

Chapter 1. Introduction

Living with an irreversible progressive dementia such as Alzheimer's disease (AD) challenges the functional, mental and emotional capabilities not only of individuals with the disease, but also the capabilities of family members and formal care providers. With AD comes a myriad of behavioral problems, including wandering, persistent worrying, and combative outbursts. Although caregivers, practitioners and researchers often label such behavior as problematic, these behaviors may actually be a method for affected individuals to continue to communicate and maintain some semblance of control in their lives. In this study, I focused on one phenomenon commonly seen in persons with AD, namely the fear of abandonment and the behaviors associated with this fear. I attempted to ascertain the frequency, meaning, and outcome of this phenomenon in the Salem VA Adult Day Care Center.

In this chapter, I will first discuss the purpose of this research. Next, I will provide an overview of Alzheimer's disease from a biopsychosocial perspective. The biopsychosocial perspective is useful to examine the disease in this study because it does not assume that the biological aspects of the disease are the sole factors in the illness trajectory, but rather also takes into account psychological and sociological factors (Wright, Hickey, Buckwalter & Clipp, 1995). Then I will describe service options available to caregivers of persons with AD, focusing on the adult day care setting. In the last part of this chapter, I will give a brief narrative of my personal experience and interest in this phenomenon.

Purpose of Research

The purpose of this research was to examine the phenomenon of abandonment fears in persons with Alzheimer's disease in the context of the adult day care setting. For this study, abandonment fears may be considered as fears related to the lack of presence of the primary caregiver. Behaviors representative of these fears include repetitive questions about going home and following caregivers, a phenomenon called "shadowing" (Lindeman, Corby, Downing & Sanborn, 1991). The research was qualitative in nature and examined the issue of abandonment

utilizing attachment theory and a symbolic interactionist perspective. Specific research questions were: What are possible psychological and social causes of these abandonment fears

in these persons with dementia who attend adult day care? How do staff members' interactions with the person with abandonment fears intensify or assuage these fears? How do staff members interpret these fears, and how efficacious are their methods of dealing with this problem? Is there an association between the premorbid attachment style of the person with AD and abandonment fears? What insight can caregivers offer about how this phenomenon works at home? I used data coming from observations of the participants while at the center, from staff interviews, and from interviews with the participants' primary caregivers. By using triangulation of the data, a more complete picture of this phenomenon was generated.

Overview of Alzheimer's Disease

With the "graying of America," health problems affecting older adults are receiving more attention as the prevalence of these problems increases in our society. One of the most severe of these problems is Alzheimer's disease (AD), a neurological disorder affecting approximately 3.75 million Americans, accounting for over 10% of the population aged 65 and older (Evans et al., 1989). With the rapid rise in the current number of older Americans and the coming baby boom explosion, researchers estimate that by the year 2040, the number of cases of AD will reach nine million.

Alzheimer's disease belongs to the family of disorders known as dementia. Persons with dementia develop multiple cognitive deficits, including memory loss. In addition to memory loss, the diagnostic criterion for AD must include at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning (DSM-IV, 1994). Aphasia consists of the deterioration of language. Apraxia is a motor impairment unrelated to sensory function and comprehension of the task involved. Agnosia refers to an inability to recognize familiar persons and objects. Executive functioning involves thinking abstractly and planning behavior.

Although researchers have focused on classifying the disease into different stages of cognitive deterioration (Reisburg, Farris, De Leon, & Crook, 1982; Hughes, Berg, Danziger et al. 1982), it is especially of note here that the American Psychiatric Association does not state that the progression of dementia is an immutable process. Dementia may be progressive, static, or remitting (DSM-IV, 1994). Level of disability depends not only on the severity of the

cognitive impairments, but also on the availability of social support. From this perspective, AD should not be viewed as a process of inevitable and immutable decline.

It is important to understand the biological processes involved in the brain of a person afflicted with AD in order to understand the nature of the disease. Due to the similarity of the disease to other dementias and to delirium, the only definitive way to diagnose someone with AD is through an autopsy (Mace & Rabins, 1981). The brains of persons with AD have neurofibrillary tangles and neuritic plaques in areas important for memory and overall intellectual ability (Andresen, 1995). Technological advancements such as CAT scans and MRIs are now enabling doctors to detect changes in the brain that occur in persons with AD. After neuropsychological testing, blood work, urinalysis, chest x-rays, electroencephalogram, computerized tomography and electrocardiogram are all performed to rule out other possibilities, the accuracy of diagnosis can be estimated at 90% (Andresen, 1995).

One of the central recurring research themes in AD is the management of problem behaviors associated with the disease. An objective definition of a problem behavior is any behavior that causes disruption to self or others and requires intervention by another person (Lindeman, Corby, Downing & Sanborn, 1991). Catastrophic reactions wherein the participant becomes overwhelmed by stimuli and suddenly becomes extremely agitated and hostile represent the most extreme problem behaviors for caregivers and formal care providers. Examples of other problem behaviors are inappropriate social behaviors such as undressing in public, eating other persons' food and inadvertently stealing another person's property.

Caregiving for persons with AD is a long process, inevitably involving many different players. In the early stages of the disease, family members most often fill the role of primary caregiver. Most of these family caregivers are thrust into this vital role with no previous caregiving experience to aid in adjusting to this new role. As the number of older persons with AD who require some form of assistance with care has increased steadily over the years, more options have become necessary to meet the differing levels of need. One such option that has evolved is the adult day care center. Caregivers who are unable to stay at home full time with a loved one and unwilling to place her or him in a long-term care facility such as a nursing home can now opt to place the family member in an adult day care center.

Adult Day Care Centers for Persons with Alzheimer's Disease

Adult day care centers fill a vital niche along the continuum of caregiving for older persons. For older persons with AD, adult day care centers have certain fundamental goals for participants that must be met in order to consider placement in the day care to be optimal. Providing a safe and supportive environment for persons with AD is important. Creating new, meaningful social roles to replace roles lost due to the disease (e.g., provider for spouse, worker) is also important. In this setting, persons with dementia can interact with persons in a similar cognitive state and form meaningful attachments (Williams & Roberts, 1995). Adult day care centers also strive to foster group spirit, again showing participants that they are desired members of a social group.

Therapy at adult day care centers often focuses on inappropriate social behaviors. Reducing the frequency and intensity of problematic behaviors has many benefits for the person with AD, for the primary caregiver, and for adult day center staff. Better relations with assisting staff could lead to a better adult day center environment, as well as a better sense of wellness for the person with AD. As the total number of adult day care centers continues to increase across the country, dealing with problem behaviors will become crucial to preventing inappropriate institutionalization.

Especially important in the family of dementias, adult day care centers can provide respite and support for overburdened caregivers (Panella, 1987). Respite from the type of round the clock care that a person with AD requires can help to reduce for caregivers the feeling that they have no resources left.

Personal Experience and Interest in Abandonment Fears

I was granted an assistantship my first year as a graduate student in Virginia Tech's Adult Day Services Center. Throughout that year, I spent a considerable amount of time reassuring one participant (who at the time of this writing still attends the center but is not the focus of this case study) that she would be allowed to go home at the end of the day. This participant would become so fearful that she would refuse to participate in any planned activities. These fears greatly restricted any meaningful social interactions with other participants or staff and interfered

with a primary goal in adult day care settings by limiting her opportunities for development. Other participants sometimes became frustrated at her constant questions. This would frequently lead to participants' withdrawal from the person with AD, leading to more alienation from the group. It was a virtual impossibility to address her concerns every three to five minutes that they arose. Although the participant's fears may have been temporarily assuaged, the actual effect of answering her questions was infinitesimal. These questions also bothered even the most patient staff members, who eventually grew so tired of answering the same questions to no avail that the participant's concerns were often ignored. As the year went on, I began to hear these same questions from other participants diagnosed with probable AD. After discussing the matter with a nurse at a nearby day care center and learning that many participants with AD at that center also exhibited these worrisome behaviors, I decided to begin researching the matter to obtain a more complete understanding of this phenomenon.

Chapter Two: Literature Review

The scholarly literature on Alzheimer's disease (AD) presents various aspects of the disease from the vantage point of the family caregivers, formal service providers, and from the person with AD. In my literature review, I focus primarily on the literature pertaining to the phenomenon of abandonment fears in persons with AD. I begin with a discussion of how abandonment fears in persons with AD manifest themselves in the context of adult day care. In the next section, I focus on the role of attachment in dementia. In the last two sections, I discuss

existing research on the experience of staff members in adult day care and briefly review the relevant caregiving and stress literature.

