

IDENTITY WORK IN INDIVIDUALS WITH EARLY ALZHEIMER'S DISEASE

By

SUSAN LEGER-KRALL

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL  
OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT  
OF THE REQUIREMENTS FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2001

Copyright 2001

by

Susan Leger-Krall

SOUTH YOUTH  
PARCHMENT DEED  
NEW COTTON FIBER

## ACKNOWLEDGMENTS

I owe thanks to many people for their assistance and encouragement in the completion of this undertaking. First, I thank Bill, my husband and friend, who has always given his quiet and undivided support to all of my endeavors. I also thank Lillian, my mother-in-law, who was the best teacher in how to live with Alzheimer's Disease. I am also truly grateful to the individuals with EAD who opened up their very private lives to me and shared their fears and hopes for their future.

I thank my committee members, Dr. Karolyn Godbey, Dr. Claydell Horne and Dr. Jaber Gubrium. I appreciate their continued guidance and input during this lengthy process. I especially wish to thank Dr. Sally Hutchinson, whose encouragement and support gave me the confidence to complete this project, and whose especially keen and scholarly insight offered direction in an uncharted field of discovery.

## TABLE OF CONTENTS

	<u>page</u>
ACKNOWLEDGMENTS.....	iii
ABSTRACT .....	vi
 CHAPTERS	
1 INTRODUCTION.....	1
Purpose of Study .....	3
Significance of the Study for Nursing.....	4
2 REVIEW OF LITERATURE .....	5
Theoretical Perspective .....	5
Perspectives on early AD .....	7
Self .....	7
Biomedical Focus and AD.....	9
Sociogenic Focus and AD .....	11
Early AD Experience .....	14
Intervention Focus.....	25
Summary.....	25
3 METHODOLOGY.....	27
Research Approach .....	27
Setting .....	29
Sample .....	29
Theoretical Sampling .....	31
Protection of Human Subjects .....	32
Data Collection .....	35
Data Analysis .....	36
Scientific Rigor .....	39
4 IDENTITY WORK IN EARLY AD .....	43
Open Awareness Context – A Condition for Identity Work .....	45
Stages of Identity Work .....	49
Explanatory Work.....	49
Recognition Work .....	52
Conditions for Recognition work.....	53
Diagnostic barriers to Recognition work.....	61
Social psychological consequences of Recognition work....	66

	Summary .....	68
5	DISCLOSURE.....	69
	Nondisclosure – Maintaining Secrecy to Save Face .....	71
	Selective Disclosure – Assistance From Others .....	79
	Forced Disclosure – Increased Disruption and Exposure .....	83
	Summary.....	94
6	CONFIRMATION WORK .....	96
	Accounts of Confirmation Work .....	98
	Outcomes of Acceptance and Confirmation.....	104
	Confirmation Work and Open Awareness Context .....	107
	Summary.....	110
7	SUMMARY AND IMPLICATIONS .....	111
	Summary .....	111
	Recommendations for Practice .....	113
	Recommendations for Research .....	119
8	APPENDIX.....	121
	A: SUBJECT INTERVIEW GUIDE .....	121
	B: DEMOGRAPHIC FORM.....	122
	C: FUNCTIONAL ACTIVITIES QUESTIONNAIRE .....	123
	D: PHYSICIAN INTERVIEW GUIDE .....	124
	E: CONSENT TO PARTICIPATE IN RESEARCH (Patient).....	125
	F: CONSENT TO PARTICIPATE IN RESEARCH (Physician).....	128
9	REFERENCES .....	131
10	BIOGRAPHICAL SKETCH.....	141

Abstract of Dissertation Presented to the Graduate School  
of the University of Florida in Partial Fulfillment of the  
Requirements for the Degree of Doctor of Philosophy

IDENTITY WORK IN INDIVIDUALS WITH EARLY ALZHEIMER'S DISEASE

By

Susan Leger-Krall

December 2001

Chairman: Sally A. Hutchinson  
Major Department: Nursing

Persons with early Alzheimer's Disease (EAD) are willing and able to share their experience of early memory loss (EML) but are rarely asked to participate in the research process. The focus of this qualitative grounded theory study was an attempt to capture the experience of memory loss from the perspective of the person with EML. A purposive convenience sample of 18 participants with early memory loss was interviewed, and data were transcribed and coded according to Glaser's constant comparative method. The grounded theory approach allowed for insight into participants' experience as their awareness of their memory loss developed, and for the identification of the basic social processes that participants used to deal with their changing self identity. Identity work emerged as the core process that participants with EML experienced along an EAD trajectory that included the stages of explanatory work, recognition work, disclosure work and confirmation work. An Open awareness context, in which the EAD was discussed, was essential to identity work. Recommendations for practice include encouraging health professionals to dialogue with the person with EML early in their AD course, in order to allow the process of identity work to occur. The offering of supportive

services such as EML participant groups for education and group support, and the inclusion of family members and caregivers in these efforts, should assist people in moving through the stages of identity work. The substantive theory of Identity work in EAD should contribute to an improved awareness and sensitivity of nurses and other health professionals towards persons with EML. Nursing interventions based on the theory will assist in improving the quality of care to this population.

## CHAPTER 1 INTRODUCTION

The pain of the mind is worse than  
the pain of the body. – Syrus

Dementia is the most common cause of mental impairment in older persons, with Alzheimer's Disease (AD) accounting for most of the dementia diagnoses (Loreck, Bylsma & Folstein, 1994; U.S. Department of Health and Human Services, 1996). Dementia is a syndrome or group of symptoms caused by a specific problem, and Alzheimer's is just one of the many types of dementia. The recognition of dementia as a major health and social problem in this country can be traced back to the late 1970s, and is most directly attributable to an increase in the growth of the elderly population (especially the over - 80 age group), and changing family support patterns, particularly the increase in the employment of the traditional female caregiver (Gilhooly & Birren, 1986; Bould, Sanborn & Reif, 1989; Corcoran, 1993). The perception of AD as a major health problem is due to the progressive pattern of irreversible and degenerative brain loss seen in the disease, resulting in loss of cognition, memory and eventually, loss of everyday living skills. Alzheimer's dementia is the fourth leading cause of death in adults, after heart disease, cancer and stroke (Alzheimer's Disease Association, 2001).

Burden, devastation, and fear of the future are common descriptors pervasive in the AD literature, and connote loss and decline for the person and their caregiver experiencing this problem. These descriptors are similar to those used for many years in the gerontological literature to describe the aging experience. Gubrium (1986) stated that

those working with AD often function from a diagnostic frame of reference, and the person with AD is viewed as a diseased person. Lyman (1993) shared these concerns, stating that the major body of knowledge currently available about AD is framed from the biomedical perspective, with many assumptions about the behavioral problems of people with dementia. Because of this prevalent view, clinicians and caregivers may begin to treat the person with AD as ill and incompetent once the diagnosis is made, unable to focus on the strengths and abilities that can still remain throughout the long course of the illness.

Jaffe and Miller (1994) lamented that although many AD studies focus on service delivery systems and methods to improve memory and cognition, the voice of the individual with the disease is conspicuously absent. Already marginalized in society because they are elderly, persons with AD are further ignored because of preconceived ideas about their inability to interact and share their world with the researcher. Thus, the world view from the perspective of the person with AD is largely absent, and people with AD are rarely given a voice through the AD literature or research. Cotrell and Schultz (1993) alluded to the patient perspective being ignored in AD research and called for the inclusion of people with EAD as research subjects, since at this stage they are able to contribute to our understanding of the illness and its course. This study is an attempt to fill this significant void. My own experience, and that of others ("Groups offer support", 1995; Cohen, 1991) indicates that persons with early AD are willing and able to talk about early memory loss and how it affects their lives. Dialoging with the person diagnosed early in the AD process places them, as suggested by Zarit and Downs (1999), on "center stage" and locates the "the person back into dementia care" (p.6).

For many experiencing their initial awareness of Alzheimer's dementia, the initial symptoms are usually subtle, but often profound enough to make one aware of a significant functional change (i.e. getting lost in a familiar area, forgetting something of importance, or noting problems with language fluency). For purposes of this study, persons were considered for inclusion if one of their current symptoms was early memory loss (EML), with the memory loss due to probable AD or any related disorder (based on the Alzheimer's Association criteria including dementias occurring from AD and other related disorders such as vascular disorders or Parkinson's disease. The emphasis was on self awareness of the early memory loss. The inclusion criteria were that the person with the EML received an initial diagnosis of probable Early Alzheimer's Disease (EAD) from their physician, and possessed a basic desire and ability to share the experience concerning his/her change in memory functioning.

#### Purpose of Study

This qualitative study was an attempt to elicit the heretofore silent voices of persons with EML due to probable early AD, and to co-create the meaning of their world, with the person as an active participant in the research process. The research focused on how individuals experiencing EML lived with the changes occurring in their lives, including how they interacted with others. The aim was the generation of a substantive theory through the use of the grounded theory method. To meet the aim of the research, individuals had to be willing and able to admit that they had EML, know that it was due to probable EAD, and agree to dialogue with me regarding these changes. The goal was to discover the basic social psychological process that persons with early memory loss experienced as they become aware of losing their connection with the world.

The research questions were (1) what is the basic social psychological process (BSPP) experienced by persons with early memory loss, (2) what contextual conditions influence the experience of early memory loss, (3) what are the consequences of early memory loss for the diagnosed person, and (4) what are the social structural problems that early memory loss clients experience with this diagnosis.

#### Significance of the Study for Nursing

The goal of qualitative research is to understand life by taking into account meaning, the interpretive processes of people, and the contexts in which these processes occur (Jaffe & Miller, 1994). This emic approach, emphasizing the view of the participant, is the hallmark of the qualitative researcher. By attempting to enter the world of the people being investigated, we can gain a better understanding of their situation. The naturalistic field work approach and qualitative data collection methods used in this study allowed me, the nurse researcher, to enter the world of the person with EML, in order to gain an authentic perspective from the client. By better understanding the experience of persons with EML, nurses can appreciate their concerns, appropriately identify their needs, and develop strategies to support them in the most appropriate environment.

## CHAPTER 2 REVIEW OF THE LITERATURE

This literature review presents an overview of symbolic interactionism (SI), the theoretical framework for the grounded theory method, and its relationship to this study. The concept of the self as viewed from the SI tradition is discussed, especially the changing self as experienced by the person with EML. The biomedical and sociogenic-focused literature on AD is reviewed, as is the subject of EML from the perspective of an early AD diagnosis, since it is in this stage of AD that a person becomes aware of the primary symptom of memory loss.

Various texts, papers, ethnographies and narrative analyses were also reviewed for their theoretical application to this subject area. As the grounded theory method suggests, the secondary literature review was done at the time that the emergent core categories presented themselves, and provided direction to an area of focus (Glaser, 1978). The initial review served to sensitize me to applicable concepts, and also served as a basis for identifying the significance of the knowledge gap in this substantive area.

### Theoretical Perspective

This study aimed to develop a substantive grounded theory about the experience of people with EML. Each research method is linked to a philosophical perspective, and symbolic interactionism (SI) provides the philosophical foundation for grounded theory and guides the research questions, interview questions, data collection strategies and data analysis (Hutchinson, 1993). There are many variants of the SI perspective; the largest

and best known of these is from the (University of) Chicago school, and articulated by Herbert Blumer (Reynolds, 1994).

Blumer's (1969) version of SI is based on three basic premises:

- "Human beings act toward things on the basis of the meanings that things have for them" (p. 2). Things can be physical objects, other human beings, institutions, ideals, activities, and any situation encountered in daily life. Traditional social-psychological science discounts these meanings, and relates behaviors to outside factors (such as stimuli, attitudes, motives or roles) rather than viewing the meaning of things as central.
- "The meaning of such things arises out of the social interaction that one has with one's fellows" (p. 2); meaning is not intrinsic to the object or a result of psychological manipulation. Real meaning arises through the process of interaction between people.
- "These meanings...are modified through an interpretive process used by the person in dealing with things he encounters" (p. 2); the person communicates with the self in order to modify or alter the meaning of objects.

Symbolic interactionism is a social-psychological theory of social action. The central organizing concepts of the SI theory are "the self, the world, and social action" (Bowers, 1989, p.36). Since the self and the world are socially constructed, and ever changing through the process of social interaction, they can only be understood within the context of social interaction (Hutchinson, 1993). Symbolic interaction suggests that people order their world by interpreting and eliciting the meanings in situations, rather than simply reacting (Morse, 1994).

By directly talking with the person with early memory loss about their experience with this phenomena, the researcher can tap directly into the person with AD's "lived experience" and attempt to find what is central to the early memory loss experience. Coenen (1991) discovered that through the use of a qualitative method (phenomenology) and a fieldwork approach with roots in the SI perspective, he was able to locate meaning and logic within the world of the demented elderly, and discover "relevance for both

theory and everyday social relations and practice" (p.316). Maines (writing in the forward to Gubrium's 1993 Speaking of Life) reminds us that..."people are creatures who communicate through symbols, and are part of the very environments they create, and their essence rests in a selved, ongoing and always partially formed intersubjectivity" (p.xii).

Because qualitative researchers attempt to understand the world from the perspective of the research subjects, this is best done by the use of a research method that will allow them direct access to this perspective. The grounded theory method provides a mode for eliciting these meanings and for describing the social and psychological processes that people use to make sense of their world (Morse, 1992). Through the process of interaction with persons with early memory loss, I gained access to how individuals with early memory loss make sense of the life changes they were experiencing.

### Perspectives on Early AD

#### Self

George Herbert Mead, from the Chicago school and a mentor to Blumer, is considered by many to be the founding father of the S.I. tradition. He developed the theory that human society is composed of persons with selves, and these selves can only be developed within an interacting, communicating society. He conceptualized the self as a social process involving two distinguishable phases known as the "I" and the "me" (Reynolds, 1990). The "me" acts as the object of self-reflection, the "I" acts as the reflector. The "me" can be identified, talked about and defined to others, and each person is composed of multiple "me's" (i.e. mother, student, nurse). The "I" interacts dynamically to interpret the environmental cues and relate them to the "me's." This interpretive

process of the "I" shows the creation of the self to be a process (Bowers, 1988). Thus, the self is shown to be socially constructed, is processual, and it is this social self that becomes the object of research.

This social sense of self is integral to the process of SI, a self that can search and test others' interpretations of their actions (Gubrium, Holstein & Buckholdt, 1994). This understanding implies that one possesses the ability to engage in social discourse, interpret the meaning of one's actions, and assess the response of others. Yet, with AD, the ability to engage in meaningful dialogue progressively deteriorates. Some researchers believe it is this cognitive deterioration that ultimately affects and prevents certain forms of discourse, resulting in a loss of connection with others and the eventual loss of self.

Goffman (1959) used a variant of the SI approach, the dramaturgical genre, to explain his theory of social interaction. His premise was that when people interact, they use symbolic devices in an attempt to manage impressions. He used the symbolic metaphor of "life as a performance upon a stage," with the goal of convincing others of the authenticity of one's self by the use of fellow actors, props, and attention being paid to front stage performance. The actor maintains his part (impression management) by careful control of his lines, and avoidance of "unmeant gestures" and "inopportune intrusions" (performance disruption). Goffman's analogies are useful in trying to understand the impact that memory loss has on social relationships, and the great effort that persons with early AD must use in an attempt to preserve their sense of self. As so poignantly expressed by McGowin (1993), a person with early AD who has written of her experience, "life had become an improvisational theater, and I was left to ad lib my way through it" (p. 64).

