this true for all members of the family or do you reserve specific information for primary caregivers?

How do you decide what information to provide?
Are there times when you wished you would have provide more (or less) information?

Patients and families often report that coping with illness is a difficult experience.

Social Support (communicated to the family)

Have you worked with families when a loved one is first diagnosed with Alzheimer's disease?
What do you say to families when a loved one is first diagnosed with Alzheimer's disease?

How do you approach the family?

Are their indications that a family member needs support?
Verbal? Nonverbal?

How do you offer support in these situations? (probe for specific details about types of support)

Tangible support? Emotional support? Esteem support? Informational support?

Describe a particular time when you offered support to a family member and you thought it was helpful.

Why do you think the support was received well?

What made you think that? (probe for multiple examples)

Describe a particular time when you offered support to a family member and you thought it was not perceived as helpful.

Why do you think the support was not received well?

What made you think that? (probe for multiple examples)

Are there times when a family member challenges a decision that you make?

How do you deal with that?

Can you describe a particular example?

Do you find it difficult or easy to offer support to families?

How did you learn to provide support?

Social Support (communicated between nurses – peer support)

One of the ways that nurses who work with patients and their families cope with stressful experiences is to talk with other nurses who have had similar experiences. We refer to these individuals as peers. One of the things that nurses might communicate about with each other involves support. When we think of support, we mean things like providing information, helping to deal with our emotions, or offering assistance or advice.

Have you experienced peer support? Have you found this type of support difficult or easy to get?

Do you feel there are specific advantages to getting support from peers? Do you feel there are any specific disadvantages to getting support from peers? (Probe for examples)

Can you think of an example of a time when a nurse was trying to give you support and you thought it was particularly helpful? What about a time when this support was unhelpful? Why was it helpful or unhelpful?

Can you think of an example of a time when you were trying to give support to another nurse was particularly helpful? What about a time when this support was unhelpful? Why was it helpful or unhelpful?

Relational Communication

How do you view your relationship with the patients and families you work with?

What type of language do you use/what words do you use to talk with patients and families?

Do you think the words you use are important?

Closing

If you wanted to provide support or help to someone whose family member were recently diagnosed with (probable) Alzheimer's disease, what would you tell him or her?

If you were helping to put together a workshop for families who had a loved one living in a nursing home, what topics would you cover/materials would you include?

Is there anything that we didn't cover that you would like to add?

Thank you for participating in this interview.

CURRICULUM VITAE

Anne M. Stone

University of Illinois
Department of Communication
1207 W. Oregon St.
Room 103
Urbana, IL 61802

Education

Ph.D., University of Illinois, Urbana-Champaign, IL

Department of Communication
Concentration: Health Communication, Interpersonal Communication
Dissertation: "We don't like to call it lying, it's just therapeutic communication":
Understanding the influence of social support on coping with illness uncertainty.
Co-Directors: Dale E. Brashers (deceased) and John P. Caughlin
Committee: Marian Huhman, Leanne Knobloch, John Lammers

Certificate of Business Management, School of Business (Spring 2010)

M.A., University of Illinois, Urbana-Champaign, IL

Department of Speech Communication, May 2007
Concentration: Interpersonal Communication, Health Communication
Director: Dale E. Brashers

B.A., University of San Francisco, San Francisco, CA

Department of Communication Studies, May 2005
Magna cum laude, Alpha Sigma Nu, Lambda Pi Eta.

Academic Appointments

2010-present Graduate Research Assistant

Department of Communication, University of Illinois at Urbana-Champaign

2009-2010 Graduate Assistant, Internship Coordinator

Department of Communication, University of Illinois at Urbana-Champaign

2005-2010 Graduate Teaching Assistant

Department of Communication, University of Illinois at Urbana-Champaign

2006-2007 Peer leader, Oral and Written Communication (CMN 111/112)