Abandonment Fears

Persons with dementia often exhibit problem behaviors as the day progresses. It is during this time that the process known as “sundowning,” a tendency towards decreased cognitive ability and increased agitation begins. Persons with AD frequently appear more confused and forget how they are going home. Panella (1987) dubbed this phenomenon “going home anxiety.” Expressed in an urge to leave throughout the day, going home anxiety can lead to repetitive questions about getting “home” and numerous attempts to leave the facility. Such behaviors often create frustration for the day care staff as the person with AD requires an increasingly unmanageable amount of the precious resource of staff time. Participants with AD can become so fearful and agitated that they become combative and pose a physical threat to staff members. Such behaviors are known as catastrophic reactions and can often lead to dismissal from the day care center, forcing the caregiver to search for an alternative source of care (Corby, Downing, Lindeman & Sanborn, 1991). Although adult day care centers serving persons with dementia experience occasional outbursts of anger, repeated catastrophic reactions must be addressed with either pharmacological or psychological interventions. If these methods fail to reduce these behaviors, the person with dementia is very likely to be released due to the danger to himself and to others (Panella, 1987).

The phenomenon of abandonment fears is also important to address because of the potential for what Breslau (1987) called “exaggerated helplessness.” Exaggerated helplessness refers to “behavior and attitudes on the part of an elderly person which highlight, in intensified form, his [sic] state of passivity, and which are intended to convey to the caretaker an inability to cope with a feared loss of care and self-esteem” (p.157). Breslau suggests that exaggerated helplessness “reduces the patient’s capacity to overcome the psychic conflict related to his disability,” and that exaggerated helplessness results in chronic maladjustment (p. 158). If expressing abandonment fears by the person with AD usually results in increased attention given to the participant by adult day center staff, it is understandable that the expressions of abandonment fears might become more frequent. In this manner, expression of abandonment fears would become a tool for the participant with AD to utilize to get staff attention.

Dementia and Attachment

Closely related to the concept of abandonment fears, researchers have recently begun to examine the role that attachment styles may play in dementia. Personality characteristics persist even throughout the course of dementia. For example, researchers report that persons suffering from depression and aggressive behavior before being diagnosed with dementia have these tendencies exaggerated by the course of the disease (Agbayewa, 1986).

John Bowlby (1979) operationalized the concept of attachment by defining certain behaviors as representing levels of attachment. Although these behaviors were described by Bowlby as being most evident during childhood, he did note that these behaviors were characteristic of persons throughout the life span, and were most evident in adults when distressed, ill, or afraid. Bowlby defined attachment behavior as “any form of behavior that results in a person attaining or retaining proximity to some other differentiated and preferred individual, who is usually conceived as stronger and/or wiser” (p.129).

Drawing from Bowlby’s discussion of attachment styles, Ainsworth, Blehar, Waters and Wall (1978) described three dominant patterns of attachment that begin in infancy and remain stable through adult years. Infants with secure attachments are joyful when reunited with the mother after a separation period. Infants with an anxious or ambivalent style of attachment frequently exhibit severe protest when separated from the mother and resist soothing efforts from others. Infants with avoidant styles of attachment will show disregard for the mother upon reuniting.

Miesen (1992) was the first researcher to confirm that patients with dementia also could be classified as having secure, avoidant, or ambivalent styles of attachment. In a study of 168 patients with mid- to late-stage dementia, Magai and Cohen (1998) found that persons with dementia with avoidant attachment had more paranoid delusions and activity disturbance, and those with an ambivalent style of attachment had greater anxiety and higher rates of depression. The researchers proposed that various components of attachment (i.e., trust, comfort with dependency) became even more important with the inevitably higher levels of dependency

caused by dementia. They suggested the need for observational data to confirm differences in agitation, anxiety, and even hostile behaviors according to the persons' attachment classification.

The Staff Experience in Adult Day Care

Although there is a multitude of articles on the adult day care experience for caregivers and participants, researchers have seldom chosen adult day care staff as focal points for investigation. A notable exception is Hasselkus and LaBelle's (1998) study of staff perceptions of favorable and unfavorable endings to adult day care. By using a narrative phenomenological approach, the researchers were able to collect narratives of satisfying and unsatisfying endings to dementia day care. These narratives revealed that Western ideologies of the value of community care versus the negativity associated with institutional care explained how the staff perceived the process of ending dementia day care. Satisfying narratives of the end of day care were often characterized by situations where institutionalization was delayed for a long time or the participant died before being placed in a nursing home. Abrupt nursing home placement emerged as an unsatisfying ending to day care staff.

More commonly, day to day staff experiences are ignored by the researchers. Staff members are more often used as tools to implement interventions driven by the researcher's theoretical frameworks, as in Baltes, Neumann and Zank's (1994) study of the dependency support script in long-term care. An example of a quantitative design, pre-intervention baseline data on resident behavior were coded and frequency data were taken in this study. These data were then compared with post-intervention frequencies to assess the efficacy of the intervention. In these types of studies, staff perceptions are often considered secondary data if they are considered at all.

Caregiver Stress and AD

A multitude of research, both quantitative and qualitative, has been conducted on Alzheimer's disease. Much of this research has focused on the family members who provide the majority of care for persons with the disease. This research focuses primarily on the detrimental effects of caregiving and on finding better coping mechanisms for persons who are placed into the role (Borden & Berlin, 1990; Haley & Jonap, 1995; Jivanjee, 1994).

Researchers also have examined the characteristics of the care recipient with dementia. Baumgarten and colleagues (1994) discovered that care recipients' initial level of behavioral disturbance was a predictor for change in the caregivers' levels of depression after a year of caregiving. Care recipients with higher levels of behavioral disturbance had caregivers who were more depressed one year later. Levesque, Cassette and LaChance (1998) found that the effect of dysfunctional behaviors as perceived by caregivers was significantly correlated with caregivers' psychological distress. Caregivers who perceived their care recipients' dysfunctional behaviors as more burdensome had more psychiatric problems themselves, such as depression, than caregivers who reported being less burdened by problem behaviors. Abandonment fears could lead to behavioral disturbances in the home setting as well as at an adult day care center, leading to increased caregiver stress.

Significance of Existing Research in Relation to Current Study

The primary focus of my study was to examine what factors at the adult day care center were involved in amplifying or reducing the participant's abandonment fears. My observational data allowed me to examine how interactions with other participants and staff members continue to affect separation anxiety and abandonment fears in persons with AD. I also asked caregivers to determine the style of attachment most descriptive of their family member before the onset of dementia. Understanding that a person with dementia has ambivalent attachment may be useful in anticipating participant behavior. But perhaps more importantly, by examining what interactions are positive and what interactions adversely affect participant well-being, more proactive interventions may be taken in the future.

Wright, Hickey, Buckwalter and Clipp (1995) examined the importance of attachment in Alzheimer's disease, but from a different perspective. Instead of focusing on the importance of classifying persons with AD into one of Bowlby's three stages, the authors hypothesized from other findings that meaningful interactions with caregivers can foster attachment and reduce feelings of losing control for the person with dementia. It is this perspective, namely that this process does not occur solely as a biological result of the progression of AD, but rather from the disease process and the participant's preexisting style of attachment and continuing socialization, that I utilized in this study.

Summary

Existing literature on attachment styles and dementia has shown that persons with dementia can be classified into attachment styles. There is cause to hypothesize that these styles become more important as the person with dementia copes with the losses inherent in dementia. In my study, I used caregiver reports to determine their care recipients' attachment styles, and looked for congruency between the caregivers' assessments and my own observation.

Chapter III: Methodology

I begin this chapter by describing the context for the research, the Salem VA adult day care center. A description of the pilot work and of my participant selection process follows. In the next section, I give my rationale for the chosen methodology and then proceed to describe my three methods of acquiring data: observations of participants at the day care center, staff interviews, and interviews with the family caregivers of the primary participants in the study. I close the chapter with a description of how I analyzed my data.

Setting

This research was undertaken at the Salem VA adult day care center. The center is divided into two different units. The dementia unit (DU) serves clients with diagnoses of

dementia who are typically in the latter stages of the disease. In a conversation with the program director of the day care center, I learned that the participants in the DU typically respond less well to the busier, more planned environment of the main unit. The program director of the center is chiefly responsible for the decision whether to place participants in the DU or in the main unit. The DU has a staff ratio of three staff members to every one participant, while the main unit has a ratio of six staff members to every one participant. Participants in the DU typically need more assistance with ADLs, creating the need for additional staffing. On a typical day at the DU, approximately six to eight participants are present. The main unit always has more participants, with anywhere from ten to twenty participants present on a typical day.

The two units are separated by a long hallway that contains most of the offices for the staff of the adult day care. Doors into both units are open from the outside, but locked on the inside for reasons related to participant safety. Meals are eaten by both groups in the same cafeteria, which is located on the main unit's end of the hallway. After an afternoon snack in the cafeteria, the participants from the DU join the participants in the main unit to wait for the vans to leave. Although I spent some time in the DU, I spent the vast majority of my time observing participants in the main unit.