For a person with an EML, the process of social interaction has the potential to alert both parties to the idea that something is different or wrong. Since meanings arise and are modified through an interpretive process, both parties might respond to this awareness by making a choice; to either deal with or avoid the meaning of the "realized" or "sensed" difference.

Cromwell and Phillips (1995) presented data from a qualitative study on the subjective experience of forgetting. They reviewed the social consequences of forgetting, and suggested specific teaching strategies focused on helping the forgetful elder learn "impression management" techniques (as in Goffman, above). Successful coping was demonstrated by the use of preventive strategies that allowed these elders to maintain their social structures.

#### Biomedical Focus and AD

Starr (1982) traced the growth of the biomedical model of medicine and science that became dominant through the late 19th and early 20th centuries. Many life processes considered "normal" over the span of centuries became "medicalized" and controlled by physicians, including aging and senility. Estes and Binney (1989) criticized this biomedical model for its effect on our perception of aging in this society, specifically the social construction of aging as a medical problem. This social construction of aging as a medical problem emphasizes diseases of the elderly, while often discounting the social and behavioral processes and problems of aging, and the positive and growth possibilities of aging. Health/public policy and research for aging are all greatly influenced by the biomedical model.

Lyman (1989) extends this critique of the biomedicalization of aging to apply to dementia. She feels that the disease/cure mindset obliterates the focus to other areas of dementia research need, such as an assessment of social settings and relationships that are contextual to the patient's functioning. Lyman (1993) examined the social organization of day care and its effect on caregivers and AD clients. She discussed the evolution of the social construction of dementia and how caregivers in the health care system have come to "medicalize" the "disease." In this context, caregivers view the behaviors that AD clients exhibit as deviant, and their response is an attempt to control those behaviors.

Society's preoccupation with defining dementia as an illness was identified by Gubrium in 1986. In his book Oldtimers and Alzheimer's, he argued that it was not always possible to distinguish normal aging from AD. He contends that the effort is one of caregivers (lay and professional) trying to make sense, or attempting to construct order, out of the very disordered situation of AD. By medicalizing AD, caregivers can attempt to bring meaning to their disordered reality. He suggests that the medicalization of AD has given legitimacy and a framework to all efforts in the AD field, especially research and practice.

One of the negative effects resulting from this medicalization construct has been a stigmatization of persons with AD, resulting in limited social opportunities, increased dependency, medical control, and the debasement of the self (Lyman, 1989; Herskovits, 1995). In early AD, one could use passing, covering, and impression management (Goffman, 1963) but these tactics require "cooperation between the stigmatized and the normals"; (p.139) an ability that is thought by some to disappear as the person with AD experiences cognitive decline.

Rather than the typical biomedical approach to studying AD, the sociogenic perspective views the person with EML as a social actor living with an impairment and interacting with others in living situations. Most importantly, this perspective emphasizes the importance of the caregiving environment (both place and personnel) as a place where the early memory loss client acts and interacts versus seeing the illness itself as a modifier of client behavior (Lyman, 1989; Jaffe & Miller, 1994).

### Sociogenic Focus and AD

The sociogenic focus increasingly seen in the literature in the last two decades developed as a reaction to the dominant biomedical focus of aging and AD. Even with this shift in focus, many perspectives exist to describe the experience of self and AD. Most of these viewpoints use an interactionist framework, but differ depending on where they locate the "self." Some feel the self is connected with loss of cognitive skills (Cohen & Eisdorfer, 1986); others see it hidden, unable to be articulated by the person with AD (Gubrium, 1986), and others locate it within one's social interaction skills that maintain (self) identity (Orona, 1990; Charmaz, 1983).

Cohen and Eisdorfer (1986) stated that with the AD diagnosis, clients and their families must come to terms with a disintegration that eventually leads to a total loss of self for the person with AD. Yet, the gradual trajectory that usually occurs with AD implies there still can be a "sense of self" for some time, and that persons with early AD are aware of and can use this "self" in an attempt to cope with the confusing changes that are happening to them. Cohen (1991) described the earlier research (hers and Eisdorfer's) on the subjective experience of persons with AD. They reported six stages of change experienced by patients with dementia, similar to the classic stages of death and dying.

Although organized in a linear fashion, the reactions do not always occur in a step progression, but the framework acknowledged the "self" component. The stages included recognition and concern ("something is wrong with me"); denial ("not me"); anger/guilt/sadness (why me"); coping (in order to go on, I must do"); maturation ("living each day til I die"); and separation from self (p. 8). This sixth stage, the separation from self, can occur much later, and the processual nature of these stages serves to emphasize that insight and ability of persons with AD does persist through the early and middle stages of AD. These authors inform us that with an AD diagnosis, there is an eventual complete loss of self, and yet the essential humanity of the person remains, because "people do not consist of memory alone," they can still touch us through their "feelings, imaginations, desires, drives, will and moral being" (p. 22).

Cromwell's (1994) grounded theory study on the subjective experience of forgetting perceived forgetting as a "personal response...between one's forgetting and one's social world" (p. 445). This interactionist perspective enabled the author to focus on how forgetting affects elders' social relationships, and how these altered relationships affect elders view of the self. The author described how forgetful elders engage in a process of self-assessment, coping and reassessment, with the goal being maintenance of a sense of self.

Kitwood and Bredin (1992) described a philosophy of dementia care that gave centrality to both subjective and intersubjective personhood. Their view of the person with dementia acknowledged the degenerative neurological changes of AD, but then emphasized the importance of including the personal psychology of the person and the social psychology of their environment. Considering each of these constructs as equally

important and interactive resulted in "good care" which was respectful of personhood; while an emphasis on only the physiological decline resulted in a "malignant social psychology" or care that was destructive to personhood. As the person with AD declined neurologically, the increasing importance of supportive others was emphasized. Kitwood (1993) further developed this theory of dementia care through an analysis of interaction with persons with AD. He emphasizes the importance of facilitating communication in a supportive manner, with an emphasis on emotion and feeling states, rather than cognition. The result can be that the person with AD maintains a state of "relative well being." Sabat and Harre (1992) supported this social interactionist framework, which emphasizes the preservation of self through the agency of others. By analyzing the discourse of persons with AD, they were able to show that "self" is maintained late into AD, and our social "selves" can be maintained through the process of social construction with others.

Golander and Raz (1996) argued that because the "I" (social) and "me" (personal) components of self become split in dementia, the conventional SI / SC approach of viewing "self" as interactive is questioned. They found that as the personal aspects of identity were lost, a social identity was often constructed for the patient by family and staff. Gubrium (1986) also noted that families socially constructed a "mind/self" for AD patients. Using Mead's theory of mind/self in his field work with AD patients and their families, he found that as the internal (private) mind/self deteriorated from AD, the caregivers became the agents responsible to preserve the mind/self, to externalize it (socialize it), and to give it voice.

Herskovits' (1995) comprehensive review of the conflicting literature concerning the self and AD yielded several models based on differing frameworks. These included: the self as:

- An internal personal identity, separate from sociality
- An intersubjective public / social project, which can be damaged by stigma / negative social interaction
- An ontological construct, (i.e. the disease defines the person)
- An ongoing linguistic process, understood via narrative processes
- A dynamic interaction between social, individual and biological.

The author noted that none of these models relied on cognitive ability as a location for self, perhaps an indication that we are progressing past the biomedical focus toward a more humanistic perception of the person with AD.

The idea of maintaining a "sense of self" emerged as a predominant theme in Kaufman's (1986) grounded theory study of aging persons and their accounts of the life course. What surfaced was the idea of stressing "self" vs the aging body; or prioritizing and privileging "self" over "body." Her informants did not perceive meaning in aging per se, but in just being a continuation of themselves in old age. She found that when they talked about themselves, they expressed a sense of self that was ageless; they maintained a continuity of self despite physical and social changes in their lives. This sense of continuity and meaning helped them cope with life's changes. This primacy of "sense of self" is what we must be concerned with and emphasize in our approach toward persons with early memory loss. It should be a moral imperative for those of us involved with persons with AD.

### Early AD Experience

The research literature on early AD from the perspective of the person with EML is particularly sparse. One possible reason for this is the problem of accurate assessment.

Early symptoms are quite insidious, and easily hidden behind a veil of well retained social skills. Only when the person with early AD begins to exhibit functional problems related to cognitive and social skills, do others become aware of their deficits.

Keady and Nolan (1994, 1995a, 1995b, 1996) from the United Kingdom developed a nursing research program focused on the early stage of dementia. Their initial studies concentrated on the needs of the informal caregiver for the person with AD; they subsequently interviewed 38 family caregivers, and used these data to develop a model of the dementia experience. Compiling the data into an AD trajectory, they identified separate stages of dementia progression, including slipping, suspecting, covering up, revealing, confirming, surviving, disorganization, decline and death (1994). This caregiver perspective of the early dementia experience was later shared with 10 EAD sufferers, and the authors report that the "model proved robust" (1996), except for the surviving stage, which was changed to a more positive maximizing stage. The authors then interviewed the 10 EAD sufferers, using the grounded theory method, to assess their subjective experience of coping with EAD (1995). The outcome was the development of the Index for Managing Memory Loss (IMMEL) instrument, suggested by the authors to be a useful tool in clinical practice to assess the EAD person's coping strategies. As these authors emphasize, only when we educate health care professionals on the need for an early and accurate diagnosis with AD, will it be possible to intervene to offer appropriate supportive assistance through these treacherous early stages.

#### Early AD: clues to diagnosis

The AD literature has increasingly begun to focus on the experience of early Alzheimer's Disease (EAD), also called mild dementia, as a separate and distinct phase of

the very long and arduous Alzheimer's Disease process. Advantages given for an EAD diagnosis include the opportunity for individuals with AD to have input into their future plans and decisions, and that a yet-to-be-developed curative or stabilizing therapy would be most effective if applied in the early stages (Berg, 1990). Advantages for the family, clinician and society should also be considered, and should include opportunities for increased communication, sharing of correct information and consideration for inclusion in research studies (Doraiswamy, Steffens, Pitchumoni & Tabrizi, 1998). Perhaps the best reason for an early diagnosis is the opportunity for the person with the problem to share their feelings, hopes, fears and desires for the future with their loved ones and their health care practitioners, and perhaps to experience the opportunity to come to an understanding about their changing sense of self.

A major problem with EAD concerns establishing the diagnosis. To further confuse, terms such as age associated memory impairment (AAMI) and mild cognitive impairment (MCI) are sometimes used interchangeably with EAD. There are no universally agreed upon-criteria for early AD, and no standardized methods of detection. Often, the only reported symptom is memory impairment, and this in itself does not allow for a dementia diagnosis. A Mayo-affiliated study identified a group of patients who had forgetfulness beyond that expected for their age, but who did not have AD (Petersen et al. 1999). These patients experienced MCI, with memory being the primary complaint, while other cognitive functions remained stable. These patients did continue to have decline over time, but not as rapid as the patients diagnosed with AD, thus prompting these authors to conclude that MCI is a different entity than either normal aging or AD. Recently, the American Academy of Neurologists (AAN) clarified the dilemma by

updating their practice guidelines for the detection, diagnosis and management of AD. They defined MCI as the clinical state of being memory impaired but otherwise able to function well. While persons with MCI did show deficits beyond normal aging, the AAN did not believe that they meet the criteria for dementia. However, they probably have a higher risk of developing dementia (Alzheimer's Disease and Other Dementias, 2001).

According to the American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> ed. (1994), criteria for dementia include multiple cognitive deficits manifested by both memory impairment (learning new information and recalling previously learned information) and deficits in one or more of the following cognitive areas: aphasia (language problems), apraxia (motor function difficulties), agnosia (recognizing and identifying objects) and higher level functioning (planning, executing, organizing, sequencing). In addition, the person exhibits social or occupational functional problems, and experiences a gradual onset and continuing cognitive decline. Criteria of an early work group of experts, the National Institute of Neurological and Communicative Disorders and Strokes-Alzheimer's Disease and Related Disorders [now called the Alzheimer's Association] (NINCDS-ADRDA) are similar to those of the DSM -IV, including changes in memory and cognitive function, except that they did not include an impairment in social or occupational functioning (McKhann et al. 1984).

The Alzheimer's Association (1995b) stated that their major goal to improve the diagnosis of AD can be assisted by "improving the ease and accuracy of testing for AD" (p.1). Some authors have called for routine screening of the elderly population in order to detect initial cognitive changes; they also stress the need for testing instruments that are disease specific, reliable and valid, and sensitive and specific (Henderson & Huppert,

1984; Storandt & Hill, 1989). Ganguli (1997) advocated screening for dementia as an important public health concern, stating that screening is critical for secondary prevention (early diagnosis and treatment) and for community surveillance and planning for health services. She stressed that objective cognitive testing is the most logical approach to screening for EAD, but also acknowledged the importance of ancillary measures, such as functional assessment scales, and self / family/ significant other reports as useful supplemental information. All authors emphasized that screening tests are only the first step in a diagnostic workup and not diagnostic in themselves, especially since many of the screening tests used for AD/ dementia have not proved sensitive enough to detect the early stages of AD.

A panel of experts, convened by the Agency for Health Care Policy and Research (AHCPR) developed the Guidelines for the Recognition and Initial Assessment of Alzheimer's Disease and Related Disorders (U.S. Department of Health and Human Services, 1996) in order to assist health care practitioners in recognizing early-stage dementias. The AHCPR panel was initially convened to develop a guideline for screening for AD and early dementias, but after exhaustive analysis of the literature on screening tests, they decided the following:

- No evidence existed to use one particular screening test over another
- None of the tests had a high sensitivity for early or mild dementia
- There was no efficacy in using a general screening test for AD given the lack of specific treatment available and the problems with EAD recognition.

Thus, they stated that routine screening for dementia is not warranted. The panel did advocate cognitive and functional assessments as part of the comprehensive diagnostic work-up of persons suspected of having AD. The panel cautioned that brief mental status tests are not diagnostic but that they are useful in developing a multidimensional clinical

picture. When used with other data, they provide a baseline to compare cognitive decline over time, they can reassess patients that presented with delirium or depression on initial evaluation, and they can document multiple areas of cognitive decline as required when diagnosing dementia.

### Diagnostic tools

Many tests exist to evaluate the cognitive, functional and behavioral problems of individuals with AD, and to assess their disease-specific stages. Clinicians, especially in the busy managed care environment of today's office practice, are interested in a test that can be used as a brief screening device but also one that accurately evaluates the difference between "normal" aging losses and those that might truly be considered pathology (Issues related to the social structural barriers with the use of routine screening are discussed in Chapter 4).

Basic clinical assessment of a client for possible dementia must minimally include a focused history, a focused physical exam, and assessments of functional and mental status (AHCPR guidelines, 1996). The focused history and physical exam should concentrate on the chronology of the mental status changes, including onset, progression and duration of symptoms, as well as examining for any problems that could contribute to changes in mental status, eg. medications, metabolic problems, and nutritional status. Many tools have been developed that assess functional and cognitive status and are used for basic screening in conjunction with the initial clinical assessment. Other measures include tools for global staging of the disease, and also neuropsychological tests that are performed by specialists and not included in this review due to their speciality focus and time demand for completion and interpretation.