Department of Communication, University of Illinois at Urbana-Champaign

Peer-Reviewed Publications

- Stone, A. M.,** & Jones, C. L. (2009). Sources of uncertainty: Experiences of Alzheimer's disease. *Issues in Mental Health Nursing* 30, 677-686.
- Martin, S. C., **Stone, A. M.,** Scott, A. M., & Brashers, D. E. (2010). Medical, personal, and social forms of uncertainty across the transplantation trajectory. *Qualitative Health Research*, 20, 182-196.
- Caughlin, J. P., Mikucki, S., Middleton, A., **Stone, A. M.,** & Brown, L. (in press). "Being open without talking about it": A rhetorical/normative approach to understanding topic avoidance in families after a lung cancer diagnosis. *Communication Monographs*.
- Golden, M. A., Whaley, B. B., & **Stone, A. M.** (in press). "The system is beginning to shut down": Utilizing caregivers' metaphors for dementia, persons with dementia, and caregiving. *Applied Nursing Research*.
- Scott, A. M., Martin, S. C., **Stone, A. M.,** & Brashers, D. E. (in press). Social support and uncertainty management for transplant patients. *Health Communication*.

Manuscripts under Review

- Stone, A. M.,** Scott, A. M., Martin, S. C., Brashers, D. E. (under review). Using information to manage uncertainty in transplantation. *Clinical Transplantation*.

Book Chapters

- Thompson, T. L., Whaley, B. B., & **Stone, A. M.** (in press). Explaining illness: Issues concerning the co-construction of explications. In T. L. Thompson, R. Parrott, J. F. Nussbaum (Eds). *Handbook of Health Communication* (2nd Ed), Mahwah, NJ. Lawrence Erlbaum and Associates.

Book Reviews

- Stone, A. M.** (2010). Applied communication for health professionals [Review of the book *Applied communication for health professionals*]. *Health Communication*, 25, 772-774.

Conference Participation

- Stone, A. M.,** Mikucki, S., Middleton, A., Brown, L., & Caughlin, J. P. (2011, May). *The role of communication in caregiving for adult children of lung cancer patients*. Paper accepted for the International Communication Association, Boston, MA.
- Stone, A. M.** (2010, November). *Improving nursing care for people with Alzheimer's disease and their families: Understanding the influence of social support on coping with illness uncertainty*. Paper presented at the National Communication Association, San Francisco, CA.
- Stone, A. M.** (2010, November). *Communicating identity: Experiences of caregivers managing uncertainty associated with Alzheimer's disease*. Paper presented at the National Communication Association, San Francisco, CA.
- Golden, M. A., Whaley, B. B., & **Stone, A. M.** (2010, November). "*The system is beginning to shut down*": Spontaneous metaphors for dementia, persons with dementia, and caregiving. Paper presented at the National Communication Association, San Francisco, CA.
- Mikucki, S., Middleton, A., **Stone, A. M.,** Brown, L., & Caughlin, J. P. (2010, November). "*She knew she was dying, we all knew she was dying, but nobody would talk about it*": A multiple goals perspective on topic avoidance after a lung cancer diagnosis. Paper presented at the National Communication Association, San Francisco, CA.
- Stone, A. M.,** Mikucki, S., Satterlee, K. Middleton, A., Brown, L., & Caughlin, J. P. (2010, April). *Communication and care among adult children of lung cancer patients*. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Stone, A. M.,** Carnett, S., Scott, A. M., & Brashers, D. E. (2010, April). *Life after organ transplantation: Experiences of revival and uncertainty*. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Stone, A. M.** (2009, November). *Social support as a tool for managing uncertainty*. Paper presented at the National Communication Association, Chicago, IL.
- Stone, A. M.,** Scott, A. M., Carnett, S., & Brashers, D. E. (2009, November). *Using information to manage uncertainty in transplantation*. Paper presented at the National Communication Association, Chicago, IL.
- Top four paper, Health Communication Division**
- Carnett, S., **Stone, A. M.,** Scott, A. M., & Brashers, D. E. (2009, May). *Forms of uncertainty in transplantation*. Paper presented at the International Communication Association, Chicago, IL.