Pilot Work/Participant Selection

I began pilot work at the day care once permission forms were signed by caregivers of persons who regularly attended the center. The pilot work consisted of about 10 hours of observation. The preliminary observation period served several purposes. Foremost, it cleared up a misconception that I had about the nature of the two units. I had initially made the incorrect assumption that all participants with dementia were placed in the dementia unit (DU). After beginning my observation in the DU and hearing staff members in the main unit describe instances of the phenomena that I wanted to examine, I learned that I needed to shift my observation time from the DU to the main unit. The pilot work also allowed me to become a familiar face to the participants in the DU, who I would later interact with in the afternoons in the main unit.

Early in my observations, it became apparent to me that two of the participants at the day care exhibited abandonment fears on a much more consistent basis than any other participants.

For the purpose of this paper, I will call them Ellen and Opel. Each came once a week on the same day, and each spent the entire day in the regular unit and not in the dementia unit.

Ellen is 78 years old. She worked as a clerical worker, first at a VA hospital and later as a Marine. She is married to her first husband, who also has been diagnosed with dementia. Ellen lives with her daughter and husband in a house, with her daughter doing the caregiving. Staff members at the center saw Ellen as “a go-getter” and as someone with a forceful personality. Ellen is quite mobile, and spent more time on her feet than almost all of the participants at the center. On days when she did not attend the center, she is cared for at home by a home health aide.

Opel is 87 years old. Opel worked in an industrial job. She is a widow who lives with her daughter. Opel is less mobile than Ellen, but still manages to be on her feet a good part of the day. Opel’s demeanor at the center ranges from gleeful to worried, and often the change is rapid. She is cared for at home by her daughter on days when she is not at the center.

Rationale for Methodology

I chose symbolic interactionism as the central theory to guide my research. I was primarily interested in examining the staff and other participants’ interpretation of different participants’ repeated queries about going home. I wanted to examine how the staff members changed their own behaviors as a result of these questions. Although I was interested in describing the behaviors relating to “going home anxiety,” I was also interested in looking at the meanings that each actor (e.g., participants with and without dementia, and staff) in the adult day care setting created for this set of behaviors.

The symbolic interactionist perspective places great importance on interaction and perception. One key tenet of this perspective is that meanings emerge from interaction. A second tenet that appealed to me was that individuals develop concepts of self through social interaction (LaRossa & Reitzes, 1993). In this study, I expected that the social interaction between participants with abandonment fears and all other actors (e.g., day care staff, other participants, primary caregivers, and even myself) was key to understanding the different

participants' abandonment fears. As dementia progresses, the self is certainly eroded, and in the face of that erosion, looking at social processes seemed of paramount importance.

In his chapter on identifying themes and patterns in qualitative research, Luborsky (1994) warned researchers not to discover themes only through after the fact reviews of field notes or other data taken from the field, as that approach places too much responsibility on the researcher to ascertain meaning. It is for this very reason that my research consisted of observation at the center, interviews with the staff members, and interviews with the primary caregivers of the two participants at the center who most consistently exhibited abandonment fears. Themes and patterns were found by examining commonalities across the three data groups.

Observation

I began my research as a participant observer at the center, in the main unit. I observed the participants almost exclusively in the afternoons after witnessing that there was a much higher prevalence of behaviors signifying abandonment fears in the afternoon. My goal was to note with accuracy the interactions between the participants, with a bias toward answering the following research questions. How often did the staff respond to participants' expressed fears? What techniques did staff utilize to deal with these fears? Did some staff members pay more attention to the participants' needs than other staff members? Did any of the participants have catastrophic reactions that were rooted in abandonment fears, and if so, were any precursors evident upon review of prior observations? Was the staff selective in whose fears were addressed, and whose were ignored? Did participants who exhibited abandonment fears seem to receive less or more staff attention than participants who did not voice these fears?

At the beginning of my study, I decided to observe the participants at the center for no less than 50 hours, with the possibility of observing up to 30 hours more. I found through the course of my observations that 50 hours was enough time to describe in sufficient detail the effect of abandonment fears on the various actors at the day care, and to answer my research questions. At the end of the 50 hours of observation, I had witnessed the key patterns involved in the phenomenon, and had reached a reasonable point of data saturation.

I planned on observing for short periods of time at the center, to be followed by breaks during which I would record what had transpired. I used this method for approximately the first third of my total observation time. Initially, I was concerned that real-time note taking would become a distraction to persons at the center, possibly upsetting participants or changing staff behavior. Once I realized that such note taking was not distressing to any of the participants or staff, I began to take notes often throughout the day. Most of the participants at the center were aware that I was a Virginia Tech student and assumed that I was doing “homework.” Staff members expressed no reservations about my note taking. This “real-time” note taking had two distinct advantages over waiting until later to write down what had occurred. First, it allowed me to detail what was happening in the most accurate way possible without using audio or video recording. Second, this style allowed me to write actual conversations almost verbatim as they happened. I believe that the exact wording of these conversations was important in identifying what issues were at the center of abandonment fears.

Staff Interviews

My second method of data collection consisted of interviewing staff members at the day care center. I conducted interviews with the nursing staff at the day care, van drivers, the program director at the center, and activities personnel. To protect anonymity, staff members are only identified by number in this paper, and not by job title. The staff interviews occurred at the center during the day when the staff had free time. The interviews focused on the participants at the center that we both believed exhibited the most abandonment fears. In these audio-recorded interviews, I was particularly interested in the staff members’ perceptions of the effects of the abandonment fears on the anxious participants themselves, other participants, and the staff. The list of questions I used during the interview is provided in Appendix A.

Caregiver Interview

As my final method of data collection, I conducted interviews with Ellen and Opel’s primary caregivers (see Appendix B for questions). These two caregivers were chosen because of the intensity of their care recipients’ abandonment fears, which far exceeded those of any other participants currently attending the center. Interviews were conducted at the day care center, apart from the participants and staff. Interviews were audio recorded and transcribed for data analysis. The caregiver interviews allowed me to learn of several important aspects of the

participants' lives that I could not know by observation alone. In the interview, I tried to determine if the participants voiced similar concerns of abandonment at home, in order to see if a symmetry between home life and the participants' time at the day care center existed. I was interested in learning if the geographic location of "home" fit with the "home" that was so longed for by the participants at the day care, and if being at the geographic location of "home" translated to a less anxiety filled state for the care recipient. In the interview, I also wanted to get a brief background of the care recipients' important relationships before dementia in order to get an estimate of the recipient's attachment style. Although these mini-life histories are admittedly biased information and cannot substitute for actual first person experience, in this instance, the caregivers' accounts were likely to be more accurate than accounts given by the participants themselves.

At the end of the open-ended interviews, each caregiver answered an attachment style questionnaire (Hazan & Shaver, 1987) which consists of three paragraphs describing the three different attachment styles (see Appendix C). The three paragraphs are based on Ainsworth et al.'s (1978) descriptions of infant attachment. Upon separation from the mother, infants with anxious/ambivalent styles exhibit protest. Infants with avoidant styles are likely to detach, showing disdain or indifference to the mother's disappearance. Infants with secure attachment are easily comforted by the mother's return, and show neither anger nor detachment. The Hazan and Shaver (1987) measure takes these same styles and applies them to adults. I asked the caregivers to pick which of the three paragraphs best described their care recipient before the participant was diagnosed with dementia.

Data Analysis

Data from this study came from my field notes and from transcripts of the staff and caregiver interviews. Data analysis was conducted on two levels. The goal of the first level of data analysis was to organize the data obtained from all three methods. I looked for themes and patterns that surfaced multiple times across the three methods. Four primary themes emerged: (a) reasons given by the participants for their abandonment fears, (b) other participants' reactions to the repetitive questions from individuals expressing abandonment fears, (c) personal theories relating to assuaging participants' fears, and (d) staff perceptions of root causes of these fears. I

grouped the data according to repetition of ideas, perceptions, and observed actions across the three data sets.

After organizing the data into these themes, I used symbolic interactionist theory and attachment theory to guide my interpretation of the data. From a symbolic interactionist perspective, I analyzed how the different interactions in the adult day care affect participants' abandonment fears. I also used a symbolic interactionist perspective to examine staff members' perception of participant behavior relating to abandonment fear and their perceived efficacy at dealing with the problem. Attachment theory played a smaller, but still significant role in the second part of the data analysis, as I looked for links between abandonment fears and attachment styles. My observation notes detailed the attachments between Ellen and Opel in depth. Primary attachments (to the caregiver) were explored through the caregiver interview.

Chapter IV. Results and Discussion

The purpose of this study was to examine how the phenomenon of abandonment fears affected the participants and staff at the adult day care center. In this chapter, I present the study findings in three sections in relation to my research questions. In the first section, I look at how the phenomenon of abandonment fears affected the participants' days at the center. In the second section, I explain the effect of these fears on the afflicted persons' interactions with staff and other participants. I end the chapter with a section on caregiver insights, relating abandonment fears to attachment theories.