### Cognitive assessment tools

Classic screening tools to assess cognitive decline include the Mini Mental State Exam (MMSE) (Folstein, Folstein and McHugh, 1975), and the Short Portable Mental Status Questionnaire (SPMSQ) (Pfeiffer, 1975). The most widely used is the MMSE, developed as a tool for the cognitive assessment of people in clinical and research settings. It tests orientation (time and place), registration, attention and calculation, immediate and delayed memory, language abilities (aphasia, agnosia, apraxia) and visuospatial abilities (copying a diagram). It is short (30 items), brief (easily completed in 5 minutes), and easily administered by professionals or trained lay persons. It is meant to be informative regarding the person's mental abilities, but not intended to be diagnostic (Cummings, 1993). Some researchers consider it reliable and valid (Anthony, LeResche, Niaz, Von Korff, and Folstein, 1982), but note that it must be interpreted with consideration of age and education (Crum, Anthony, Bassett, and Folstein, 1993). Critiques of the MMSE include the negative influence of low educational achievement levels (below 8th grade) and its lack of usefulness in assessing late stage AD clients (Kluger and Ferris, 1991). Also, a flaw in the scoring method for the MMSE was identified, but many still use the MMSE in the original form (Schulzer, Calne, Snow and Mak, 1993).

The Short Portable Mental Status Questionnaire (SPMSQ) is a 10 item tool which tests short and long term memory, orientation to person, place and time, and mental calculation ability. It was developed to be used as an initial quick screening tool in any setting (hence the terms short and portable). It was specifically designed to be used with the elderly population and was standardized and validated with this population (Pfeiffer, 1975). It is considered a useful test for later stage AD clients (Baker, 1989), although a

deficiency is that it does not include all the components that must be measured according to the DSM - IV criteria for dementia.

The Blessed Information - Memory - Concentration (BIMC) test (Katzman, Brown, Fuld et al, 1983) has 29 items measuring short term memory and information recall, and concentration ability. A shortened version of this test, the Blessed Orientation-Memory - Concentration (BOMC) test was developed by the same authors by selecting 6 of the 29 original BIMC items (based on a series of statistical analyses) and giving them weighted scores. Some authors suggest combining instruments, for example the BIMC and the MMSE, in order to assess a broader range of cognitive functioning (Weiler, Chiriboga & Black, 1994). The Short Test of Mental Status (STMS), developed by a group of Mayo physicians (Kokman, Naessens & Offord, 1987), tests eight areas of cognitive functioning, including orientation, attention, immediate and short term recall, calculation, abstraction, construction / copying (praxis), and information storage.

The AHCPR panel did a meta analysis of the most commonly used brief mental status assessment instruments, and reported that four tests are largely equivalent in terms of their ability to differentiate between persons with and without dementia. These tests include the MMSE (Mini Mental Status Exam), the BIMC (Blessed Information Memory Concentration test), the BOMC (Blessed Orientation Memory Concentration test), and the STMS (the Short Test of Mental Status). The panel purports that any of these four screening tests are largely equivalent. They acknowledged the MMSE as the most widely used test, and also the most comprehensive. It is the one test that documents multiple cognitive components, including all but two components (judgement and abstract thinking) required in the DSM - IV criteria for dementia diagnosis, as well as testing the

requirements of verbal response, reading, writing, mathematical ability, and vision and motor control skills.

The Seven Minute Screen test was developed after the publication of the AHCPR guidelines and thus was not included in their meta analysis. It uses words and pictures to assess orientation, memory and language, and tests visuospatial ability by use of the clock drawing (Soloman et al.1998). The authors report a high sensitivity and specificity for AD, and report the test is helpful in making initial distinctions between patients experiencing cognitive changes related to the normal aging process and those relating to dementia. It is also reliable and valid (Soloman & Pendlebury, 1998). The Alzheimer's Association hailed this test as "extremely useful," especially in differentiating early changes indicative of EAD (Alzheimer's Association, 1998).

The clock test has been available for many years as a quick and simple test that can be used in any clinical setting. Multiple versions of this test are in publication, and the problem becomes a lack of consistent directions or a consistent scoring method: it can be administered either by drawing-to-command or copying, it can include correct placement of numbers, correct placement of clock hands drawn to a specific time, or verbally having the person indicate the correct time on a predrawn clock. In practice, many clinicians use the clock test as a supplement to the MMSE or other tests of mental status. It is considered useful as a screening tool in tracking rates of disease progression (Rouleau, Salmon, & Butters, 1996), and identifying AD in later stages, but is not particularly sensitive for early AD (Lee, Swanwick, Coen, & Lawlor, 1996).

#### Functional assessment tools

Tools have been available for many years to assess the functional ability of clients, including the Katz Index (Katz, 1983) and the Barthel Index (Mahoney & Barthel,1965)

which assess activities of daily living (ADL's) such as bathing, dressing, toileting, and mobility, and the Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969) which assess IADL's such as shopping for food, obtaining transportation and paying bills. While some decline in ADL's is required to establish a diagnosis of AD (Kluger & Ferris, 1991), the tools currently available were developed for use with the physically impaired, and are not sensitive to the difficulties experienced by the AD client (Tappen, 1994).

While the above tools are useful in their ability to standardize screening procedures, can be administered rapidly and are able to communicate the range of the deficit (Baker, 1989), they are not sensitive enough to assess AD in the early stages. They are useful in assessing basic functional problems with ADL's and IADL's, but do not identify available strengths, especially in the early stages. They also do not allow for insight into the meaning of the emotional state of the person with memory deficits.

Impairment in functional ability is part of the DSM-IV criteria for AD, and an adequate assessment tool is crucial. Often, the first signs of dementia that are noticed are in the functional domain; they are usually reflective of a change in cognition. The AHCPR panel did recommend early assessment of a person's functional ability by use of the Functional Assessment Questionnaire (FAQ) (Pfeffer, Kurosaki, Harrah, Chance & Filos, 1982) because of its ability to discriminate for early stage dementia. The FAQ is an informant based test that evaluates complex, higher order functional activities such as the IADL skills mentioned above. A reliable informant familiar with changes in the person with EAD's abilities is necessary, although the panel did acknowledge that a person with very mild dementia might be able to provide valid reports of their own functional ability.

Although not included in the AHCPR guidelines, another component of the clinical assessment involves the staging of a person by use of a global staging tool. These tools measure the overall symptom severity of AD and include the Clinical Dementia Rating scale (CDR) (Berg, 1990) and the Reisberg Global Deterioration Scale (GDS) (Reisberg, Ferris & de Leon, 1988). Global scales are based on clinical signs, symptoms and behaviors, with information elicited from both the client and the caregiver (Kluger & Ferris, 1991). Caregiver input is believed to allow for a more complete picture of the AD client's total functioning. The CDR scale describes 5 stages of impairment along a Lickert scale rating system. It consists of six categories of impairment, including memory, orientation, judgement and problem solving, community affairs, home and hobbies, and personal care. The GDS, the most widely used tool, uses a 7 point rating system with a scale that indicates a predictable and ordinal progression of AD symptoms. Eiserdorfer et al (1992) evaluated the use of the GDS and found that significant psychopathology occurred at even earlier stages than predicted by the GDS. While acknowledging the clinical usefulness of a rating scale type of tool that can focus attention on the level of patient decline, these authors recommended that the most accurate way to describe AD would be to use separate instruments to rate cognitive status, functional status and psychiatric symptoms. Kluger and Ferris (1991) compared the GDS and the CDR scale, finding they are similar in describing the middle stage dementias, but that the GDS scale better differentiates at both the early stage and the most severe stage of impairment.

Diagnosing early AD remains a problem, even though diagnostic criteria have existed to evaluate AD since the mid 1990's, including the DSM - IV criteria and the tests suggested for use in the AHCPR guidelines. The experts do not advocate routine

screening for EAD, but do suggest use of specific tools for cognitive and functional assessment when warranted from findings of the clinical exam, most specifically the MMSE for cognitive testing and the FAQ for functional assessment, as well as a sensitive and careful discussion with clients, and their families if warranted, to evaluate cognitive and functional changes.

### Intervention Focus

Strategies designed to assist persons with early memory loss were suggested by some authors. McDougall's (1995) quantitative study reported that cognitively impaired older adults tend to use memory strategies of an internal type (i.e. repetition) versus use of external devices (i.e. notes or lists used by the cognitively intact). Arkin (1991) suggested that the use of memory stimulation strategies from the field of cognitive rehabilitation could be useful with persons with early AD who still have many functional abilities intact. The common theme of these authors was enhancement of functional ability, and they expressed an infusion of hope and optimism for the person with early memory loss and their caregivers.

### Summary

This chapter reviewed the literature for the theoretical perspective of Symbolic Interactionism, the basis for the grounded theory research method used in the study. Blumer's approach to SI was adopted, as it best articulates an approach that offers us insight and understanding of the person with AD's lived experience, and allows us an understand of the changing sense of the self experienced by person's with EAD. Viewpoints to understanding the AD experience were reviewed, with a comprehensive analysis of the sociogenic literature, including the literature on the EAD experience. An

extensive examination of the EAD diagnostic literature was also done, since it was realized during data collection that early diagnosis remained an ambiguous and elusive process.

CHAPTER 3  
METHODOLOGY  
Research Approach

The qualitative method used in this study was grounded theory (GT), first described by Glaser and Strauss in 1967. The method was developed for the purpose of studying social phenomena from the perspective of symbolic interactionism (Bowers, 1989). The SI tradition gave researchers the perspective of the actor's point of view, but lacked an organized procedure for data analysis (Stern, Allen & Moxley, 1982). Glaser and Strauss were convinced of the need to develop a research methodology that focused on data gathered in the field, and based on a theory inclusive of the subject's perspective (Glaser, 1992); they were also concerned with adding scientific rigor to the SI qualitative methodology.

The development of the grounded theory methodology by Glaser and Strauss was influenced by Strauss' research experience at the University of Chicago, which emphasized the development of a methodology to fit the naturalistic focus of data collection from the field, and to generate theory grounded in reality. Glaser's background was inductive theory generation from both quantitative and qualitative research. Their combined strengths allowed them to develop a field research method that revealed the perspectives of the research subjects (Glaser, 1992).

The goal of grounded theory is to discover theory from data, systematically obtained from social research. The emphasis is on the use of the inductive mode to generate theory from empirical data vs. reliance on the deductive mode of verifying theory

through theory testing. Another goal of this type of research is to predict and explain behavior, as well as develop a perspective on behavior (Bowers, 1988; Glaser & Strauss, 1967). Grounded theory is an especially useful methodology when one wishes to investigate new or uncharted areas of concern where no theories exist to explain the phenomenon (Stern, Allen & Moxley, 1982), such as currently exists with persons with early memory loss. Grounded theory is also a useful method which allows for change over time, and the description of stages and phases within an experience (Morse, 1994) such as that which occurs with the progression of AD and its concomitant interactional problems.

Qualitative researchers recognize that people construct meanings in relation to the world in which they exist (Boyd, 1993). People sharing common circumstances experience shared meanings and behaviors that constitute the substance of grounded theory (Hutchinson, 1993). An assumption of grounded theory is that people will make sense of their world, even if that world appears disordered or nonsensical to others. Another important assumption is that each group of people share a basic social psychological problem (BSP), not necessarily articulated, and this problem is resolved by means of a social psychological process (Hutchinson, 1993). The goal of grounded theory research is thus to discover the intrinsic problem(s), and the inherent processes used to resolve them.

Unlike the quantitative researcher who desires objectivity, the role of the researcher with grounded theory is to become immersed in the world of the research participant, in an attempt to view the world from the participant's perspective. A theoretically sensitive researcher is both "at one" with the data, while at the same time entering the process with as few "a priori" hypotheses as possible (Glaser, 1978).

Data gathering for this study was done in the field, using field techniques that generated data, and included interviews with persons with early AD, as well as analysis of print and audio-visual media. A diversity of information sources, along with the theoretical sensitivity of the researcher, should yield data that is dense and a theory that is complete (Hutchinson, 1993).

### Setting

The natural setting is the ideal place to interview and observe individuals. In this study, all of the participants still lived in their own homes, and most chose to be interviewed there (N=11); others chose places of mutual convenience or neutrality (i.e. a church office, or my office) (N=5). The interview consisted of a semi-structured set of interview questions (appendix A) focusing on the person's perspective of the meaning of their memory loss. The client is considered the expert in describing what is happening, with the researcher gently probing, if necessary, for more information or clarity, but always maintaining the focus on the participant's perspective (Bowers, 1989).

### Sample

The sampling was opportunistic (Germain, 1993), also called a volunteer or convenience sample (Morse, 1986). Prospective study participants were initially recruited through a university affiliated neurology clinic, an AD specific day care center, the Alzheimer's Association, two primary care medical residency program clinics with known geriatric components, two church affiliated congregate living facilities, a church affiliated Meals on Wheels / case management program, a Parish Nurse program, a hospital affiliated home care program, a hospital affiliated geriatric health assessment program, and

an ARNP practice council group, all in N.E. Florida. An attempted affiliation with a Memory Disorder Clinic was not approved by that agency.

I visited each of the above named sites, meeting with each director and usually, other staff members, explaining the nature of my research and the criteria for the subjects (as described in Chapter I, pg. 5). This approach supported the idea that staff members can act as key informants in the identification of potential participants, after careful explanation of the inclusion criteria by the researcher (Rapp, Topps-Uriri & Beck, 1994).

Obtaining referrals for this study proved to be extremely difficult; in actuality, very few referrals came from any of the above agencies (6 came from the neurology clinic, 1 from the AD association, 1 from the geriatric outreach program). Continued opportunities for sampling were obtained from a word of mouth network that I had developed over many years in the geriatric nursing field (also known as "a snowballing or nominated sample," Morse, 1986, p. 184); in fact, this method proved to be the most effective for obtaining the research participants.

A sample size of 18 EAD participants was achieved, although data collection and sampling were directed entirely toward the emergent model, seeking "indices of saturation" (Morse, 1994, p. 230) rather than a specific number of cases. Participants ranged in age from 70 - 89, with the exception of one person who was 47 years old and shared his known familial trait for early onset AD. Six were male and 12 female, consistent with aging demographics favoring female longevity. Six participants were married, eleven were widowed, and one (the 47 year old) was divorced but living with a partner.

Four interviews with EAD clients were done when I was a research assistant for a NINR grant study entitled "An Observational Study of Alzheimer's Disease Behavioral

Symptoms" (1994-1997, P. I. Sally Hutchinson, PhD. R.N., University of Florida, College of Nursing, Health Science Center, Jacksonville), and this data provided sensitization to the interviewing process with EAD clients. Due to the inherent nature of AD, not all participants referred to me were the best informants; for example, some of the persons admitted to having memory problems and agreed to an interview, but were past the point in their AD progression where they could articulate with any depth their thoughts and concerns. This led me to question how clinicians, especially physicians, distinguished the early stage of AD; subsequently I interviewed five doctors (all specializing in family medicine or internal medicine with a focus in geriatrics) for their understanding of EAD and their approach to the diagnostic process (appendix D).

To obtain a fuller understanding of the EAD experience from the perspective of the diagnosed person, an early stage AD support group for 4 participants living in a retirement complex was developed, with the participants agreeing to be research participants. This data was especially fruitful for insight gained into the EAD experience, and it's subsequent problems and concerns. Data was also obtained experientially from ongoing clinical experiences in my functional role as a geriatric nurse practitioner.