- Stone, A. M.** (2009, April). *Identity and Alzheimer's disease*. Paper presented at the Central States Communication Association, St. Louis, MO.
- Brashers, D. E., Scott, A. M., Carnett, S., & **Stone, A. M.** (2009, March). *Communicating about transplantation*. Poster presented at the annual Health and Wellness Conference, Champaign, IL.
- Scott, A. M., Carnett, S., **Stone, A. M.**, & Brashers, D. E. (2008, November). *Social support and uncertainty management for transplant patients*. Paper presented at the National Communication Association, San Diego, CA.
- Stone, A. M.**, & Jones, C. L. (2008, November). *Sources of uncertainty: Experiences of Alzheimer's disease*. Paper presented at the National Communication Association, San Diego, CA.
- Whaley, B. B., & **Stone, A. M.** (2008, November). *Communication, disability and social (in) justice*. Poster presented at the National Communication Association, San Diego, CA.
- Stone, A. M.**, Carnett, S., Scott, A. M., & Brashers, D. E. (2008, April). *Uncertainty and information management for transplant patients*. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Carnett, S., Prigg, E., Seaman, A. T., & **Stone, A. M.** (2007, November). *HIV disclosure to children: A metasynthesis*. Paper presented at the National Communication Association, Chicago, IL.
- Clark, R. A., Farrit, J., Figueroa, N., Harnden, B., Josey, C., Kramer, N., Seaman, A., **Stone, A. M.**, Surratt, J. (2006, November). *Flirting among college students: Behaviors, motives, targets, and reactions*. Paper presented at the National Communication Association, San Antonio, Texas.
- Stone, A. M.** & Seaman, A. T. (2006, April). *There's no easy way to say this... or is there? Examining the message design of bad news delivery in patient-provider communication*. Paper presented at the Kentucky Conference on Health Communication, Lexington, KY.
- Stone, A. M.**, Lee, S., Anderson, J., Brodersen, M., Flemming, E., Leeds, C., Doohan, E. M., & Ho, E. Y. (2006, February). *Kappa Iota chapter: A graduation celebration: Annual career night and alumni presentation*. Poster presented at the annual meeting of the Western States Communication Association on a panel entitled "Bring the resume builder to life: The rewards and challenges of NCA student organizations for your department," Palm Springs, CA.

Research Experience

Graduate Research Assistant, University of Illinois, Department of Communication

Project: Increasing Organ Donation in Illinois (Spring 2010 – Spring 2011)

Supervisor: Brian Quick

Duties included developing coding rubric, coding newspaper stories for information about organ donation, analyzing data, and writing manuscript.

Project: Communication and Lung Cancer Interviews (Summer 2009)

Supervisor: John P. Caughlin

Duties included conducting interviews with research participants, and transcribing and coding interviews.

Project: Medical School Interaction Coding (Summer 2008)

Supervisor: Dale E. Brashers

Duties included coding medical interactions between medical residents and standardized patients for empathic opportunities.

Project: Edit ALTA Conference Journal (Fall 2007-Spring 2008)

Supervisor: Scott Jacobs

Duties included editing journal entries and copyediting.

Project: Presentation at Medical School Research Day (Spring 2007)

Supervisor: Dale E. Brashers

Duties included collecting sources on provider-patient communication, creating scenarios for role-play activity, and preparing handouts for presentation.

Research Funding (internal)

Communicating about Alzheimer's Disease: The Role of Nurses. Graduate College Dissertation Travel Grant, University of Illinois, \$980 (Fall 2009-Summer 2010) (principal investigator)

Communication and Alzheimer's Disease: Experiences of Adult Children. Pilot Grant Program of the Center for Healthy Minds, University of Illinois, \$5,000 (Summer 2007-Summer 2008) (principal investigator)

Research Funding (external)

A Comparison of Campaigns to Increase Organ Donation to African American, Caucasian, and Hispanic 18-Year Olds. Department of Health and Human Services, \$580,000 (Spring 2010) (research assistant)

Honors and Awards

The Ruth S. and Charles H. Bowman Award, University of Illinois (Spring 2011)

Awarded to the department's most outstanding graduate student, based on the student's total record of scholarship, teaching, and service.

Marion Morse Wood Graduate College Fellowship, University of Illinois (Fall 2010)

Competitively selected fellowship to fund interpersonal communication scholarship.

Ruth Anne Clark Student Scholar Award, University of Illinois (Spring 2010)

Competitively selected to fund dissertation research.

Dissertation Completion Fellowship, University of Illinois (Summer 2009)

Stafford H. Thomas Award, University of Illinois (Spring 2008)

Awarded for exemplary service to the department.