Abandonment Fears

Evidence of abandonment fears at the day care center was plentiful. For Ellen and Opel, the fear of being left alone at the day care center was voiced frequently by both participants. Their fears dominated their days at the center, changing the way that they interacted with other participants and staff, and arresting any hope for productive, meaningful interactions in a social setting. In this section, I discuss the most prominent behaviors exhibited by Ellen, Opel, and other participants at the center with abandonment fears. I then discuss the persistence and intensity of these behaviors. Finally, I classified these fears into two categories to examine why these fears arise beyond simple biological explanations.

Manifestations of Abandonment Fears

The most prominent indication of abandonment fears among the adult day care participants with dementia was repeated questions about going home. Of all the participants that I observed, Ellen and Opel were the most persistent and vocal in their fears of not getting to go home. Although I did not formally assess the women, I suspect that both Ellen and Opel were in the middle stage of Alzheimer's disease. The women were generally disoriented for time and place, a characteristic of middle stage AD (Hamilton, 1994). Although they were sometimes disoriented for person, a characteristic of late stage AD, I believe their levels of communication and awareness of others seemed more representative of middle than late stage AD. Both women spoke clearly, although not always coherently. Ellen's speech had more elements of aphasia, substituting inappropriate words that resulted in bizarre sentences (DSM-IV, 1994). For instance, on one occasion when worried about going home, Ellen became exasperated when Opel voiced similar fears. After Opel asked if Ellen could take her home, Ellen expressed her agitation at being left at the center by saying "Please don't ask me anything. My tongue is all biting my stomach and my stomach is biting my tongue." Opel expressed her fears about going home more coherently than Ellen, asking questions such as "When do I get to go home?" or "Who's going to come pick me up?"

Although Ellen and Opel were the most vocal about their expressed fears at the day care center, there were other participants who exhibited agitation that, in all likelihood, were manifestations of abandonment fears. At the very least, their agitation was indicative of confusion as to the nature of their environment. Heather, whose speech was considerably more disjointed than Ellen or Opel's, spent mornings in the dementia unit, but joined the main unit along with the rest of the dementia unit participants after the afternoon snack. She spent much of her time in the afternoons wandering from participant to participant trying to begin a conversation. Heather would often begin her conversations with question words, but spoke in incomplete sentences, asking, "Do you....If I come with....Are you my...." Toward the end of the day, her speech would fragment further, and her fears became more evident as other participants left. On one occasion, Heather was having a conversation with another participant with dementia, Stan. After Stan's wife arrived and took him home, Heather approached me and asked "Was he happy that his wife came?" I told her that Stan was indeed happy and that he had already left to go home. She became exasperated, saying "This is awful! Now I can't....I'm

stuck here!” Heather then began wringing her hands together, a physical manifestation that I saw on many occasions when she appeared fearful.

Stan, like Heather, appeared to be in a later stage of dementia than either Ellen or Opel. Stan also stayed in the dementia unit until the afternoon snack. He spent almost the entire time in the unit wandering, and often seemed to project his abandonment fears onto others. A common behavior for Stan was to walk up to participants who were resting and not interacting with anyone else and begin to touch them. For example, the following conversation occurred after Stan woke up another participant, Sally.

Stan: You going out?

Sally: No.

Stan: You CAN go out! There’s nothing on you! Any time you want!

Sally: I’m sorry.

Stan spent much of his time wandering in a corridor that went from the unit to the cafeteria. This was a common place for participants who were agitated to wander. The door out of the day care was located in this short hallway and locked from the inside. Participants who verbally expressed the desire to leave the center would frequently turn the knob of the door to leave, find it locked, and either resume wandering in the hall, or return to the main group.

In summary, abandonment fears were primarily discerned through participants’ repetitive questions about going home and attempts to leave the facility. Although Ellen and Opel were the most distressed, other participants occasionally expressed concern about going home, and at times verbally communicated their distress. I should note here that it would be dubious to conclude that because I did not witness the fears in more persons that these fears were only held by a few of participants at the center. I believe that some of the other participants with dementia who were in later stages may well have been experiencing the same torment, but could not express themselves because they were further along in the progression of the disease.

Frequency of Abandonment Fears

During my observation, perhaps the most surprising aspect of abandonment fears was the persistence of this phenomenon. The severity of the participants’ fears often disrupted Ellen and Opel’s entire day at the center. It was not pragmatic to keep a running record of the two

women's constant questions, but I would estimate that Opel asked a series of questions about going home at least ten times an hour each afternoon. Questions would often begin with "Do you know how I am going to get home?" Upon hearing the answer to the question, Opel would then typically ask two to five follow-up questions. There were brief periods of tranquility after Opel's questions were answered. In the following example, Opel began asking questions of another participant who did not have dementia.

Opel: Can I come home with you?

Lara: I'm not going to my home. I'm going home to my daughter's.

Opel: Well, maybe I can call from there. They can pick you and me up. (long pause)
I'm just about to sweat. Do you know the way to our home?

Lara: No.

Opel: Who can show us the way?

Lara: I don't know.

Opel: We're going to have to walk anyway. How much do you pay your son or brother to pick you up?

Lara: Nothing (looks amused). They LOVE me.

Opel: Well, I was thinking I could pay something to take me home. My next check, it's going to be a big one (broad smile).

Wayne: Opel, honey, your daughter is going to be here at 4:30.

Opel: Really? How do you know?

Wayne: (lying) I just got off the phone with her. She said for you not to worry and that she would come like she always does at 4:30.

Opel: You're not just pulling my leg, are you?

Wayne: No, Opel. I promise.

Opel: Well, I am going to give you a reward. (grabs Becky) Do you see what a gentleman we have here?

In this example, the persistence of Opel's fears is evident. Lara's answers to Opel's questions only elicited more questions about going home. Although on many occasions, Lara explained the nature of the adult day care to Opel upon being questioned, on this occasion she did not. Opel was temporarily relieved after I told her that I had spoken with her daughter. This approach

(i.e., deception) worked as well as any method that I observed being used at the center, calming her for about fifteen minutes before her questions began again.

Intensity of Abandonment Fears

I was surprised that in my 50 hours of observation I did not find one instance of a behavior associated with abandonment fears that could be classified as a violent catastrophic reaction (Lindeman, Downing, Corby & Sanborn, 1991). However, Ellen and Opel often became very distraught at their situation, routinely refusing to engage in any of the day care activities. An example of the disruption associated with their fears, taken from my observation notes, follows.

Occasionally, Opel asks Ellen about when or how they are to go home. Ellen snaps on several of these occasions at her. "Please don't ask me that again! I don't know. I'm trying to find that out myself. Please, I'm very upset." The two wander ceaselessly around the day care. They often walk into the hallway. . . She [Ellen] repeatedly says she is leaving and tries to leave the locked door, but at first is surprisingly calm when she finds it locked. However, later in the day, I find her crying by the door alone. I ask her what is wrong, and she tells me that she can not get out. I tell her that someone will be there for her shortly, and that she should come back with me to sit awhile and wait, which she does for about five minutes before the pacing resumes anew.

The staff discussed past instances where participants' abandonment fears had more severe behavioral repercussions than what I witnessed with Ellen and Opel. Most of the reports centered on a participant with problematic behavior who no longer attended the center. Staff members commented on his violent behavior below.

S3: We did at one time have a man that, it got to the point where he would kick doors, push people, kick staff. . . And it got to the place where he was taken off the van because he was a hazard. I, myself, was scared. . . Once he was out of here, he was fine. Once he knew he was going home, he was fine, but as long as he was in here, he was kicking that door, pushing and shoving. (Note: another staff member described this same man as "real violent" and mentioned the identical behaviors).

S4: We've had one that we had to do that [discharge because participant was scared about going home and became hostile], and several that have spells and rattle the doors. One we've discharged that I can remember in the time that I've been here. Usually by the time they're to that stage, they're being placed. But this guy. . .He was getting mean to staff, hitting people. Sometimes if they'll hit staff, they'll hit other participants and we can't have that. . . We've had a couple that at times are upset, rattling the doors, kicking and screaming. We have to take them home for the day. Then they're back the next day, and maybe they're OK.

These examples illustrate the potential problems that can occur as a result of the same types of abandonment fears that Ellen and Opel exhibited. Although both women became severely distressed over their plight at the center, their behavior was more reserved than the man the staff members discussed in the interviews. I believe that traditional gender roles, especially in this cohort, might explain differences in the manifestations of abandonment fears between men and women with dementia. In their most worried state, I would find one of the women crying, or refusing to listen to staff assurances. It is easy to see how the same phenomenon could become a much bigger problem to all staff members with a more aggressive (and physically stronger) person who desires to leave.