#### Theoretical Sampling

Theoretical sampling is the process of data collection for generating theory whereby the analyst "jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop the theory as it emerges" (Glaser, 1978, p. 37). Theoretical sampling was a way of checking on the emerging conceptual framework, as the researcher continually asked questions as to fit, relevance and workability about the emerging categories. Published narratives of the EAD experience

(both print and video) were used as data, as it was deemed that these peoples viewpoints would be useful to elaborate and verify the emerging categories and codes. This source of data served to validate that person's with EAD did in fact progress through a trajectory that included the earlier stages of Identity work discussed by this study's participants. The published narratives also offered a view of people as they progressed through the last stage of EAD, data that I was not able to obtain from a one time interview with participants, allowing for a fuller understanding of the last stage of Identity work. Theoretical sampling is a more powerful type of sampling as it permitted me to select information according to research needs (Morse, 1986). The researcher is being more purposive in seeking specificity about the evolving categories. As redundancy occurs and each category is saturated, theoretical sampling ceases (Glaser, 1978; 1992).

### Protection of Human Subjects

#### IRB Process

Institutional Review Board (IRB) approval was sought and obtained through the University of Florida, Jacksonville IRB office. When it was deemed necessary to collect additional data, such as from physicians and from participants in an early stage support group, an addendum was submitted and approved. I also applied and received approval through the IRB office of St. Vincent's Medical Center, but this source proved unfruitful for participants and I did not continue to maintain the protocol approval.

#### Procedure for data collection

In language which could be easily understood by the participant, I explained the basic idea of the research (i.e. "I would like your permission to use a tape recorder to talk with you about your experience with memory changes - this is for the purpose of research about people with early memory changes"). The informed consent was also verbally

explained in language that the participant could grasp. If the participant agreed to participate in the research, an informed consent was then signed by the person with EML.

It was decided that for purposes of this research on EML, if the person could not understand the discussion adequately in order to give consent, then they were already too far progressed in their AD to participate. All persons that were asked agreed to participate, and all family members contacted voiced agreement, as well as support and enthusiasm. In subsequent contacts, ongoing process consent (Munhall, 1993) was obtained, by asking the client if they continued to agree to participate in the research project. If the research process appeared to be causing discomfort to the participant, data gathering would have been terminated; this did not occur in the study, and, in fact, all participants voiced relief in being able to discuss their EAD (further discussed in chapters 4 and 5).

If there was a family member living with the person, or a family member who maintained close contact with the participant, he/she was verbally informed of the research and the participant's agreement to participate. Some family members chose to be present for the interview; this was always with the participant's permission, and in some cases, their request. Demographic information was obtained from participants, and if necessary, family members or other caretakers when available were also asked to share demographic and contextual information (Appendix B). Obtaining some of this initial information, such as birth date or place of diagnosis from a reliable caregiver eliminated the need to "put the client on the spot" regarding information that their very condition of memory loss might preclude them from sharing.

When a family member was available who was knowledgeable about the person with EAD's day to day functioning, the plan was to ask them to complete the Functional Assessment Questionnaire (FAQ), (Appendix C), since this tool was suggested by the AHCPR panel to be sensitive for assessing early stage AD. However, this data source was completed by only 3 of the participants caregivers (out of the 7 who had family members living with them) as it seemed to not provide a "true" score of functional ability, since many couples had learned to compensate, both for the EML and the aging process, by "sharing" the functional tasks of living. For example, Mr. M.'s score for the FAQ was difficult to calculate because his wife, typical of many caregivers, assisted him in the completion of the many IADL functions so that they were done as a shared activity, as a couple. Together they paid the bills and kept the household accounts; also they shared in the shopping and light cooking. They lived in a senior housing complex which provided a supportive living environment for the more complicated meal preparation and housekeeping. He still drove, although they both admitted to discussing directions if driving in new or crowded areas. She admitted to keeping track of important dates such as family birthdays, and he kept up with appointments by keeping notes on calendars. Other participants disclosed that they had already turned over to complex tasks, such as money management, to their children; many admitted to voluntarily giving up driving.

Anonymity of the participants was protected at all times by the use of initials instead of names. Even though precise information from transcripts was included in the findings, the identity of the participants was never disclosed. Only faculty, research seminar students and a transcriptionist shared access to the data, and confidentiality of the

participants was maintained at all times. Cassette tapes were transcribed and coded so as not to disclose the identity of participants.

This research was physically noninvasive, and posed minimal participant risks. If a participant had become upset by the interview process, as an Advanced Geriatric Nurse Practitioner with many years of practice, I possessed skills to calm the client. Munhall (1993) discussed how the sharing of one's fears and problems in the context of an interview is construed by many to have a therapeutic effect. In fact, the participants in this research continually told me how relieved they were to be able to dialogue with someone about their fears and concerns.

### Data Collection

#### Interviews

Data was collected via participant interviews in a setting convenient for the participant (and caregiver, when involved). The informed consent was signed before the interview began (Appendix E-1 for client, E-2 for physicians). Interview time for the participant depended on their ability to continue to answer a set of semi structured questions without being redundant or circuitous, but on average did not exceed 45 minutes (Appendix A-interview questions for EAD participants, appendix D for physicians). All interviews were tape recorded, transcribed and coded/analyzed according to the method of Glaser (1992).

#### Participant observation

Participant observation data was only obtained when the interview was done in the home (N =11). Boyd (1993) stated that the researcher should strive to collect data which best describes the person-environment relationship, and behavior is best understood in the

context in which it occurs. Also, it is important with elders to collect more than one type of data, for example, observation and interview data, to create a more thorough picture of the phenomena being studied (West, Bondy, & Hutchinson, 1991). This idea proved to be applicable to this research, as I was able to identify more about the functional ability of the person with EAD when I observed them in their own home environment. I was able to observe the compensatory strategies used by persons to function at their optimum level; for example, the complex system devised by Ms. H to safely take her daily medications, the calendar system used by Ms. J with her day to day life reflected in items that were recorded, and the detailed listing of tasks that assisted Mr. B. to be able to operate independently in his home during the day when his girlfriend was at work.

### Data Analysis

#### Constant Comparative Method and Substantive Coding

With the grounded theory method, data are simultaneously collected and analyzed according to the constant comparative method. After the interviews were transcribed, I looked for codes within the data. The initial process, called substantive coding, began with an open coding process, whereby each line of data was analyzed, thus fracturing the data. These initial substantive codes were constantly compared, in order to yield categories and properties which were indicative of the core variable or Basic Social Process (Glaser, 1978). For example, initial level 1 codes such as covering, excusing, hiding behaviors, and telling friends, became level 2 categories under disclosure work. The researcher constantly attempts to elevate concepts to a theoretical level, and ask questions about the relationship of codes to each other (Hutchinson, 1993). This method is both inductive as well as deductive, in that the codes that are inductively developed are

constantly compared, then reduced into categories (clusters) in a manner reflective of factor analysis (Stern, Allen & Moxley, 1982). As data were jointly collected, coded and analyzed, the theory began to emerge; continued data collection was controlled by theoretical, or purposive sampling according to the emerging theory; for example, collecting further data from the published narratives.

### Theoretical Coding

Substantive coding evolves into theoretical coding when relationships between substantive codes are discovered and theoretical linkages are made to contain, describe, and explain the data (Sandelowski, Davis & Harris, 1989). Just as the substantive codes help to fracture the data, theoretical coding helps to weave the data back together. Theoretical codes conceptualize how the substantive codes may relate to each other as hypotheses which can be integrated into a theory (Glaser, 1978). There are a number of basic sociological codes that can be used; Glaser calls them the basic coding families. These codes include the six C's (causes, contexts, contingencies, consequences, conditions and covariances), as well as codes relating to process, degree, dimension, type, strategy and many others. The purpose of these coding families is to pull the researcher out of the data and elevate the thinking to a theoretical level. In this research, these basic codes proved useful in identifying the process of Identity work, and the conditions and consequences for the various stages and phases.

### Memoing

The relationships between codes are discovered through the process of memoing. As the researcher sorts and integrates the memos, the theoretical ideas emerge and are recorded. Memoing is a vital part of the research process, is used from the very

beginning with the open coding step, and continues through to the end of the research process. "Memos are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding" (Glaser, 1978, p. 83). Memos serve to raise the data to a conceptual level, develop the properties of each category and begin the process of making connections between categories and their properties. The coding process constantly stimulates the researcher to develop ideas about the codes and their relationships, and it is these ideas conceptualized into memos that result in the theoretical codes that lead to a generated theory.

The process of memoing is simple but crucial. The researcher stops and writes a memo whenever an idea or a thought about the research strikes him/her; it is a process of recording ideas about the research as the ideas occur. Memos are written up as short sentences, paragraphs or pages; they can be written as methodological notes, (MNs), personal notes (PNs), or theoretical notes (TNs). They must be kept separate from the data, and in a retrievable form, but referenced to the field notes from which they emerged for later checking. The memoing process in this research was crucial in identifying ideas about codes and categories, and which became the basis for theoretical thinking, developing the codes into categories and then theoretical constructs. The memos regarding method were especially crucial in this research, since interviewing people with EAD is such an uncharted area; often leading to clinical judgement and even change in procedure. In this research, memos regarding the difficulty in finding appropriate subjects for the study led to the idea for interviewing the doctors concerning how they identified and diagnosed people in the early stages of AD.

Memos can assist in the development of an audit trail to substantiate trustworthiness in qualitative research (Rodgers & Cowles, 1993). Even as the memoing process begins during the joint collection, coding and analyzing of data, and peaks as coding saturates, it is truly never over; it can continue on to provide ideas for later research (Glaser, 1978).

### Basic Social Process

Codes become saturated when the researcher realizes that all data can be subsumed as an indicator of some category. It is at this point that selective coding can begin, delimiting coding to only those variables that relate to the core variable and can be used in a parsimonious theory (Glaser, 1978). The technique of constant comparison is used to discover the core category that accounts for most of the variation in data and that integrates the data, codes and memos. (Sandelowski, Davis & Harris, 1989). Criteria for a core category include its centrality to the categories generated; it must account for much of the variation in the patterns of behavior. A core category must also reoccur frequently in the data, relate or be connected with the other categories, have relevance or explanatory power, and be completely variable in all conditions (Glaser, 1978). The core process that emerged in this study was the concept of Identity work; it was the basic social psychological process necessary to experience the work of EAD. Identity work included the stages of Explanatory work, Recognition work and Disclosure work, which led towards Confirmation work and the eventual acceptance of themselves as a person with EAD.

### Scientific Rigor

The typical positivist criteria of validity and reliability are not particularly applicable to qualitative research (Altheide & Johnson, 1994); yet academic rigor can be

assured via other methods that contribute to trustworthiness. Glaser (1978) emphasized criteria that included the fit of the theory (the categories generated must fit the data), the relevance of the theory (it must allow core problems and processes to emerge without forcing), the theories ability to work (does it explain, predict or interpret) and the modifiability of the theory (from the addition of more data). Other qualitative research criteria for scientific rigor include a theory that is conceptually dense (Strauss & Corbin, 1994).

This study fits Glaser's criteria (above), since the codes and subsequent categories were generated from the research data, and they seemed to naturally fit this practice area of early dementia care. The theory is relevant; the core process of Identity work and the stages of Identity work emerged from the data. The theory also was able to explain what was happening to people as they progressed in their AD, meeting the criteria of workability. As to the idea of modifiability, this substantive theory of stages, conditions and consequences of identity work could be modified as new/ additional data becomes available from additional persons with EAD.

The published narratives that were used as additional sources of data for the stage of confirmation work were considered a source of validity for the earlier stages of Explanatory work, Recognition work and Disclosure work. The accounts by the Rev. Davis, Dr. Henderson and Attorney Baron gave specific examples of their individual struggles, beginning with their early questions and concerns regarding diagnosis in the explanatory stage, to their similarities in experiencing the conditions for Recognition work, as well as the barriers and consequences of this stage. Each of them was able to do the Identity work requiring passage through Disclosure work towards Confirmation work.

Their stories were an affirmation for Identity work being a core process for the problem of living with EAD.

I did attempt to obtain new participants, to use as verification for content validity, but the same barriers were present as for the initial sample. For example, I recently gave a talk on EAD, and shared with the audience that I was interested in any new participant contacts. A lady approached, readily shared with me information regarding her diagnosis, and gave me her phone number. I made multiple attempts to contact her, but she did not return my calls. This presented a quandary - do I continue to call and leave messages; perhaps she was having second thoughts and did not wish the exposure, and further attempts might be considered harassment, or perhaps she had forgotten who I was!

Auditability (reliability) is an essential component of any rigorous qualitative study and an audit trail should assist the researcher greatly in maintaining the criteria of trustworthiness (Rodgers & Cowles, 1993). The audit trail is maintained by the researcher's careful and consistent recording of all data, including notes regarding method, analysis/theory and personal issues and responses. A careful audit or decision trail should allow others to follow the ideas and logic of how the study progressed. A careful audit trail was maintained in this study, including all tapes, notes, and transcribed data; much of this data was reviewed by my chairperson.

Morse (1986) stressed the sample must be such that it provides data that is adequate and appropriate. Adequacy refers to the amount of data collected; adequacy of data can be presumed when the data are saturated and no new categories emerge. The sample size in this research was considered adequate as the data became saturated and no new categories were emerging in the interviews; thus interviewing was halted.

Appropriateness (or fit) refers to the degree in which the method of sampling fits the purpose of the study as determined by the research question. An appropriate sample will allow for the selection of information according to the theoretical needs of the study and the emerging model; it should provide insight and understanding to the problem. The question can be asked - do the concepts reflect / explain the situation under study? (Hutchinson, 1993). As mentioned earlier, the published narratives supported the theoretical model grounded in this present research. The following chapters present the findings of the grounded theory research, answering the research questions initially posed in chapter one.

## CHAPTER 4 IDENTITY WORK IN EARLY AD- EXPLANATORY WORK AND RECOGNITION WORK

In this research, the concept of Identity work emerged as the core process during data analysis. Identity work concerned individuals with EML viewpoints of their transformation of their sense of identity, and the work required to deal with the changes. Analysis involved discovering the various dimensions of Identity work that an individual experienced while living with EAD, including the work of initially recognizing and dealing with the changing self, adjusting to the changing self, and moving towards living with, and for some, accepting the progressive changes of EAD. The theoretical perspective in this dissertation research included acknowledging the importance of the substantive theory of awareness context (Glaser & Strauss, 1965), as well as seeking to develop a theory that further articulated the significance of EML for individuals as they struggled to find meaning in their cognitive and affective changes. This chapter focuses on the concept of Identity work, the condition necessary for Identity work (open awareness context), the first two stages of Identity work (Explanatory work and Recognition work), the conditions for Recognition work, the diagnostic barriers to Recognition work, and the social psychological consequences of Recognition work. The stages that are discussed in this chapter and throughout the study are not necessarily lock step, occurring in a set sequence; they do occur over time, may occur simultaneously, or they may occur over and over again before the person can progress to the next stage in their Identity work process.

The phenomenon of work surfaced early in the analytical process as an organizing framework to explain what happens as a person diagnosed with EAD adjusts to living with the disease. The concept of work suggests an active involvement in a process, with an end towards accomplishing something or attaining a goal. Work can have many components, such as body, mind, and spirit work, it can be done individually or in groups. It contains the suggestion of energy, which can be physical, as in the connotation of "hard work," it can also suggest the use of psychic energy, such as in the social psychological work of living with EAD. Work also denotes a process occurring over time, thus containing a temporal aspect. The time trajectory can be a long and arduous one, such as that which occurs when AD develops over many years. Work is an iterative process in individuals with EAD, who vacillate back and forth in their minds about the reality and meaning of their symptoms.