Friend of UIUC Department of Communication Travel Grant, University of Illinois (Spring 2006, Fall 2006, Spring 2008, Fall 2008, Spring 2009, Fall 2009, Spring 2010)

List of Teachers Rated as Excellent, University of Illinois (Fall 2005, Spring 2006, Spring 2007, Fall 2007, Spring 2008, Fall 2008, Spring 2009)

Elizabeth Winters Young Fellow, University of Illinois (Summer 2006)

Excellence in Communication Award, University of San Francisco (Spring 2005)

Honor is awarded to an outstanding undergraduate in the Communication Department.

Teaching Experience

Graduate Teaching Assistant, University of Illinois, Department of Communication

SPCM 111 Oral and Written Communication I (Fall 2005, Fall 2006)

SPCM 112 Oral and Written Communication II (Spring 2006, Spring 2007)

SPCM 102 Communication Theory and Research (Summer 2007)

CMN 323 Argumentation (Fall 2007, Spring 2008, Fall 2008, Spring 2009)

CMN 220 Communicating Public (Health) Policy (Fall 2009)

CMN 260 Introduction to Health Communication (Summer 2010)

Professional Development

Graduate Teacher Certificate, Center for Teaching Excellence, University of Illinois
Project: Documented teaching effectiveness (Fall 2007 – Fall 2008)
Supervisor: Grace Giorgio

Blended Learning Seminar, CITES, University of Illinois (Spring 2010)

Online Learning Seminar, LAS Teaching Academy, University of Illinois (Spring 2010)

Advising

Director for undergraduate research assistantship

Ashley Ariebe (2007)

Gregory Hammond (2007)

Sarah Wallace (2007)

Director for undergraduate teaching internship

Kara Spudic (2006)

Clara Wong (2008)

Benjamin Sanchez (2008)

Bethany Steigmeier (2008)

Lisa Medearis (2008)

David Grider (2009)

Roberta Jorge (2009)

Director for undergraduate independent study

Morgan Pick (2008)

Whitney Toone (2010)

Supervisor for James Scholar honors work

Dominique Thomas (2006)

Allison Lively (2008)

Clara Wong (2008)

Katerina Georgiantis (2009)

Jonathan Padish (2009)

Service

Reviewer for *Journal of Applied Communication Research* (2011)

Guest Lecture, CMN 230: Interpersonal Communication, University of Illinois (2010)
Presented data from my dissertation on the impact of burnout on nursing outcomes.

Guest Lecture, CMN 260: Introduction to Health Communication, University of Illinois (2010)
Presented data from a research project on the role of information management in coping with transplantation.

Reviewer, *International Communication Association*, Health Communication Division (2010)

Reviewer for *Western Journal of Nursing Research* (2010)

Reviewer for *Journal of Social and Personal Relationships* (2009)

Facilitator for Geriatrics Workshop, Medical School, University of Illinois (2009)
Reviewed research materials and worked with older adults to prepare for a panel discussion to teach medical students about ageism in medicine.

Guest Lecture, CMN 260: Introduction to Health Communication, University of Illinois (2009)
Presented data from a research project on the importance of social support when communicating with families in the context of Alzheimer's disease.

Communication Consultant, Department of Surgery, Carle Hospital (2008)
Assessed the surgical waiting room experience for family members of patients by interviewing hospital staff and developed recommendations for improved support for staff and family members.

Communication Consultant, Department of Surgery, University of Chicago Hospitals (2007)
Assessed the surgical waiting room experience for family members of patients and developed a format for alerting family members of a patient's surgery progress.

Facilitator for Patient-Provider Communication Workshop, Medical School, University of Illinois (2007)
Developed materials for an interactive, role-play exercise on the importance of communication when discussing sensitive topics with patients.

Vice President, Graduate Student Association, University of Illinois (2007-2008)
Developed materials to orient new graduate students to the Department and organized professional development seminars.

Professional Memberships

National Communication Association (2005-present)

Interpersonal Communication Division

Health Communication Division

International Communication Association (2008-present)

Health Communication Division

Central States Communication Association (2008-present)

Health Communication Division

American Academy of Communication and Healthcare (2010-present)

ⁱ This interview was from a study of adult children coping with a parent's death from lung cancer.

ⁱⁱ Alzheimer's disease is diagnosed solely on the basis of symptoms exhibited. Medical professionals may diagnosis a person with possible Alzheimer's disease based on the results of a Mini Mental exam. As the disease progresses and cognitive function declines further a person might be diagnosed with probable Alzheimer's disease. I will not distinguish between particular stages in this manuscript.