Rationalizations of Abandonment Fears

Participants expressed their abandonment fears orally in fairly predictable patterns. Certain statements or questions were repeated and seen during every day of my observations. Through my analysis of these indicators of abandonment fears, I classified their fears into two categories: (a) fears that were indicative of confusion as to their present context, and (b) fears relating to barriers between themselves and their caregivers or homes.

The anxiety of being left in an unfamiliar environment was something I saw etched in the faces of Ellen and Opel on every day I observed them. For these two participants, the concept of the adult day care center was too difficult to truly grasp for any meaningful period of time, if it was ever understood at all. This is illustrated in the following excerpt from my observation notes.

At around four o'clock, Opel and Ellen are sitting down and Opel says, "I tell you one thing. I am NEVER coming back here (chuckle)." Ellen nods her head

vigorously in agreement and says “But you have said that before.” Opel says, “Yes, but I mean it. I don’t know where I am.” Ellen says, “You think I do? I don’t know.” I tell them that they are at the Salem Day Care Center where they come to eat and socialize, and that they always get to go home at the end of the day. Ellen says, “That sounds nice,” as if this were some abstraction, instead of the setting that she is currently in.

A staff member commented on this confusion for the person with dementia in my interview. Below, she discussed how a person with dementia could easily mistake the day care environment for a nursing home.

S4: When you go with your family member and they just all of a sudden bring you to this place and say “Well here, you have to stay here until I can do what I have to do. I’ll be back.” When they come into this strange place and they see all these other people in situations as themselves. . . I think it’s a fear of thinking, “I’m stuck here. Nobody’s ever coming back for me.” Because you do have those who are placed in a nursing home. The family never comes back. . . They don’t know that this is not an actual nursing home. When they come here and see all the people, and the staff and wonder, “I eat lunch here. I get a snack here. What’s going on? Am I going to be here?”

Confusion related to the current surrounding was often concurrent with confusion about past events (e.g., how the participant arrived at the center) and confusion as to the expected end of the day at the center (e.g., the participant’s means home). A conversation between Ellen, Opel, and Becky illustrates the point.

Opel: I don’t know who I’m waiting on.

Ellen: Well, I don’t know either. I’m Ellen.

Opel: Who am I waiting on?

Becky: Your daughter.

Opel: Can she come in here? I can’t stay all night. Did she get you to stay with me?

Ellen: I don’t think so.

Becky: No, you can’t stay here all night! Nobody does that!

Ellen and Opel were not the only participants to exhibit confusion about their presence at the adult day care center. Stan's confusion at his surroundings and his desire to leave are evident in the next vignette, which I observed between himself and a staff member.

Stan: I sure do want to leave this place.

Staff: Why? Where do you want to go?

Stan: (agitated) I live here!

Staff: You do?

Stan: Yeah, I'll tell you one thing. I DO KNOW WHERE TO GO!

Staff: Where?

Stan: To the...

Staff: Where?

Stan: Yeah!

The second group of concerns stemmed from practical considerations regarding the participants' planned departures at the end of the day. This set of fears was sometimes expressed alone, but they often surfaced after earlier, context confusion statements were addressed by the staff or other participants. The locked doors out of the unit were of particular concern for the worried participants, not only because they prohibited their exit, but because they feared that their caregivers could not get in to take them home. An example from my notes follows.

Heather beckoned me to her once I left Stan, with the puzzle completed. She again began to ask me in very jumbled language about going home. Pointing at the locked door, she asked, "Can they come in? If the door is locked, then...."

The locked doors were regularly tried by many of the participants with dementia. This behavior can be explained two different ways. The participants may be trying the doors as part of typical wandering behavior that accompanies Alzheimer's disease (Andresen, 1995), with the door out leading to more wandering room. Alternatively, the participants may be trying the doors hoping to exit the building and go home. From my own observation, I sometimes found it difficult to tell why a participant was trying the door out. For Ellen, Opel, and some of the other participants, the locked doors presented a distressing problem. Another example from my notes follows.

She (Ellen) repeatedly says she is leaving and tries to leave the locked door, but at first is surprisingly calm when she finds it locked. Later in the day, I find her crying by the door

though, alone. I ask her what is wrong, and she tells me that she cannot get out. I tell her that someone will be there for her shortly, and that she should come back with me to sit awhile and wait, which she does for about five minutes before the pacing resumes anew.

When participants who were anxious could remember who was transporting them home (often after being told), they frequently found it difficult to simply wait for their “ride” and instead feared that they might be (or already had been) somehow overlooked by their caregiver. The participants who exhibited abandonment fears always stayed near the exit where family members would arrive. For example, Thomas consistently walked to the locked door, cupped his hands over his eyes, and peered out the grating, looking for his wife to arrive. His speech was often disjointed, but good natured, and although he seldom asked about going home, his repeated late afternoon shuffling over to peer down into the hallway suggested that he was very concerned about his situation.

In the next conversation, both kinds of fears are displayed as I tried to assuage Opel’s fears that her daughter would not arrive. When Opel first expressed confusion as to her situation, I responded by giving factual answers to her questions. Then, she began to worry that something would prevent her caregiver from arriving.

Opel: Who’s supposed to come get me?

Wayne: Your daughter is going to pick you up. Lisa.

Opel: You know my daughter?

Wayne: Yes, I sure do, Opel. She’s very nice.

Opel: Why’d she put me here?

Wayne: She had some errands to run, Opel. But she’ll be back in just a couple of hours.

Opel: I hope so.

Wayne: She’s never left you before, Opel. You did a very good job of raising her. She’s very responsible.

Opel: Thank you. I know she is. But...What if something happens and she can’t. . . Things happen.

In this instance, Opel had the information that her caregiver was coming and had faith in the caregiver’s desire and ability to come, but was afraid that events beyond her daughter’s control might prevent her from being picked up. In past instances, I saw participants with dementia rationalize their fears by similar means, fearing for their caregiver’s health. During my graduate

assistantship at the Virginia Tech adult day care center, one woman with dementia who constantly asked about going home often talked of her son's heart condition. It is possible that despite close attachments to the primary caregiver, persons with abandonment fears may still dwell on possible, although not plausible, worst case scenarios that would prohibit their caregivers from picking them up.

Recruiting Behavior

I observed one phenomenon regarding abandonment fears that I have not seen reported in the literature. Every day that Ellen and Opel both attended the center, Ellen would begin asking questions about going home. She would often receive answers to her questions from participants who were more cognitively aware. These responses were usually in the form of a kind of "reassurance by fact" where the other participants would tell her what time and how she was going home. These reassurances seldom worked. Eventually, Opel would ask questions of Ellen about going home. Opel, upon seeing that another person (most frequently Ellen) was concerned about going home, would become more anxious. Ellen would then often ask Opel to come with her and find a way out. This desire to have another person to assist in "getting home" was commonly exhibited. I termed this behavior "recruiting." The ease with which Ellen could remove Opel from interaction with other participants is illustrated in the following example. Ellen and Opel had just returned from lunch, where they would almost always sit together.

Opel: I don't know who I am.

Ellen: I don't know who I am either. Let's go.

Opel: Ok.

In this instance, Ellen clearly does not offer Opel any additional insight into her situation. In fact, she confirms Opel's confusion at her surroundings and merely adds a proactive approach to the problem. Although Opel is usually content to just ask others about her plight, this example shows how easy it was for Ellen to recruit her to begin looking for a way out of the center.

On several instances, Opel verbally acknowledged her attachment to Ellen. The following example, taken from my observation notes, reveals more about how she perceived their unique bond.

After telling Ellen and Opel repeatedly that their daughters would be coming to take them home, I told the two women that they needed to just try to relax. I ask

them to smile for me, and they adamantly refuse. “I have nothing to smile about” Opel says. “We’ve got business we have to see.” Opel mentions another time, “I’m following her [Ellen]. We’re together.”

I observed only one occasion where Ellen’s recruiting of Opel failed. Opel asked Reva, another participant with dementia, if Reva was her daughter. Reva replied in the affirmative. Opel then said, “Then I guess I’m with you.” Later in the day, when Ellen began recruiting attempts toward Opel, Opel said, “I’d better stay put. I’m with her [Reva], I think.” This is noteworthy because it seems that Opel may not actually be forming an attachment to Ellen because of her personality, but rather follows her because she sees Ellen as someone who is more competent that she “must be with.”

Staff members talked a good deal about the relationship between Opel and Ellen, supporting much of what I found in my own observation. Staff members focused on the similar emotional states of the two participants and contrasted their days at the center with those of the other, non-worried participants. In the following excerpts, staff members talk about how they perceive the unique bond between these two women.

S2: I think Opel sees Ellen as someone, in her mind, Ellen is more competent, the authoritative person because she is walking all over the place and asking questions. Everyone else is sitting here, not worried. Opel is thinking, “Why are these people not worried?”