A few qualitative researchers have focused on the concept of work. Strauss et al. (1984) used the notion of work in their classic book on the social organization of caring for the chronically ill. In privileging the social and psychological aspects of chronic disease over the medical, they enumerated the multiple tasks of coping with chronic illness that the patient, the family and the health care workers face, and organized them into work types, for example, crisis work, symptom control work, comfort work and ward work, to name a few. Pinnick (1984) further elaborated on types of work in her study of chronically ill children on a pediatric ward, identifying food procurement work, comfort work, composure work and body work, and cautioning that nurses need to evaluate how their own work impedes or facilitates patient's work.

Vittoria (1998) discussed the concept of identity work in a qualitative study of the environment of an Alzheimer's unit. She described identity work from the perspective of the staff's interaction with AD residents and their efforts at preserving the resident's sense of self through efforts at social construction of positive resident identities. Saunders (1998) examined the social construction of identity by older patients with later stage dementia being evaluated in a memory disorder clinic. Their use of various account types illustrate how they construct and reconstruct their identities in social interaction, in an attempt to manage and protect their self image. Mathieson and Stam (1995) discussed identity work from the perspective of the patient with cancer, and the meaning of their identity - altering illness within the context of organized social relationships, including the medical system.

Identity work emerged as the core process with the most overall explanatory power for describing the experiences of people with EAD. These individuals struggled through a long and difficult disease course, as they gradually came to realize their memory changes had great meaning for them, that they had probable EAD. This study discusses how people with EML came to view their memory changes within a framework of a changing identity.

#### Open Awareness Context, a Condition for Identity Work

Open awareness context (OAC) emerged as an important condition for Identity work. The importance of being able to dialogue with the person early in the experience of their memory changes made knowledge of the person's awareness context of fundamental relevance to this research. Interviewing was a process of discovery and assessment of the individual's awareness context. Ideally, persons with EML were in an open awareness

context, so that I could initiate the dialogue that could offer me insight into the changes they were experiencing. Although not all people interviewed were in an open awareness context, it was clearly the ideal state for the sharing of information regarding EML.

The original research on Awareness Context Theory with dying patients and their caregivers identified four awareness contexts: closed awareness, suspected awareness, mutual pretense awareness and open awareness (Glaser & Strauss, 1965). Closed awareness context refers to persons having knowledge about a situation but being careful not to divulge it to anyone. Suspected awareness context refers to an interaction in which both participants suspect a particular condition. Mutual pretense awareness context refers to participants having knowledge about a condition, but feigning ignorance. In open awareness context, participants openly discuss the condition. It is important to emphasize that mere awareness of EML changes does not coincide with an open awareness context; in fact the person may work to conceal or reveal their EML changes, dependant on their social interaction with others. Even if revealed, it requires dialogue with someone else to become an open awareness context.

Awareness Context Theory was found to have relevance to social interactional issues in early AD when nurse researchers used the emergent fit mode to build on the theoretical application of Glaser and Strauss's previous work of Awareness Contexts (Hutchinson, Leger-Krall & Wilson, 1997). The authors noted the importance of awareness contexts as "phenomena that shape the social interaction in the experience of early AD" (p.1407). They emphasized that it was not so much the awareness of the AD that was crucial, but the awareness context surrounding and influencing the interactions between the person with EML changes and their social world.

The majority of people with EML in this study were in varied awareness contexts at the time of interview. For example, all participants were initially in closed awareness context with their physicians, but were able to move into different contexts with other people. Both Mr. M. and Ms. B. were in mutual pretense context with their spouses, meaning each spouse in the relationship knew of the EML condition but did not discuss it. Ms. B. stated "We don't talk about it, but he knows;" in fact it was her husband who initiated the diagnostic visit to the neurologist, and he was present for her interview with me. Mr. M. related that "I have confided in my wife but we don't discuss it;" rather they gave their numerous other medical problems center stage. He and his children were also in a mutual pretense context. He stated, "They know, but to be truthful we have not discussed it." At one time, his out of town daughter called and shared with me her knowledge of her father's EML condition, but also agreed that "it isn't something we talk about." He used the opportunity of driving a neighbor, Ms. W., to the pharmacy to move into an open awareness context. When she shared with him "I can't go without taking my memory pills," he responded "I sure need some of those, I'm having a terrible time with my memory." She encouraged him to join my early memory loss support group; he subsequently came to the office to speak with me, sharing his recent changes in memory and functioning, and stated "I sure appreciate being able to talk to someone about this problem I'm having." This statement indicates how social interaction can be an opportunity to move people with EML towards a different awareness context, and give them the opportunity to begin the process of identity work identified in this research. It also is an important example of how professionals can help guide patients in their

awareness contexts, an idea discussed by Glaser and Strauss (1965) regarding the power of other people to “change or maintain a particular awareness context” (p. 270).

Both Ms. A. and Ms. W. were in open awareness context with their doctors and their children, but were in mutual pretense context with their friends. Ms. W. stated “How could they [friends] not know, they see me everyday.” In turn, her neighbors and dinner companions would frequently share with me “H. is having such problems, it’s a shame, but we just try to help her as best we can.” Some, like Mr. H. and Ms. J., remained in closed awareness context with their physician, family members and friends, even while fully admitting to me their problems with memory, and the various compensatory strategies they used. For example, Mr. H. was able to discuss his initial EML changes with me, including the tremendous impact they had on his law practice. “I was lost and frustrated and I was glad when I had to eventually give it up.” However, he discounted the idea that he had anything more than normal memory loss, because “my doctor said it was normal aging.”

Since none of the individual’s interviewed for this research could recall a direct diagnosis of EAD by their physician, (many were given the euphemism of memory problems or memory changes) the condition of non-disclosure of a diagnosis makes it easier for the person to remain hopeful, and discount their memory changes, or simply to deny their EML changes have meaning beyond that of normal aging. For some, it is not until their suspicions are aroused by further testing and workups, or the prescribing of specific prescription drugs for their memory changes, that they begin to wonder. After being evaluated for EAD and started on Aricept, Ms. F. acknowledged that “I did not ask any questions,” although she did admit to “wondering” about the implications of her

memory changes. She readily admitted to the EML changes, but for her the meaning of these changes was to remain hidden and nonexistent. EML was a sign of aging, but not indicative of a specific disease. She and her husband stated they did not discuss the EML changes, and denied any functional problems for Ms. F.

An open awareness context, or any context that could lead to an open awareness context (i.e. suspected awareness or mutual pretense context) was critical if people with EML were to begin the process of "self work" necessary to address the changes of EAD. Self work involved an initial dialogue with self, or thinking about themselves and their situation. It involved the self reflective process discussed by Blumer (1969) as "...an internalized social process in that the actor is interacting with himself"(p.5). Wanting to do the self work was the first step in an awareness context that had the potential to progress from closed, mutual pretense, or suspected awareness context, towards an open awareness context.

### Stages of Identity Work

#### Explanatory Work

Identity work occurred in degrees, over time, starting with the person's initial efforts at developing early explanatory models for their EML. Explanatory work, the first phase of Identity work, assisted them to begin sorting through various ideas of causation for memory loss. Models in research are symbolic representations of an idea (Wilson & Hutchinson, 1996) that assist us in explaining a concept to another person. An explanatory model offers a theory of causation or a descriptive explanation for a phenomenon. McSweeney, Allan, and Mayo (1997), building on the work of Kleinman,

discussed using explanatory models in their nursing research and practice as a mechanism to link beliefs and behaviors, in an effort for persons to make sense of their illness.

Most of the participants in this research had an explanatory model for their initial changes of EML. Some expressed conflicting ideas about whether or not they really had EAD, and discussion of their ambivalence seemed to assist them in sorting out their ideas and making initial sense of their EML changes. Most of the people interviewed and chosen for this study did not continue with their initial self protective ideas but were able to move on to further dialogue and eventually come to some sense of acceptance of their EML changes, a fact I believe due in large part to interactions occurring in this research.

Some individuals initially expressed the idea that their changes were “no more than normal aging - all our friends have this problem.” Ms. J. admitted to having EML, but also seemed to take comfort in the fact that “my neighbor told me that all old people have this problem and not to worry about it.” She also medicalized her memory changes by relating them to “dizziness and headaches.” Some readily made a genetic connection, remembering that “actually my mother was like this” but they would also offer other explanations, such as “maybe I’m just not trying hard enough,” or “your brain is a muscle that needs exercise and I’m working on that.” These people initially appeared to be holding out hope that hard work and effort could overcome the changes they were experiencing.

One husband of a person with EML attributed his wife’s changes to “her lack of paying attention... we remember what we are interested in.” He further shared “she is not really caring, she could do better if she tried.” Ms. W. divulged her son’s comments to her on a recent visit - “they tell me I have to remember.” At one point, she also saw her

initial changes simply as “something I need to overcome, like bad behavior.” These family members were enforcing their belief that with effort comes improvement in memory. They were not prepared to view the memory impaired person as someone with a changing identity.

Ms. A. shared her varied explanations for her EML, while at the same time readily admitting to “memory problems caused by Alzheimer’s;”... “I think by the time you get to our age, your mind has too many memories and we have experienced too much stress, what with having to give up so much and move to a smaller place.” She further opined, “some memory loss is really self protective, especially if it is something sad or miserable from your past. I think the Lord helps you to forget these things, don’t you?” This person had been a nationally renowned plant specialist/ nursery owner and she poignantly expressed, “I think my problem is I miss my garden, digging in the soil and making things grow, and I miss my pets running around in the yard.” Perhaps she is suggesting that the cumulative stresses and losses of life are causative factors for her EML. At another time, Ms. A. was able to ask many questions concerning “brain changes” and “what really causes this disease.” In contrast, Mr. M.. did not have any suggestions regarding causative factors for his EAD. Prior to entering the EML group, he was able to dialogue with me at length, interchanging the words “memory problems” and “Alzheimer’s” to explain his condition. When asked why he was using the word “Alzheimer’s” he stated “It seems like that’s what it is, doesn’t it?” Both of these persons with EML were interviewed prior to a formal diagnosis, but already attached significance to their memory changes. In fact, many study participants acknowledged that their changes were more than just forgetfulness. They expressed a concern about the changes, at times vacillating

and using other explanatory models as reasons for the changes, but always returning to “is it more?”

### Recognition Work

That the person with EML possessed a willingness to admit to early changes in memory and functioning was a key criterion of the study. During analysis I asked, “what are the conditions that allow some people with EML to recognize their changes?” The critical behavior at this point was for the person to question their changes in memory and functioning. Recognition work, the second phase of Identity work, centered on the person with EML being cognizant of the fact that something within themselves was wrong and admitting that the changes were more than just the memory loss of aging. It was a critical step at this stage for the person with EML to imbue these changes with meaning and render their changes problematic.

Creating meaning is social, it emerges in and through social interaction (Jaffe & Miller, 1994). For many, a crucial factor in creating meaning from these EML changes was the current level of functional status for the individual. Many of the clients who very early recognized the changes and sought answers were in highly functional roles; their EML changes affected their ability to continue performing and interacting in an effective manner. If finding meaning in their EML changes did not occur, then the person could not progress to the next step of EML work.

Once people became more focused towards recognition of their EML changes, some were able to advance slowly towards creating an identity of self with EAD, while a few circumvented the idea, readily discussing doctor visits and pharmaceutical prescriptions for memory changes but never stating a diagnosis. Crucial at this stage were

the conditions for Recognition work, which included an initial heightened self awareness, which led to a questioning and dialogue with the self, an ability to monitor one's changes, and the diagnostic process itself.

#### Conditions for Recognition work

Increasing self - awareness. For the initial self recognition and acceptance of the meaning of the EML changes to occur, a condition of increasing self awareness was found to be requisite. The individuals who could admit to their EML experienced an increased sensitivity to changes in self functioning; and this self awareness allowed them to question their changes. Mr. H. stated "I'm clinical, so I kinda asked, what's happening here?" They could admit to themselves that they noticed the changes in memory. For many, this step allowed them to graduate to admitting to others their experience with EML, leading to a possible diagnosis of EAD, and over time, the identity of oneself as a person with EAD.

People with EML discussed noticing the early functional changes; they recognized and were willing to admit to themselves that something was different. Many spoke of the typical changes often discussed in the literature, for example, lost name recognition or inability to remember phone numbers. One person stated, "I can't remember names of family members when calling them; I have to list their names on a card and use it as a prompt." Another person, new to a congregate senior living site, recognized the consequences of this early stage change when he asked, "How can I form friendships if I can't even recall their names!" Mr. M. expressed frustration with word finding problems and loss of concentration, "I can't remember the punch lines for the joke and I get lost in conversation with friends, it's just easier to forget it." These early changes were already more bothersome than benign forgetfulness; they were causing the loss of ability for

positive social interaction. For some of these people, it was easier to not bother keeping in touch, or to avoid interactions altogether. Social withdrawal became a byproduct of EML.

Memory changes for some persons had more meaning because they were still engaged in activities in the public eye. Rev. V., a Presbyterian minister, had noted significant changes in his functional abilities, especially since he had retired but was continuing in a high powered consultant position. He stated that he knew his changes were more than just memory problems, and he knew they affected his higher functioning abilities, "I have no trouble remembering the bible information, it's the process thinking, the problem solving that I have trouble with now." He shared that he had tried validating his memory changes with his wife and coworkers, "they said I was fine, but I knew better." He was aware of their efforts to ignore the problem rather than validate his concerns and engage in open discussion, an example of a closed awareness context. An attorney, Mr. H, noted that "during the final two years of my law practice I really began to notice it. I would get up out of my chair with something on my mind but by the time I got the judge's attention, I'd have forgotten." When asked if he thought the judge and others noticed this, he stated "I think they thought I was stupid... like that guy isn't much of a lawyer." These feelings of decreased self worth and awareness of his decreasing functional abilities eventually forced him to close his practice. "I didn't feel like the client was getting his money's worth."

Many were able to discuss the typical spatial, temporal and sensory changes consistent with EAD. For example, Ms. H. spoke of getting lost while driving in familiar surroundings and the resultant "feelings of frustration and fright," even articulating the

high risk consequences of these safety issues. Upon realizing she had been lost while driving to the mall for her early morning walk, she asked "can you imagine what could have happened to me if I hadn't found my way back?" She eventually gave up driving significant distances. Two gentlemen admitted to noticing significant memory changes as many as 10 years previous, and giving up their golf game because of the changes. One stated "I gave up my golf game long ago because I knew something was wrong and I couldn't keep up, names of new golf partners, scores, it was too much." Some people articulated their changes in relation to sensory responses. Ms. B. expressed, "I sensed something wrong, but it was difficult to grasp ... I just felt funny, things were leaving me, I had less energy." One man stated "I know I'm not as sharp, I seem to be going backwards."

These clients could express the early awareness of, and the significance of their EML changes for their daily lives. The challenge is to have people recognize and act upon these signal events early in the change process, in order for correct evaluation, diagnosis and appropriate treatment to begin. The difficulty in this particular research was finding people in the EML state that had the heightened self awareness and an awareness context that allowed for diagnosis and support to occur.

Monitoring personal changes. A second condition for recognition work was that persons with EML who could admit that they were experiencing EAD were able to discuss ways that they could monitor changes in their progression. By the process of using personal markers (comparing their functional ability against previous capacities) and comparative appraisals (comparing self against actions of others) as the gold standard, they were able to evaluate their functioning and indirectly, their sense of self identity.

The use of personal markers are evident in the following examples. Ms. V. proudly claimed that she could still cook without looking at a recipe, especially her prized apple cake that she had been baking for years. Another took pride in the fact that she was still able to memorize piano music. She stated, "I play for my self enjoyment and besides, I know my brain still works if I can continue to memorize pieces; in fact I think memorizing helps make my brain stronger; it's a muscle you know." Some of the ladies involved in the EAD support group still played bridge weekly and more than one was heard to remark, "I had a good game this week so I guess I'm doing ok." Another lady interjected, "success with my bridge game sustains me," and in fact it was often the "high" she needed to continue on during the week. These women were reassured by the belief that success breeds success.

Comparative appraisals assisted some individuals to feel better about themselves. Ms. B. took strength from knowing she was not the only person trying to function with the problem of memory loss. She stated "if others can deal with this then I can too." One lady compared her ability to play cards by evaluating herself against her friends competence in card playing. "I have to be able to keep up with them and they are good." In the same conversation she admitted to doing "foolish things" now, which reinforced her understanding that she has a memory problem.

Comparative appraisals can also leave the person who does the comparison wanting. One lady in the group compared herself to her neighbor who also has EAD. She remarked, "you are doing so much better than I am," and complemented him on his organizational skills. She explained her theory that he was making use of his past organizational skills from his background in the business world and this assisted him now in coping with his EAD changes. However, this particular lady had also been a business

professional and at one time probably had the same organizational skills. During the group, another lady remarked to a neighbor, "I never would have known you had any memory problems like me, you seem so fine." These comments further elaborate the hidden quality of the signs and symptoms of EAD, allowing the person with EAD to vacillate in their work stages, perhaps even reverting back to explanatory work, revealing the fluid nature of these stages.

Seeking answers. A third condition necessary for recognition work evolved around the diagnostic process itself. Individuals with EML changes must recognize that their changes have significance in order for them to present their concerns to a health care professional for investigation. They must be willing to seek answers for their troubling behaviors. For many persons with EML, their families initiate the visit for diagnosis as the changes become undeniable. Much focus in the literature has already been placed on the family's perspective and role in the diagnostic process. For this study, however, the patient's perspective was sought for people with EML very early in the change process of probable EAD. Just as the patient must recognize the significance of their early changes in memory and functioning, so also must the physician and other health care professionals be cognizant of the significance of these reported functional changes. Crucial at this point is the attitude of the diagnosticians towards listening to the person and giving credence to their concerns. In fact, at this point the clinician can be a critical motivator in moving the client towards a more open awareness context.

Varied avenues of diagnosis existed for the people with EML in this study. Some actively sought input from their physicians, stating their EML changes were the trigger to seek help. Rev. V., the minister, had noted changes many years previously but "back then

I figured then I was just getting older.” As the EML changes became more persistent, he mentioned this problem to the doctor, but was told to “wait and see.” When he mentioned the EML changes again on his next annual visit, “my doctor said since this is the second time you mentioned it, I guess we can do some testing.” He acknowledged “my memory changes are what drove me to the doctors that time.”

Some were able to share their changes with a close friend who then encouraged them to receive further evaluation and assistance. Mr. M., a retired salesman stated “It wasn’t a physical or a medical problem, so I saw no need to share it with the doctor ... I had enough heart problems and things to worry him [the doctor] with.” When questioned further for the reason he did not share this change with his doctor, he stated “I didn’t think that this was the kind of thing that you bothered the doctor with.” This particular gentleman was able to share his EML with a neighbor who had the same problems, and it was she who referred him to this study, and I in turn referred him to his primary physician.

Some people who possessed the initial recognition of symptoms needed further prompting by health care professionals to assist them in realizing the significance of the changes. Ms. A, a retired nurse, was aware of her problems with forgetfulness; she was even able to use the term “early memory loss” as a self diagnostic label for her problems. She was seen carrying around a copy of a recent Newsweek magazine with a cover story on Alzheimer’s, perhaps gleaning information and diagnostic terms from this. When she spoke with me concerning her memory changes, she shared that “I wouldn’t think of discussing EML with my doctor.” When it was suggested during our interview that she might have a significant problem, she voiced her amazement, stating “Do you really think this [memory changes] is a problem?” When her sons actually initiated taking her to the

physician for the assessment and workup, Ms. A. acknowledged that the confirmation of her diagnosis “came as a blow.” Perhaps it was the official validation that was so devastating, because she had been telling me for months “there is something wrong with me.” When asked, she did not remember dialoging on that day with her doctor regarding the EML changes, she just remembered that “my sons were with me in this meeting about my life ... and she [doctor] gave me a new pill.” These stories confirm the perception that some people are not trying to deny their symptoms; they simply believe that only medical problems are of interest to doctors, and they do not perceive memory changes as “medical” or a reportable symptom.

Some did not initiate the encounter for diagnosis, waiting for a family caregiver or family doctor to initiate the conversation, but then readily participated in the dialogue. Ms. F. admitted that it was her doctor who initially noticed her changes and then validated these changes with her and her husband during an office visit. She was evaluated and started on drug treatment (Aricept). In this case her physician knew her well enough to notice slight changes in functioning, and was proactive in seeking a cause. Both of the F’s expressed great comfort that their physician “knew her well and knew what he was doing.”

Some individuals were “put on diagnostic hold” by their physicians, not receiving a definitive diagnosis so they assumed other causes for their EML until it was too late in the disease process for open interaction. Mr. H., the attorney, shared his experience of being tested at a large research and diagnostic center. “I went through some tests, I think G [wife] was concerned whether there was any disease factor involved or if it was just a normal memory loss. As near as I can recall they said no ‘disease’.” His wife shared with

me, "I was furious, as it left [husband] thinking nothing was wrong with him, and more importantly he could have been put on Aricept much earlier in his disease process." A number of people with EML and their families in this study shared the same process of being told a "non diagnosis," and/or being asked to "wait and see" if symptoms progressed. Families were often given the Alzheimer's diagnosis much later in the disease process, when EML changes were quite obvious, but the person with EML's ability to meaningfully interact was lost. Since the doctors never discussed the possibility of Alzheimer's, the clients with the EML changes were left in a diagnostic limbo, unable to benefit from dialogue and the work process described in this research.

Ms. W. was acutely aware of her EAD changes and had been in an open awareness context with most people for some time; however her physician was not as open with her as she wished. She expressed exasperation after one visit to her family practice doctor, complaining that he focused on how well she was doing. "He said, H., you should be proud of how well you are doing" but, she continued, "that doesn't give me a memory!" Perhaps she was looking for support for her memory changes, and she felt that he focused only on her physical status. Perhaps he was minimizing her memory problems, not to be insensitive but to accentuate the positive. The end result, however, was her frustration with his inability or unwillingness to dialogue with her about her memory changes.

Again, awareness context was an important condition for diagnosis. For some persons, especially if they were in an open or suspected awareness context, the diagnostic process confirmed their initial suspicions. For others, it was the signal event for their recognition of the severity of the problem; still for others it was simply permission to continue in a phase of closed awareness context. The consequences of continuing in a

closed or mutual pretense context is that the diagnosis is not pursued and the person with EML remains uncertain about the cause of their EML.

#### Diagnostic barriers to Recognition work

What should the role of the physician or health care practitioner be in the diagnostic process, the process that could possibly confirm EAD and assist the patient in moving towards the process of recognition work? If diagnosed, when and how should the person be told about probable EAD? The American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society compiled a consensus statement, stressing the importance of early evaluation and accurate diagnosis (Smalls, Rabins & Barry 1997). However, many barriers still exist to the diagnosis of memory problems which are true dementias. Some studies suggest that the under - diagnosis of dementia might be as great as 50% (Callahan, Hendrie, & Tierney, 1995; Doraiswamy, Steffens, Pitchumoni & Tabrizi, 1998). Barriers to correct identification of this group of clients include failure of physicians to recognize and respond to dementia symptoms, perceived lack of need to determine a specific diagnosis, limited time for evaluation, and negative attitudes on the part of the diagnosticians towards the assessment and diagnosis of EAD (Boise, Camicioli, Morgan, Rose & Congleton, 1999).

In an effort to better understand the reasons that primary care physicians do not diagnose people early in the dementia process, 5 primary care physicians specializing in the care of the elderly were interviewed as a subsample of this study. Each of these physicians had a significant geriatric practice, and were well versed in the care of this population.

When comparing the diagnosis of AD to other medical diagnoses of aging, few of these physicians felt that anyone gave the diagnosis of AD much attention or priority. One

doctor shared that “the disease is too elusive, too insidious and too unpredictable,” emphasizing that the very nature of the disease itself interferes with an accurate diagnostic. He compared AD with heart disease with its well known risk factors, symptomology, and treatment protocols. He went on to say, “Alzheimer’s is very negative, it’s like a big cloud out there that we still are not grasping.”

All the physicians did the initial diagnostic workup for suspected AD in their office, only referring to a neurologist if the patient presented as “something different, like very rapid or progressive changes,” “something I’m not sure of,” or “if the family wants a second opinion.” One noted geriatrician discussed neurology referrals. “No, it’s not cost effective, it takes 3 - 4 hours, it’s a very labor intensive exam and it’s difficult for the patient with dementia to tolerate this.” This is an interesting comment because most elders routinely receive referrals to specialists for many of their other chronic illnesses, including cancer, coronary artery disease and urology problems. Perhaps the physicians are attempting to “protect” the patient from an accurate diagnosis, suggesting that the diagnostic process is too traumatic, related to the social stigma discussed below.

Consistent with the Boise et al. (1999) study, none of these physicians felt that a real priority could be placed on AD diagnosis until more effective treatments options were available to patients and their families. As one long time practitioner stated, “When it deals with the glory of medicine, the gratification of a cure, there is a lot of that. If there isn’t hope for a cure, then people tend to look at other things.” These doctors were expressing the social contextual values of medicine, which are centered on curative factors. If cure is not a possibility, then many practitioners simply minimize the problem of AD until behavioral symptoms emerge later in the disease process and require management. By this time, the patient and their families are often in crisis. One doctor

succinctly voiced what appeared to be a common condition for diagnosis to occur when he stated, "For us to have an interest to diagnose them early, we need to have something we can do."

What makes the physician initially suspect a memory problem and what are the signs they look for? When does a symptom (i.e. memory loss) become a sign of a disease (i.e. EAD)? Some of the physicians stated they could pick up diagnostic clues during the office visit, for example, a patient's hesitancy in answering questions. Dr. A. stated that he watches for hints while taking the history and physical. "I ask them questions about a scar, or what medicines they take, if they hesitate or look to their family for coaching, I know there is a problem." Dr. M. stated, "rarely does a patient come in and self report, a family member usually clues me in first ...and they tell me in secret, so I have to be careful not to divulge to the patient what I know." He felt he was walking a careful line of trying to diagnose the patient and have them discuss memory problems while not revealing the source of his information.

All the physicians cited similar social structural barriers to the diagnostic process, including temporal issues and concerns of stigma. The temporal barrier of "lack of allotted diagnostic time" was especially pertinent if the person did not present with specific memory loss complaints. As one doctor stated "Medicare pays [only] for the chief complaint, so unless they come in stating they have that problem, and mostly they don't, then the whole organization is focused on the chief complaint." These physicians were commenting on the current social organization of medical care delivery, which emphasizes the reimbursement system rather than the person with the problem. Another temporal issue concerns the insidious nature of the disease itself. As Dr. M. stated, "It's not like

someone walking down the street experiences chest pain and boom, you go to the ER and you know right then ... this other thing [EAD] kind of comes and goes, waxes and wanes over time, you have good days and bad days..." The problem becomes one of knowing when to pursue the symptom, for example, when does the memory change become significant enough to require further diagnostic testing? Perhaps the patient experiences symptoms that are not of significance to them at the time, and /or the symptoms are so varied and hidden so as to not arouse suspicions, thus they are easily ignored. The problem is compounded by the hidden nature of the symptoms, and the patients' discounting of their changes discussed in the previous section.

All of the physicians spoke of the social stigma of the AD diagnosis as a barrier to early AD diagnosis. There was a strong sense that no one, neither the physician nor the patient, discusses this disease unless forced to. One doctor used the comparative analogy of an AD diagnosis to "people coming out," paralleling the stigma of being gay to that of dementia. He also discussed how famous people such as President Reagan admitting to AD helped the cause of early detection and diagnosis, again much like famous people acted as "cause celebs" early on in the gay movement. He further went on to discuss the "triple jeopardy of aging, mental illness and a dementia," stating "there is no glory, and lots of fear, with this diagnosis."

None of the interviewed physicians routinely screened for memory changes. Dr. O. stated, "It's interesting, we screen for hypertension every time someone comes in, [by taking blood pressures] but we don't routinely screen for dementia, so we don't pick up a lot of people." Dr. Mc., a female family practitioner, was holding out hope for the efficacy of Aricept before she began routine screenings for EML. "If there is nothing that

can be done for it, than no .... because the diagnosis is so devastating. But if Aricept does what it is supposed to, then yes, screening is warranted.” All the physicians mentioned the issue of nonpayment for screenings. Dr. A. stated “... you have to deal with the simple fact that Medicare and other payors don’t reimburse for screening for dementia, ...so we don’t actively pursue it unless it’s brought to us,” meaning the patient or family member must present with memory loss as a focused complaint. Of course, this lack of screening in general medical practice is contrary to the consensus that early evaluation and accurate diagnosis of AD are critical to improved outcomes in this population. One study that looked at the issue of under diagnosis of dementia in general practice suggested that when a physician has an established relationship with a patient, he/she needs only to take a few minutes to use brief cognitive tests and ask a few questions of relatives regarding functional abilities, which would “improve their diagnostic accuracy considerably” (O’Connor, Pollitt, Hyde, Brook, Reiss, & Roth, 1988).

All the physicians mentioned the importance of the family and the need for social support for the patient and the caregiver. Yet this focus on the need for social support did not translate easily to the typical medical model of practice. The lack of social structural supports, and the fact that diseases such as EAD require a biopsychosocial approach to care was evident in many of their statements. Dr. M. spoke passionately about the need for a supportive network to assist physicians working with EAD patients and their families. “I can’t tell you how many times that I had a hard time saying, ok, this is what happens but I can’t tell you where you can go ...I ended up calling [the hospital social worker] and saying “what is out there?” Again he compared the lack of resources readily available in the community for the AD population to what is available for the AIDS

population, citing that the HIV community has pulled together a cohesive network of community support that other groups could emulate.

Another physician stated he was not even aware of what the Alzheimer's Association could offer, or even that there was such an organization locally. Others knew of the organization and had pamphlets to give to people but no real time to spend with families and clients to explore the best care options. My own experience with a family member with AD was to have a physician offer nursing home care as "the best option" after the initial diagnostic visit! It was I who shared with him our preference for adult day care and other in-home options until long term care was necessary. One physician, Dr. B., seemed quite focused on the emotional needs of the caregiver, stating that he uses the office visit time as an opportunity to teach and listen "because they get very caught in 24 hours a day care taking and before you know it they don't have a life. They're unhappy and care needs to be given to the care giver." He allows them time to talk and ventilate, acting as teacher and advocate. None of the physicians mentioned the emotional needs of the EAD client, another important focus of this particular research.