S3: I don’t know how they found each other, but they totally cling to each other. I think they feed off each other’s anxiety. The things that Ellen is afraid of and the things Opel is afraid of, we all tell them that there’s no need to fear that. That we’re here, we’ll all stay with you, but whatever is happening to them inside, with each other, they are saying their own worst fears. So at that point...it’s like, “You know me, you understand!”

S4: They connect because they feel like they’re both stranded. They’ve both been placed here and no one’s coming after them. Then I think they see that no one else is worrying about anything, so they kind of connect to one another’s thinking, well we can get through this together. She needs me. I need her. Maybe I can comfort her. Maybe she can comfort me.

S5: Ellen gets Opel started on when she’s going home. She’s a nervous wreck, Ellen is. Ellen has her (Opel) walking up and down the hall and wondering what time her daughter comes...When that person (Ellen) isn’t here, Opel is fine. She’s content.

Ellen's tendency to aggravate Opel's fears, as mentioned by staff member five, was especially evident on days when Opel was present without Ellen. Opel would still ask questions about going home, but her demeanor was much more calm. She would often smile on these days, when asking questions, and was more easily reassured.

Intervention as a Precipitating Event

On two occasions, efforts to calm Ellen and Opel actually intensified their distress. The following two examples, taken from my observation notes, illustrate the difficulty in addressing this problem from a staff member's standpoint. After "reassurance by fact" failed miserably on repeated occasions, I tried to reassure Opel on the first occasion by writing a note explaining her way home, a technique that is recommended in the popular literature of Alzheimer's care (Panella, 1987).

At 1:30, I write in large letters for Opel: YOUR DAUGHTER IS COMING TO PICK YOU UP HERE AT 4:30. I hand it to her after one of her nonstop queries about going home. She reads it aloud. Then, the questions turn to the note that I have written.

Opel: Your daughter is coming to pick you up here at 4:30. Who wrote this?

Wayne: I did, Opel. It's to remind you that you are going home so that you don't have to worry all the time.

Opel: Is it true?

Wayne: Yes, Opel.

Opel: (Reading note again) Your daughter... So who is your daughter?

Wayne: It's not my daughter, Opel. It's your daughter.

Opel: My daughter? What's her name?

Wayne: (after asking around) Lisa. Lisa is your daughter.

Opel: (reads note again) I don't understand this. I don't know who wrote it.

This episode with the note lasted long enough to completely exhaust myself, aggravate a nearby participant, and ended with Opel asking if her daughter had the note that she was holding in her hand. Despite numerous attempts to clarify the purpose of the note for her, Opel was not reassured by the note, but rather shifted her attention to the origins of it.

The next example shows how staff must attempt to deal with the problem of abandonment fears carefully, or risk exacerbating the problem.

Three staff members were all paying particular attention to my conversation with Ellen after lunch. All three women begin talking to Ellen in different turns, and Ellen, who usually only has to interact in simple, turn-taking styles, gets understandably angry, then confused. One of the staff members tells me that she is going to try and give her “nice thoughts” to distract her. She asks Ellen if she would like a hand massage. Ellen says that she doesn’t want a damn thing, and that all of them are hateful. “I just don’t like any of you!”

On this occasion, Ellen’s contempt for the three staff members lasted for most of the rest of her day at the center. After the episode above was over, Ellen was calmed by a volunteer, who simply agreed with Ellen’s remarks that the staff was treating her badly. Ellen befriended this volunteer, and spent most of the rest of the day with her.

Effects of Abandonment Fears on Other Participants

The participants with dementia who frequently expressed abandonment fears comprised a small number of the total number of participants at the center. The other participants reacted in different ways to Ellen and Opel’s near constant requests. Some participants tried to reassure them, others ignored them, and some were understandably frustrated. The following examples, taken from my observation notes, illustrate the various responses that different participants had to Ellen and Opel’s behavior.

Ellen asks a new participant, Mark, about going home and I hear a loud and angry “I don’t know!” Ellen does not recoil from this, but rather just goes on talking. “Well, I don’t know either and I’m just very upset.”

Some of the other participants are acutely aware of Ellen and Opel’s condition. Lara tells me “I think the biggest problem here is confusion. I’ve tried to befriend some of the people here and they ask me, “How did I get here?” and “Why am I here?” That’s a hard question to answer.

I ask Becky if she is tired. She points to Opel, and says, “If this wouldn’t tire you out, I don’t know what would!”

Arnold asks me, “Is Ellen making sense today?” I tell him that she isn’t making much, that she’s afraid again. He says, “I think she’s afraid of someone leaving her here.”

Today, another participant speaks about Opel’s worried nature. Marvin tells me, “She’ll ask the same thing over and over. She’ll get up and leave soon (laughs). Poor little thing. She’s just confused.”

From my observations it appeared that there was a clear, consistent pattern regarding how Ellen and Opel’s constant questions affected the participants. Participants who were close in proximity to the two women (e.g., sitting at their table for the entire day) were more likely to become frustrated at their constant questioning. Some participants even left the table because they tired of hearing the same questions. Meanwhile, participants at other tables or chairs who were involved in other activities (e.g., rummy or television watching) often were unaffected by the behavior.

In my interviews with staff members, I asked them what effects, if any, Ellen and Opel’s behavior had on other participants. The following two examples show the difference in opinion on this issue. In the following example, staff member number four discusses whether Ellen and Opel’s repetitive questions bother the other participants at the day care center.

I don’t think that it [repetitive questions] does, because you have some participants like Lara and Becky who try themselves to reassure them, because they know themselves they’re going home. They know nobody stays here, so they try to reassure those participants that they are going home too. They tell them, “Your son or daughter will be here to get you. Mine’s coming to get me, yours is coming to get you.” In a way I think it’s helpful for the ones who do know, because they can help you also.

Not every staff member held this symbiotic view of other participants being glad to assist staff in calming Ellen and Opel. In the following example, staff member five portrays the interaction more as I perceived it.

It [repetitive questions] annoys a lot of them. Especially if they’re sitting close by, asking them questions. You can see a little annoyance on the ones that know when they’re going. Becky, it annoys her when they ask “What time am I going home?”

She'll get annoyed and say, "You going home. You know they're coming back after you." She'll get mad and turn around. That's about the only one I see that it annoys.

In these two statements, the two staff members almost seem to be describing two different situations. Staff member four implies that Becky likes to reassure Opel and Ellen, while staff member five sees a totally different, and more negative interaction. Having spent much time around Becky, I believe that she was consistently annoyed by Opel's questions. I routinely saw her react in a manner consistent with what staff member five said.

Staff Members' Perceptions of Abandonment Fears

In this section, I discuss how staff members dealt with and interpreted abandonment fears in their day-to-day work with the participants. Using data from the staff interviews, I begin this section by examining how staff coped with such a persistent problem. I then describe the staff members' feelings of dealing effectively with the problem. I close the section with a discussion of the staff hypotheses about the importance (or lack thereof) of frequent attendance for Ellen and Opel.

Coping Strategies

I learned that staff members often addressed participant fears initially by what I call "reassurance by fact." As the day went on, the staff changed their approach and were more likely to use the strategy of redirection. The first few times that participants asked questions about going home, I usually saw the staff try to reassure them by telling them that they would get to go home at a certain time, or who was taking them. In later queries about going home, the staff members were more likely to try to divert the participant's attention to a different matter. My observations concerning redirection were supported by the following staff remarks.

S1: We usually will try to keep them in the dining room or start an activity so their minds won't be on that [going home].

S3: Most of them, you tell them something you like that they have on, and they are so busy with "Thank you, thank you very much" that for the moment they forget about going home.

Perceived Efficacy

As persistent as the abandonment fears were with Ellen and Opel, staff efficacy became an interesting issue. It appeared impossible to extinguish these fears entirely, thus making success with dealing with the problem a subjective matter. Staff members talked about their own perceived efficacy of dealing with the problem.

S4: It [Redirecting participant's attention] usually works every time, except 10 minutes later they're back with the same question. And we just redirect them in another way. I see that daily.

S3: I think on some of them it [redirection] works for maybe 10 minutes, until they think about what they were thinking about. . . It's almost like they have a one track mind. That's all they think about when they get it on their minds.

Wayne: Do you think anything can reassure them long term?

S6: No. With their disease, no. It goes back to the forgetfulness. They've forgot they even asked. They can ask you one minute. . . They are forgetting that they asked you five minutes, a minute ago. They don't remember.

In the first two of these remarks, the staff members' use of redirection is portrayed as having a temporary positive effect on the behaviors, but they know that the return of the questions is imminent. Staff member six sees the disease's impact on short-term memory as key to the problem, and therefore, insurmountable.

Frequency of Attendance Theories

One particularly salient aspect of abandonment fears that emerged from the data was the possibility that Ellen and Opel's infrequent attendance at the center contributed to their fears. Because they were in this setting only one day out of seven, their day at the center was anything but routine for Ellen and Opel. Several staff members expressed similar views on whether or not Ellen and Opel's sporadic attendance played a part in their abandonment fears.

S1: . . .they [Ellen and Opel] don't really understand why they're here, once or twice, or what is really happening. I feel like if they came on a regular basis that they would get acquainted with people here, look forward to seeing other little ladies that they associate with here. . . They come so little that it's scary to them that they're coming here. In a week's time they come here two days a week. Those other three days, we might have gotten five different people, and they don't recognize those faces.

S2: I think coming once a week does not do her [Opel] any justice. I'm not saying that it harms her, but if she came more often, it would make her more relaxed. . . The experience from other participants, newer ones like Sally, who when she first came was always asking to go home. We informed the family that she should come more often, and now she doesn't have a problem. She likes coming.

S3: Sporadically, [attendance at the center], it does them no good at all, I think. At that level, I think that we are more of a babysitting than a helping thing. Because they're not getting any benefit at all. Their whole day is, "Why am I here? Again?" Spin around looking to go back to where they are familiar.

Other staff members did not believe that more frequent attendance would make a difference for these women. These staff members seemed to place more importance on the stage of the disease that the participants were in, rather than the nature of their environment.

S4: It [more frequent attendance] wouldn't even matter. Ellen is just at that stage, where...

Wayne: You think she's just too far gone?

S4: Too far gone. Opel is so used to her daughter now. It wouldn't even matter for either one how many days they brought them. They couldn't relate to it.

Wayne: Do you think that if Ellen and Opel came more often it would help?

S5: I think it would be worse. Because they would be in here every day and it is going to get to the point where they don't remember a lot of things. They don't remember, "Hey, I come in here every day." I think it would be worse.

Attachment Theory and Caregiver Insights

Interviews with Ellen and Opel's primary caregivers (in both instances, daughters) were insightful in gaining a brief life history that included important attachments in the women's lives. Although the attachment questionnaire used was a simple three paragraph tool, researchers have found that caregiver assessments of their care recipients' premorbid personality have acceptable reliability and validity (Siegler, Dawson, & Welsh, 1994). I used the questionnaire to supplement my observation data and test my hypothesis that both women had insecure attachment styles.

Ellen: Answers in the Past?

Ellen's daughter, Karen, revealed to me that Ellen grew up in an orphanage. Ellen's mother died from pneumonia when Ellen was very young (age not known). Her father "decided that he didn't know how to take care of the kids" and sent her and her brother and sister to an orphanage. In a very real way, Ellen was abandoned by her parents at a young age. Without a mother or father to depend on, Ellen formed a close relationship to her sister. Her brother was killed in World War II.

When I asked about Ellen's marriage, I learned that she was still with her first husband, whom she married in 1940. Karen told me of many difficulties that their marriage endured.

It's so hard to say...What do I know about their marriage? I assumed they were okay, but who knows? They seemed to be affectionate a lot of the time. They didn't argue a lot because my father doesn't. He worked really hard and was out of town a lot. It seemed that they didn't have that good a time. . . Once I got older, I would look at them and think, "Why are these people together? What do they have in common? What do they enjoy together? Almost nothing, besides bridge."

Karen also spoke of recent troubles before Ellen and her husband were both afflicted with dementia.

He [her husband] worked a lot, management type, and he retired kind of early and he didn't have enough interests. He'd play golf. And he started drinking. That was what he did for something to do. It got awful and she was so angry at him. Whether he was drunk or not drunk, she'd be on him.

Karen classified herself and Ellen as having avoidant attachment according (Hazan & Shaver, 1987). In avoidant individuals, attachment behaviors are normally suppressed and caregivers are distrusted (Ainsworth, Blehar, Walters, & Wall, 1978). This pattern of behavior fit Ellen's profile at the center. Ellen was distrustful of staff, seldom accepting their reassurances that she would get to go home. Ellen instead chose to deal with the problem herself, although she would recruit Opel to assist her in finding "a way out." Persons with an avoidant attachment

style often exhibit defensiveness, compulsive self-reliance, and hostility (Magai & Passman, 1997), all of which Ellen exhibited at some point during the observation period. Although Ellen showed a definite preference to be with Opel, I believe that Ellen's recruiting of Opel should not be seen as being dependent. She never looked to Opel as a leader, but rather seemed to like being Opel's "boss."

Opel: Security lost?

In the following interview excerpt, Opel's daughter, Amy, described her mother's relationship with her husband, who is now deceased.

My dad was a very dominating person and mother catered to everything. Then he had eye problems where he couldn't drive, but that didn't slow him down from wanting to go when and where he wanted to. She would drop everything she was doing and she catered to him. This was her life...I think he made her life very insecure, where she became dependent and I think that's what she needs now. That's what she never outgrew, never changed.

Surprisingly, Amy described her mother and herself as having a secure attachment style. I expected her to select the description of ambivalent attachment for Opel. Persons with ambivalent attachment are more likely to display the kind of anxiety and depression that Opel would frequently exhibit at the center. I never witnessed any sort of behavior from Opel which indicated secure attachment. Persons with secure attachment should have few if any abandonment fears, and should be easy to reassure when concerned (Sadavoy ref). This description does not fit at all with how I saw Opel act at the day care center.

"Home"

Ellen and Opel most often expressed their abandonment fears in terms relating to going "home". I was interested in examining if their use of "home" was simply the geographic location where they lived, or if "home" actually was a representation of peace and comfort to them. Zingmark, Norberg, and Sandman (1995) found that people from age 2 to 102 attributed several dimensions to "being at home" that went beyond simple geographic location: safety, rootedness, harmony, togetherness, recognition and freedom were just a few of these. Ellen and Opel's dementia-related deficiencies in these areas make it quite possible that their expressions

for “home” are in fact expressions of their discomfort in their current location and desire for a more peaceful state of mind, which may or may not be attainable with a change of environment.

In the interview with Opel’s daughter, Amy, I asked her if Opel ever talked of “going home” when she actually was at home with Amy. Amy’s response is evidence that persons with dementia may be trying to say something more than the content of their questions would indicate.

Yes. “When am I going home?” I explain to her that her home is with me now.

The majority of the time, she’ll say, “Good.” But there’s always that fear of being by herself, I think. Insecurity is what I keep going back to.

Amy’s description of her mother’s behavior at home showed the intense desire that Opel has to be near her daughter. Even at “home,” Opel is apparently not calm, and still desires to be with her caregiver.

She doesn’t want me to leave her. She wants me with her every minute. I can’t get up to leave the room to do anything myself. She doesn’t. Two minutes, two minutes by herself, total. At night, when I put her to bed, it’s, “Who’s going to sleep with me? Am I going to have to go in there and sleep by myself?” She doesn’t want to go to bed unless I go to bed.

Ellen’s daughter Karen responded in a like manner when I asked her if Ellen ever talked about home when she was at home.

Yes. And often says that she’s going home. It starts when she’s unhappy about something. If we’re not doing exactly what she wants, she’ll say, “I’m going home.”

Chapter Summary

Abandonment fears were most frequently expressed as repetitive questions. For Ellen and Opel, the extent of their fears made personal development at the day care virtually impossible. Participants who exhibited abandonment fears seemed to do so for two reasons: confusion about their present context, and barriers to caregiver access. Participants who were anxious sometimes “recruited” another worried participant to be with while searching for a way

“home,” which may actually translate to a calmer, more peaceful state of mind for the person with dementia.

Chapter V. Conclusions and Implications

This study was based upon my observation of participants and interviews with staff members and family caregivers at the Salem VA adult day care center. Using symbolic interactionism and attachment theory, I begin this chapter by discussing the found effects of abandonment fears on the participants at the center, the center staff, and Ellen and Opel’s caregivers. I then summarize the staff’s method for dealing with the two womens’ fears and discuss possible alternative methods of dealing with the problem that my research inspired. I end the chapter by addresssing the limitations of the study and providing suggestions and direction for future researchers and practitioners concerning the topic of abandonment fears.

Impact of Abandonment Fears

As I expected, the phenomenon of abandonment fears influenced every group involved in my study. For Ellen and Opel, their fears limited their social interaction with the other participants at the center. There was no social group that they could join that provided a sense of “togetherness” that adult day care centers must strive to cultivate (Williams & Roberts, 1995).

It was striking to see the difference between a day at the center for Ellen or Opel and a day at the center for most of the other participants. While most participants participated in either staff directed activities or their own group activity, Ellen and Opel steadfastly refused to participate in any group activity. Ironically, their only social group was a tragicomic pairing that validated and amplified each other’s groundless fears. However, to these two women, their fears were very real and of paramount importance. Other participants were annoyed at the constant questions, perhaps even fearing (whether for a reason or not) that they might one day be in the same fearful state. For me, as a 24 year old, I can say that the prospect of living in the kind of psychic anguish that Ellen and Opel endured was a disconcerting prospect. For individuals of a similar age who find themselves in the same environment, distancing oneself from someone like Ellen or Opel may be seen as a normal coping mechanism (Lazarus & Folkman, 1984).