#### Social psychological consequences of Recognition work

Many people could readily articulate the social psychological consequences of recognition work regarding their EML. They spoke of being embarrassed, frustrated, irritated with themselves, and self critical. For many of them, their response was to withdraw, immobilize, and "feel frustrated," "helpless" and "not in control." Mr. M. stated, "I have flashes of frustration, especially when I'm driving and I realize I don't know where I am." He voiced concerns which indicated his awareness of the resultant safety issue of continued driving.

Mr. B, who had early age onset AD, shared that his initial memory problems caused frustration, especially in his relationship with his wife. This client was especially apprehensive because his father had been diagnosed with early age onset dementia and had died at a young age. He stated that because of this familial history he became more fatalistic in outlook and depressed to the point of being suicidal. He expressed that his diagnosis caused him "apprehension to the point of sheer terror."

In contrast to those who responded to their EML changes, the issue of memory change and loss seemed to be a nonevent/nonissue for one woman. She would vacillate in her admission, and only occasionally in the context of a support group would she would admit to changes. At one point she did acknowledge "it's the hardest thing to admit" and shared "it sometimes makes me feel bad." In another group session she recalled a conversation she had with another group participant, where she agreed she was "not as capable as 2 years ago." Perhaps this opportunity to connect with someone and find a commonality was enough to allow her open and honest expression. Her lapses into denial could simply be attempts at self preservation, or, possibly, her disease progression was able to ameliorate any frustrations.

Another client stated, "At first I just tried to ignore it and keep on" but after her physician diagnosed her as probable EAD and gave her a prescription she stated, "I just trust in the Lord's will and use plenty of prayer." She spoke of accepting the changes of the disease but still expressed the hope that she could maintain some normalcy. She adapted to her changes by choosing a lower level of involvement in her community volunteering, and was able to express satisfaction that this was the correct decision for her.

### Summary

This chapter identified the core concept of identity work for people with EML, and the importance of the condition of an open awareness context. It included discussion of Explanatory work and Recognition work, the first two stages of Identity work. Conditions necessary for Recognition work included increasing self awareness, monitoring personal changes, and seeking answers for their changes via the diagnostic process. Diagnostic barriers to Identity work were identified, as well as consequences of Recognition work. For most people, Recognition work required effort for them to come to know they had a problem with EML and probable EAD. With an increasing self awareness, monitoring the changes in self, and seeking reasons for the changes, they worked to understand what was happening to them. The gradually developing awareness initiated a changing identity and led to the need for Disclosure work, involving disclosing the meaning of EML to others, discussed in the next chapter.

## CHAPTER 5 DISCLOSURE WORK

The previous chapter explicated the core process of Identity work, and the initial stages of Explanatory work and Recognition work, the latter involving the beginning of acknowledgment of the meaning of EML to the self. Recognition work set the stage for Disclosure work because it elicited concerns such as, “can I measure up,” or “can I function?” This next stage of Disclosure work involves revealing the meaning of EML to others. The continuum of Disclosure work involves nondisclosure, selective disclosure, and finally, open disclosure. Emotion work was required throughout this disclosure continuum as participants dealt with their increasing vulnerability. Initially, participants had as a goal nondisclosure, and aimed their efforts at masking, or saving face, because, as they realized their EAD was intensifying, they expended increasing efforts to conceal the progression. With time and disease continuance, some participants gradually confided their changes to family and friends through a process of selective disclosure. Subsequent open disclosure, either deliberate or inadvertent, resulted in revealing EAD, and, often, losing face. Losing face frequently strained the relationships between family and friends, unveiling the emotion work fundamental to this stage of Identity work.

MacRae (1998), building on the earlier work of Hochschild, discussed emotion work from the perspective of the caregiver, showing the human costs of caregiving work. The former author described emotion work as “...the type of work it takes to cope with feeling rules” which in turn “guide emotion work” (p. 142) and how failure of emotion

management negatively affected the caregiver's sense of self. While these and other studies focused on caregiving as emotion work, there were no studies found which discussed the concept of emotion work from the perspective of the person with EAD. Keady and Nolan (1995a) did interview 10 early dementia sufferer's, assessing their strategies on coping and compiling their accounts into the Index for Managing Memory Loss (IMMEL), a tool useful for gauging the coping responses used by persons with EAD.

Emotion work in this study can be described as the intense psychological work necessary to adjust to the changes of EAD, and subsequent living with the diagnosis. Emotional pain surfaced as the participants attempted to come to grips with their losses. It was emotionally stressful and challenging to keep the secret of EML, and tension escalated as the ability to maintain their secret broke down and disclosure of their EML loomed as an immediate threat. Awareness of the Emotion work involved in planning and executing covering strategies surfaced through the participants' stories of compensatory behavior. Early in Disclosure work, the participants described the emotional challenge of keeping their EML secret, followed by the stress involved in selectively revealing their secret, and finally the flood of emotions and upheaval associated with open disclosure, especially forced disclosure. The element of Emotion work inherent in Disclosure work assists in understanding the person with EAD's increasing need to manage their emotions in response to their actions and interactions as they cope with their loss and decline in their changing sense of self.

### Nondisclosure - Maintaining Secrecy to Save Face

The goal of secrecy became especially evident as covering increased, requiring much psychic energy. Many people described the intense efforts required to cover and hide their worsening disabilities by employing the use of secrecy. Bok (1989) discussed secrecy as “a related set of tensions: between concealing and revealing...” (p.36). She suggested secrecy functions as a “safety valve” between privacy and openness. At a later point, some people were able to disclose their EML changes to others, but at this point in their disclosure work, most admitted to embracing the goal of “concealment, or hiding ... the defining trait of secrecy” (Bok, 1989, p. 6). Ms. J. admitted to the use of secretive behavior when she expressed, “I don’t discuss this with anyone ... there’s not much they can do anyhow.” Ms. V. also admitted, during a discussion with the EML group, “you do not talk about it.” Acting in her usual mode of mutual pretense awareness context, she also stated she would not consider sharing her changes of EML with others, since “I don’t know if they are trustworthy.” At this point in their disease, these efforts at secrecy and concealment act as a protective mantel, and are effective as long as the person can maintain the techniques of impression management. Many were able to verbalize their efforts at nondisclosure. Mr. H. stated, “I didn’t choose to advertise it, I’m concealing my disability.” Mr. T. admitted to the negative repercussions of exposure when he said, “You can’t tell others, it would be too costly in terms of my job.” For some persons with EAD, the fear of exposure affected their self image. Ms. V. admitted that her fear of not doing something right often led to “not doing some things at all;” Ms. A. also admitted to fear of ridicule with exposure of her EAD changes.

In another support group (Alzheimer's Association, 1995a), participants consciously maintained secrecy, since, in EAD, one can often still deliberately choose effective strategies to assure success. One woman stated, "...to me, succeeding with this disease was always keeping a smile on my face, [and seeing] how many people I could keep this from, because the last thing I wanted was sympathy, and that's what I always ended up getting." A gentleman, still engaged in sales, stated in response, "You ask whether I tell business people [about EML]. I do a lot of advising, how to do this in business, how to do that. And no, I don't tell them, then they would have no faith in me." A family member attending a support group that I offer for family caregivers, shared with the others, "her [wife's] doctor told us not to tell people she has this dementia, since she still can function quite well in social situations." The temporal nature of EAD, with its slow onset and progression, would appear to give direction to people as to the timing of disclosure. Unlike a disease with a sudden onset, in the early stage there is time to think, consider consequences and use compensatory strategies in an effort to maintain the goal of secrecy for as long as possible.

#### Use of Covering Strategies to Maintain Non Disclosure

Before individuals with EML could begin sharing their EML changes with others, their ability to function in the world had to begin changing and declining, and they had to be willing to admit these changes to themselves. Even though changing functional patterns were noted by people with EML in the explanatory and recognition stages described in Chapter 4, the individuals now described intensifying efforts to deal with their increasing decline. It was at this time that the social interactional strategy of covering was increasingly used in an attempt to maintain their secret and deflect the

meaning of the changes to others. Many participants with EML freely discussed using this strategy, which was compensatory in nature and helpful for persons as they tried to pass as normal.

Goffman (1959) wrote extensively about the scenarios which take place as individuals with abnormalities interact, and the interpretation of these actions by others. He elaborated on the person's need to control "performance disruptions" through "impression management techniques" such as with the use of compensatory strategies. For example, when the person with EAD can no longer sustain the expected interactional norms, they often use increased efforts to "cover" in an attempt to "pass" as normal (Goffman, 1963). Aware of the stigma attached to their changes, and the subsequent consequences from these changed interactions, the person becomes more guarded in his/her interactions with others. As the following examples illustrate, people with EML in this phase of their identity work were aware of their lapses, and made every attempt to hide their problem.

For many, the resultant functional problems that developed from EML, and the increased stress from the use of compensatory strategies was especially evident if the person was still engaged with others while working in a professional capacity. Rev. V., a retired minister, was still working as a consultant; Mr. H. related the problems he experienced while trying to maintain his law practice; and Mr. T. shared his dilemma of trying to continue working as a technical engineer. Each told how they developed adaptive strategies by managing their environment differently, in order to survive. They described how they knew their sense of self and their interaction with their world was deteriorating. They were able to recognize their "changing self" and respond

appropriately, even if only for a brief period of time. The strategies were creative and specific to the persons' perceived deficit, and there were as many types of covering strategies as there were different situations:

#### Getting help from others

The minister consultant missed the previous "structure" that his office provided. He recognized that "all the things that could keep me straight, like calendars and a secretary to remind me, are all gone now and those things helped. ... I try to cover it up but inside I'm scrambling." He developed specific strategies to cope with these losses, (i.e. delegating to others, telling others close to him, and asking for help). He was aware of the loss of his abilities in the higher level cognitive functioning areas such as "problem solving" or "putting things together," and he expressed that he knew that he must now "plan in advance," and even faced the possibility of retiring.

#### Writing down, looking up

For some individuals, job performance was affected because of the work effort involved in developing compensatory tactics. The attorney shared his difficulties of trying to listen to comments from the opposing attorney or directions from the judge. "To the extent that I could take notes, I could then refer to them but it was difficult because people were talking fast and I couldn't take notes, then I couldn't remember what was said. When I got up to cross examine, it wasn't there, I was lost." The technical engineer admitted that he began to forget verbal instructions, especially the steps involved in the sequencing of procedures. He noted that he was more inattentive and had to compensate by an elaborate system of writing down the instructions, then transposing the information

to audio tapes, then making notes from the tapes. The strategies became "exhausting" and finally "unmanageable;" eventually he lost his job.

For those not actively employed, various strategies were still required for them to continue to function independently. Ms. J. demonstrated how she wrote everything down on multiple calendars. She also summarized her conversations in mini-notes to act as a memory aide, "if you forget it, it doesn't come back ... writing it down allows me to forget it and be at peace." She stated she was "aware that this is different than regular memory loss" and consequently "I have enough sense to not get involved in anything legal ... I know I would need the help of someone trustworthy." Ms. H. also admitted to keeping multiple calendars, one with summary notes of daily activities on it, one for appointments, and one for "anything extra." For these women, the multiple calendars became a visible and symbolic replacement for their loss of memory.

Emotion work emerged as people shared the increased tension in this phase, resulting from their cycle of ever increasing failures, and the continual need to cover by producing creative responses to their deteriorating memory. Interactions with family and friends were especially stressful as the person with EML could be easily "found out," particularly as they began to forget basic information like names for family and friends. Mr. M. kept these names and phone numbers in his wallet for "handy reference." He also frequently found himself rushing back to his apartment to look up friends' names in his housing directory, especially after immediately passing them in the hall and being unable to remember their names. His voice tone conveyed his stress and frustration with these necessary strategies, especially with their increasing occurrence; "every time I pass someone in the hall I have to come home and look up their names, this is no way to live!"

Both Mr. H. and Mr. T. wrote the names of their grandchildren and family members in their rolodex to use as hidden reminders as they were speaking to them, and several people discussed the common strategy of writing “everything down in multiple places.”

Two of the gentlemen discussed their increasing reliance on maps to continue driving around a familiar city. Mr. T. stated, “I really feel in control when I know I can stop and use my map as a backup, then I don’t have to depend on anyone to take me places. I still feel safe and so far it is working.” Mr. H. was actually able to drive himself to our first scheduled interview without any difficulties, stating he had “written directions, and a map as a backup, which I didn’t need to use.” The use of familiar strategies, like using a map as if they were in a strange city, gave these gentlemen a sense of continued involvement and self reliance. Mr. M. also admitted to changes in his driving ability when he stated “I don’t feel in complete control.” He voiced his need to “concentrate and be more alert,” a compensatory strategy that continues to work for him in his early stage of EAD.

### Bluffing

As functioning progressively worsened, developing complex strategies became necessary to survive. Mr. T. used his previous verbal skills, “I bull my way through.” Mr. M. also used his verbal skills, with his approach of “telling jokes” to cover, while stating “if I can remember the punch lines.” Ms. F. shared with amusement that she specifically allowed herself to memorize the responses to the “test questions” [MMSE] asked by the neurologist and took great delight in giving the correct responses on the follow up visit; her husband verified that she in fact did this. Ms. A. confided that she was able to “fool her son” regarding taking her daily medicines. When he called her to ask if

she had taken the medicines, she replied in the affirmative, and then used this cue to take her pills. She admitted to this being “a little white lie;” she was strategizing to cover herself. She also proudly related a clever strategy to cover her problem of forgetting names in conversations; “I ask them, how do you spell your name?” She believed this allowed her the ability for continued interaction while covering her forgetfulness.

#### Self correcting errors

Two of the respondents had been librarians and were quite aware of their early efforts to compensate and “cover up mistakes” in an arena of work that required perfection. Ms. H. said, “When it was quiet and I was able to think about it, I could fix the problems and no one would see.” The husband of Ms. E., the other librarian, shared that “her coworkers told me later that they were finding lots of whiteout being used on the cards and that just wasn’t like her, she used to be perfect at that job.”

#### Avoiding by using the sick role

Some participants chose to hide behind the sick role, since this role is socially acceptable and can be useful in avoiding interactions. Mr. M. stated that he began to avoid the early morning walks with the guys in his retirement complex by using the excuse that he was the caregiver for his sick wife, even though he had a home health aide in to perform the heavy “bed and body work” (Gubrium, 1975) each morning. Mr. H. used his chronic bad back as a reason to give up his law practice, when in reality it was the excuse he needed to close his practice. He shared, “the hospital stay, along with the recuperation made it difficult to get back with any continuity to the practice so I closed it out and I’ve always been glad that I did. I really shouldn’t have been practicing law probably as long as I was because of the memory thing.” Ms. W. at one point related her new onset

problems with reading to “aging eye problems” but later admitted that the problem was more; it was a difficulty with concentration. Mr. M. also admitted to the same problems with reading and concentration, finally conceding his problem had more to do with memory changes.

At this stage in their disease, it was evident that the recognition work done in the earlier phase allowed people with probable EAD to make use of their increased awareness, and this insight allowed them to use compensatory strategies to focus on important tasks, such as driving. Since the typical story ones hears regarding AD and driving is that the person just drives until he/she is “lost or out of gas,” these stories show us how the creative use of personal strategies allows individuals with EAD to facilitate their abilities early in the disease process.