For Ellen and Opel’s caregivers, their care recipients’ fears created much distress. Ellen’s daughter had tried unsuccessfully to place Ellen in several other respite facilities, with no success. Staff members informed me that Ellen became extremely distressed at other respite facilities as well as at the Salem VA. As of this writing, Ellen herself has not been at the Salem VA adult day care center in over a month. Opel’s daughter, Amy, spoke about how Opel insists on being with her at all times. For example, Amy informed me that the only reason that she had not attended caregiver support meetings was that she did not want to leave her husband with her mother, who would be agitated and fearful in her absence.

Staff Methods for Dealing with Abandonment Fears

Staff members seemed somewhat resigned to Ellen’s and Opel’s fears. This phenomenon poses a unique problem to staff members. What constitutes success in dealing with these fears? After observing the phenomenon and listening to staff interviews, it seems unreasonable to

expect any “silver bullet” to appear which consistently erases this intense fear for all participants who are worried about going home. Indeed, it is possible that there is no solace to be found once the disease has progressed to a certain stage in some individuals.

Staff members were coping with participants’ abandonment fears long before I began my observation at the day care center. Two methods of dealing with the repetitive questions voiced by Ellen and Opel were prominent in the observation and interview data. The first strategy was to simply state the factual answer to the participants’ questions. This was what I called “reassurance by fact.” It should be noted here that two staff members could (and did) answer the same question in a different way using this method. For instance, when asked “When do I get to go home?”, staff member one might answer “At four o’clock,” whereas staff member two might answer, “After the bingo game,” or “When Karen gets done with her shopping.” The other method, almost uniformly cited by staff as the preferred way of dealing with the problem, was to redirect the participants, diverting their attention. During my observation, I felt that staff members utilized the first method more frequently, although there was a tendency for them to switch and use the second method in the late afternoons.

Although Opel’s daughter Amy surprisingly classified her mother’s attachment style as secure, the hypothesis still remains that persons with insecure attachment styles, formed long before they were diagnosed with Alzheimer’s, are more likely to suffer from these kinds of fears and subsequent behavioral problems. Opel’s daughter answered the attachment questionnaire based on her own perceptions of her mother’s attachments. Her perception may not be congruent with the actual attachment style that best fit Opel’s premorbid personality. Another possibility is that persons with secure attachment styles can also experience these fears in dementia. Opel’s daughter made several comments vacillating between the secure and insecure styles before picking the secure attachment style. Comments made then also indicated that she seemed to be placing a much larger weight on Opel’s past relationships with church friends and non-relatives than on her turbulent-sounding marriage.

Limitations of this Study

This research was not without limitations. As a participant observer, I could only write down a small portion of the total activity at the center. Videorecording of the events would have

provided for a more complete picture of the various activities at the center. With video footage, more than one group of persons could be accounted for at any given time. Contextual precedents to repetitive questions and other displays of abandonment fears could be better analyzed. However, researchers using this technique may learn that finding a site and caregivers willing to comply with such an invasive procedure would be difficult.

A separate problem that I encountered had to do with my role at the center as a participant observer. Although my focus quickly turned to Ellen and Opel, I became friends with many of the different participants at the center, and would not have wanted it any other way. There were occasions, however, that these friendships prevented me from gaining more data on Ellen and Opel. It is not easy or even possible to play a game of rummy while conversing with the other players and keep notes on a wandering Ellen. Often, I would politely disengage myself from conversations with other participants to observe Ellen or Opel for a while, but there were potentially numerous conversational vignettes representative of abandonment fears which I may have failed to record.

Lastly, my observations took place over a fairly short period of time, lasting approximately a month. Documentation of a probable progression of these fears with longitudinal data was not possible. Whether or not these fears intensify over a period of time in individuals at day care centers was not examined, and would be a useful piece of information for practitioners, who could try interventions earlier to try to halt the escalation of fears.

Implications for Practitioners

My research points to at least three issues that practitioners need to address concerning abandonment fears. First, the severity of the problem requires that staff members are innovative and persistent in devising new methods of dealing with the problem for different participants. In staff meetings, the efficacy or inefficacy of different methods needs to be addressed.

Second, staff members need to evaluate more closely the nature of the different participant-participant interactions at the adult day care center. It was surprising to me that some staff members actually saw Ellen and Opel's interaction as a positive for either participant. The recruiting phenomenon showed the harmful effects that Ellen had on Opel. Interactions need to be assessed for quality, and not quantity.

Last, administrators at adult day care centers would do well to require regular attendance by participants with such fears, at least in their first days in an unfamiliar environment. Hopefully, this period of time could acclimate the participant to the center. With Ellen and Opel, neither participant had ever attended more than twice a week, so the importance of frequency of attendance was an unknown variable.

Implications for Future Research

I believe that the greatest contribution of this study may not necessarily be in the descriptive findings themselves, but instead might lie in the many questions that were raised throughout the course of my observations and interviews. Ellen and Opel's infrequent attendance at the center may have been related to their abandonment fears. Neither participant ever came to the center on a consistent basis more than twice a week. Even participants who did not have dementia talked to me about initial confusion in their first few days or weeks at the center. A larger study that compared abandonment fears in groups that attended the center regularly versus groups that did not attend regularly could learn more about the importance of regular attendance.

In this exploratory study, I did not formulate any interventions to reduce Ellen and Opel's constant questioning. Studies assessing the efficacy of various interventions are needed. Ideas from staff, relevant literature, and from family caregivers can all be utilized and quantitatively tested. From my study, one possible intervention to examine is benevolent deception. Telling Opel that I had recently spoke with her daughter on the phone seemed to calm her more than simple "reassurance by fact." The pragmatism and relief generated here seemed to offset ethical concerns.

Another method that would be useful to employ would be to try to instill confidence in the person's own abilities. I did not observe the staff members at the Salem VA ever trying to engage either of these women in any sort of empowering way. From an attachment standpoint, Ellen and Opel are anxious because they are separated from someone they perceive as more competent. I believe that neither of these women trusts their own minds. I found that Opel could often answer her own questions, but did not trust her own mind. For instance, I would sometimes answer Opel's question, "When do I get to go home?" by telling her that I had recently answered the question and that I knew she could remember it. When I asked her,

roughly half the time, she would give the correct answer. I would usually then compliment her on her memory, and tell her that she needed to trust herself. I believe that it is certainly possible that interventions with this goal in mind might lead to a decrease in “exaggerated helplessness” behaviors (Breslau, 1987). From a symbolic interactionist standpoint, the self that is created through interaction with others at the day care center is a helpless self. With the loss of memory implicit in Alzheimer’s disease, the self becomes even more of a temporal creation, shifting with emotional changes, and in Ellen and Opel’s case, emotional distress. By fostering a sense of competence in these women, I hope that adult day care can offer them benefits that other participants reap.

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Appendix A: Adult Day Care Staff Interview Questions

1. In my fieldwork at the center, I have noticed that some participants repeatedly become anxious in the afternoon about going home. Describe for me how you deal with their anxiety. How effective do you believe your methods are for calming them?
2. What do you think are the primary causes of these fears?
3. Why do you think that some of the participants have these fears, while others don't?
4. In the short time that I have observed here at the center, I have seen you deal with these fears by _____. Have you tried other methods to calm the participants in the past, or do you have any plans to try different strategies in the future?

Appendix B: Caregiver Questions

1. How does (care recipient's name) talk of "home"? Does he/she ever refer to "home" as a place besides where he/she resides?
2. Tell me about an instance where (care recipient's name) tried to leave the house in order to go "home"? How often does this occur?
3. Tell me a bit about (care recipient's name)'s earlier relationships with others, before he/she became ill? I would like to know about relationships that he/she had that were the most important (e.g., spouse, children, others).
4. As an adult, who would you say that (care recipient's name) consistently relied on for a sustained period of time, emotionally? Tell me about that relationship, and about that other person?

Appendix C

Attachment Profile Questionnaire (Hazan & Shaver, 1987)

1. I am going to read to you three different paragraphs that describe different kinds of personalities. I will then give you note cards with each of the three descriptions. I would like for you to pick which one of these paragraphs best describes (care recipient's name) before he/she became ill.

A. I find it relatively easy to get close to others and am comfortable depending on them and having them depend on me. I don't often worry about being abandoned or about someone getting too close to me.

B. I am somewhat uncomfortable being close to others; I find it difficult to trust them completely, difficult to allow myself to depend on them. I am nervous when anyone gets too close, and often, love partners want me to be more intimate than I feel comfortable being.

C. I find that others are reluctant to get as close as I would like. I often worry that my partner doesn't really love me or won't want to stay with me. I want to merge completely with another person, and this desire sometimes scares people away.

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