For each of these participants, preplanning ways to cover for their changes was an important social interactional strategy necessary to continue functioning with EML. The ability to compensate and self correct early in the disease and thus attempt to hide the functional changes was evident, but the effort involved became more difficult with disease progression. Exposure of their EML to others became a real threat of continued interaction. As Goffman (1959) expressed, performance disruptions have real consequences at the level of interaction; such that “life may not be much of a gamble, but interaction is” (pg. 243).

At this juncture in their disease process, some person’s with EML were able to begin the necessary step toward identifying themselves as persons with EAD. Again, an open awareness context was central to persons being able to progress to this step. If family members and/or physicians were in a closed awareness or mutual pretense

awareness context, then persons with EML were not encouraged to progress to the next step of Identity work.

#### Selective Disclosure - Assistance From Others

People desired to “name” their EAD changes; they also experienced increased tension from attempts to prevent inadvertent self disclosure. This increase in Emotion work, and the drive to search for a cause of their changing symptoms, eventually allowed for selective disclosure to others. The process of disclosure can be considered a type of social work, occurring in response to social interaction. Since the self is constructed through social interaction, and people derive meaning from these interactions, many persons with EML recognized the changes in themselves and reacted to them in response to others. Timko and Moos (1991), in analyzing various dimensions of social climate, found that increased self disclosure, in interaction with others, to be a construct of personal growth. For many in this study, the concept of self disclosure through interaction encouraged persons with EML in their work of admitting to the disease of EAD and to a changing identity. Conditions that facilitated the self disclosure process included the group process, the opportunity to talk with an interested professional, and interaction with friends.

#### Group Process

In an effort to interact with people who were experiencing the early stages of memory loss, I initiated a time limited, closed support group in a religiously affiliated retirement complex. Four people with EML agreed to dialogue about their condition, meeting bi-weekly for six sessions in a semistructured format focused on issues of concern to all. The participants initially shared comments such as “I don’t think we would have ever known that the other people in the room were having the same problem as us.”

Their difficulties remained well hidden at this early stage and were simple to cover, thus it was easy to maintain a closed or mutual pretense awareness context with others, until the person felt safe to disclose their changes. It became apparent that the group process was therapeutic for these participants, as some shared that they were talking for the first time about the changes happening to them and the effects of their interactions with others. Ms. W. stated, "I think it's [EAD] terrible and hard to admit to. But I think once you admit it, you can say it out loud and you say it to somebody else, you don't feel as badly. This is what I have done." Mr. M. admitted, "Well, frankly I didn't really pay too much attention to it [memory problems] till H. was telling us [he and wife] about it and then I told H, well you're not the only one that has memory problems - I have them too".

Yale (1991), credited with starting the first early stage support groups for patients with EAD, stated that support groups allow for "anticipatory grieving for the losses and planning for changes which the disease will render" (p. 1) and have the effect of a "mental health intervention" (p. 2). Keady and Nolan (1995b) found that "not all early sufferer's wanted to continually share their experiences with family and friends, and would have valued a confidante who was less intensively and personally involved" (p. 378). In this study, the group process allowed and even facilitated some participants to progress to an open awareness, and an admission of their EML problems. During the remaining sessions, those able to continue on the path towards an open awareness context experienced the benefits of interpersonal sharing, which translated into personal growth and acceptance.

#### Availability of a Professional

I ran an ad in the newsletter for the senior retirement facility where my office is located, soliciting people for a support group who were in early stages of memory change,

and also on medications for their memory, e.g. Aricept. Ms. W. responded, "That's what made me answer, when I read your ad." "I thought about it for quite awhile, because it is a kind of exposure." She continued, "and I had that [article] put away and I had a circle around it. And it took me a long time." When asked the reason for her hesitancy she shared "... it is easier to admit to a physical problem that everybody can see anyway than something that is mental. I have always been bright. I was a good student ... and then all of a sudden to find out that it was a mental disability of some kind was hard for me to swallow." She went on to tell me that the article, and her decision to talk with me, spurred her to confide in her friend, and also her son, "... and I told her about this appointment I had with you. I hadn't told anybody. I'm a little ashamed of it for the reason [EAD]." She continued, "... I had written on the article "tell M [son]. And I didn't tell him for the longest time. And when I did he said "mom, good for you, I'm proud of you."

Many residents of the retirement complex often stop by my office to chat and share their problems. The "word of mouth" approach had spread the word that I was "studying memory problems," and prompted people to seek me out. It was during these "drop in" visits that some of the participants met and confided in me their initial memory loss story. As previously stated in Chapter 4, in the section on awareness context, and also in the section on seeking answers, the availability of a professional who can encourage an open awareness context, as well as give credible information and feedback, is crucial for many people to begin their efforts at sharing their problems with EML. Conversations with some of the group participants continued after the group ended, since they had a habit of frequently dropping by my office and sharing their changes and struggles. Ms. A. stated,

“If I didn’t have you to talk to around this place I think I’d go crazy.” Ms. W. stated, “You know what’s going on with me so I can tell you...”

### Friends

For many, the initial disclosure process involved selective sharing with friends. Ms. W. admitted that she would not expose herself or her confusion to just anyone by talking about EML. Rather, she selectively chose to get to know some people better before allowing the exposure of her self. Friends seemed able to facilitate the work of disclosure because they appeared understanding of EML. Mr. M. stated, “They know it, and accept us.” One of the matriarchs of the group shared with me “I went through this [dementia] with my husband, so I can understand her [friend].” Ms. C. stated that her friends were aware of her memory problem and supportive of her, “I don’t have any friends who do not know that something is happening to me - and they respect that.” Her strategy was to alert them, “I let them know ahead of time, I tell them I may not remember what you did ... I let them know.”

Interacting with friends involved the friend’s efforts at normalizing and minimizing problems with EML. If someone in the group had EML problems, it appeared easier to interact if they had been long time friends, for they were able to draw on long term familiarity to help with connections, as well as trust. Many of the people in the retirement community were religiously and familialy connected as “lifelong friends and family” and most had known each other since childhood. Ms. R. stated “I’ve known these people since I was a girl, I can keep up with the conversation because I know who they are talking about, it’s all familiar to me.”

Those able to do the disclosure work successfully, even with the decompensation from EAD, had improved interaction among friends, because friends were generally supportive and accepting of the changes. Friends seemed able to facilitate the emotion work required in this phase; they were able to realign the emotions of the participants and help mitigate the emotional pain associated with the EML. Ms. W. admitted that she felt friends were more understanding than family because "they are not as critical, and they can also help us fill in the pieces we forget." Ms. W. also shared that she was able to admit to friends when she was having good days versus bad days, and she conceded to feeling comfortable doing this. Probably it was her open awareness context with her friends that allowed for this comfort. In contrast, when Ms. V. expressed to the group that sharing your EML with close friends can "put you right," she also felt she had no one with whom to share her EML troubles. Ms. W. chided her for "being a loner" and told Ms. V. that she was responsible for being alone. She encouraged her "to reach out," that "being open is better," while admitting to Ms. V. that the hardest part is admitting to EML and asking for help.

All of the efforts at this point were compensatory in nature and focused on the idea of saving face in interaction with others. The next phase demonstrates the progression of EAD, and people's realization that the power of interaction can lead to loss of face. Emotion work now becomes palpable, as the full effects of disclosure are felt.

#### Forced Disclosure - Increased Disruption and Exposure

As the disease trajectory continued, people shared their frustrations of living with the increased failings of EAD, and the implications of the decline. The EML support groups provided a safe forum for the participants to share their fears and frustrations. Ms. A. disclosed that in the past she had used association of ideas to assist her in remembering,

but this strategy no longer worked for her, as it was too difficult to remember the associations. The plan of writing reminder notes did not help her now either, since she either lost the notes or did not remember to check them. Rather, the reminder notes only served to “make me think badly of myself. ...that would be telling me I’m going down in the hole fast.” The meaning to her was clear, “if I need these notes I must be declining.” She poignantly shared her feelings concerning her sense of the effects of her EAD changes; “you lose your personality, you lose your get up and go, your will to do.”

Many participants were aware of and able to discuss their experiences with what Goffman (1963) described as an episode of failed cover, or inability to sustain norms. During her second group meeting, Ms. A. announced, “This is my first meeting.” When the group corrected her, she began to cry, realizing her exposure. She lamented ...“I have sorta prided myself on my intelligence. I thought I was smart and now it is very degrading to have something like this happen to you. You can’t remember whether you have been to the bathroom in the morning or not. That’s bad!” Her sad and then facetious comments reveal her feelings in response to a forced awareness of her limitations. Ms. W. demonstrated that the problems of EAD were shared by the group when she commiserated with her and stated, “it’s the pits.”

Some families came to notice problems after an extended visit with their loved one; others came to the realization that there were problems when a specific incident forced them to take notice. These critical incidents or catastrophic events are often the cutting points that can force the exposure of the person’s EAD problems. Families then take notice, often for the first time. When catastrophic acts become public, someone intervenes and increases vigilance. Initially, Ms. A. experienced a mix up of medications that led to a

hospitalization; the family response was to monitor her more closely by bringing her medications to her apartment every morning. The critical juncture came when she had two dramatic episodes within a short time span, burning food and engulfing her apartment in smoke, and flooding the apartment while watering her plants; their response then was to turn off her stove for safety reasons. She interpreted this as "they don't trust me to do a thing by myself anymore, ..." and "hurt feelings." She frequently related her troubling incidents during the following group meetings; the incident clearly had made a dramatic impression on her. She voiced an understanding of the causation and consequences of her actions, "it's my memory that's gone," and "I did some crazy things that got me in trouble, now they don't trust me."

Rather than one dramatic event, families and people with EAD often noticed a series of small slips that could not be denied. Ms. W.'s exposure with her out-of-town son occurred when she ran out of medications and admitted this to him on the telephone. She reported that he became upset and berated her, "Don't you know you have to take these medications for your blood pressure and your memory?" During his next visit, she was "caught" taking her pills incorrectly, and this incident, plus others that the family had been noticing, provided the opportunity for mother and son to discuss her worsening memory changes. He increased his vigilance by enrolling his mother in a support program that monitors her medication and day-to-day functioning. Interestingly, she let me know that she is grateful for this monitoring, because she is aware of her decline and appreciative of the outside support.

### Responses of Families

While friends were able to facilitate disclosure, families often hindered the process. As the trajectory of EAD continued and decline became more evident, there was often a

period of discord, or increased strain during family interaction. Tension management is part of the emotion work that caregivers face in caring for people with AD (MacRae, 1998) and in this research, both the people with EAD, and their families experienced the need for tension management. Much has been written about the strain involved with being a caregiver, but this study highlights the strain felt by both the family and the person with EAD. Transitioning with EAD led to changes in the role of family members, and an increase in conflict. Some families became enmeshed, and the consequence for persons with EAD was their fear of a loss of independence. Many participants discussed incidents of family relationship problems, expressing anger at their families for taking over, and frustration with knowing that now there was more interdependence in their relationship.

#### Increased family criticism

Forced disclosure, which was evidence of the participant's failing compensatory strategies, often caused increased strain in family relationships, and the support system of some family members was often found to be less than helpful. Ms. W. shared the strain that occurred after a family visit. She came in late to one of the support group meetings and expressed frustration that she had forgotten the meeting. She announced to a member of the group, "You were supposed to remind me!" She chuckled, but shared with the group how disruptive it was to have family visits. Her son had just left from a week long visit; she was visibly shaken and exhausted, and he left distraught and frustrated, later calling me to discuss the week's events. She mimicked his responses to her during the visit, "how come you didn't remember?" and "why didn't you?" She continued, "I'm beginning to feel with my son ... that I'm just down the drain." My observation has

shown that the increased pressure from these family visits can be very disruptive to the daily equilibrium of the EAD participant. In the case of Ms. W., each time that her son or her sister have come for an extended visit, she has experienced a period of decompensation, displaying incidences of increased confusion that are not the norm for her day to day functioning, even with EAD. For example, they were critical that she did not take her medications correctly, that she had problems with the telephone and radio, and she repeated herself more than usual, to the point that I suggested different arrangements for them on their next visit, to include separate lodging and limited periods of exposure. She was aware of her son's aggravation, "he meant it to be pleasant but instead stayed frustrated." It is as if the person with EAD feels the pressure of being on stage and having to perform correctly; they can only sustain their "up front performance" (Goffman, 1959, p.22) for a limited period of time, experiencing a type of performance anxiety and performing worse. When families leave, the person is exhausted, more disoriented, and needs time to regain his/her previous level of functioning.

#### Enmeshed / changed roles

Forced disclosure caused further erosion in the relationships between families and the person with EAD. During the support group process, participants freely discussed the changes they were experiencing as their boundaries began to change and their families became more involved in their changing lives. Their increased family discord mirrored the changing family relationships, especially as the roles of parent and children began a reversal. Many voiced the concern that their children had become their parents; in the words of Ms. W., "my son has become my father," Ms. L., "my daughter acts like my mother, you know" and Ms. A., "my son treats me like a child." The frustration of these

changed relationships came about when the participant felt that their child was overstepping their bounds in acting as a caregiver. Ms. A. vented, "my kid shows up like clock work every morning to give me a hand full of pills, including my daily forgetfulness pill; I'm a nurse [retired] for goodness sake, doesn't he know I know how to take pills? I don't need him to do this." Her frustration and anger at this stage was related to her family "taking over and making her decisions;" which is a typical reaction to enmeshed behavior. She often has mentioned that she appreciates her son's efforts to care for her, but resents the intrusion into her life. She interprets her sons efforts as being overprotective of her, allowing for no privacy; "they even want to go the the doctor with me!" Added to a loss of memory is now a loss of privacy. Her tactics to deal with her children varied from deception, "I'm going to switch doctors and not tell them," to resistance, one day she actually refused to go to a doctors appointment with her son, "he made the appointment, let *him* go." Her efforts to set limits relates to her need to maintain some semblance of control, at a time of loss and decline. She vacillated between a realization that her sons want to help, versus anger at them taking over, emphasizing the fine balance that family caregivers must walk when offering assistance to the memory impaired person. It is interesting that many participants expressed little problem with transferring the money management component of their lives over to their children; it appears that some areas of life functioning such as financial management might be felt to be less invasive than others such as personal and medical monitoring.

### Responses of Participants

Participants responded to their exposure and perceived lack of familial support with a noticeable change in their feelings of self worth. Their ultimate loss, losing face,

was taking place, and they reacted by withdrawing from activities that could cause them further embarrassment. The theme for this phase of disclosure work focused on loss and forced withdrawal; for example, Mr. H. and Rev. V. giving up their high profile jobs rather than face further discomfort, Ms. B. and Ms. T. leaving their volunteer roles, Mr. T. and Ms. J. losing their jobs because they could no longer hide their mistakes, and Mr. M. withdrawing from social situations. For many people with EAD, performance fear caused them to be self protective, and retreat from potentially humiliating situations. Participants spoke of giving up various recreational activities that no longer offered success, such as crossword puzzles, reading, and golf. They shared their emotional responses to these changes and losses, such as feelings of self deprecation, embarrassment, and frustration.

#### Changes in sense of self

Participants in the group were able to verbalize their increased feelings of self deprecation in convincing terms. Ms. A. expressed that she “feels like an idiot” because she was aware of “losing reasoning abilities;” she further opined that her problems with memory disrupts her daily living routine, “I still have so much that I want to do” and expresses disgust with herself for not accomplishing it. Ms. W. chimed in that she often “feels like the idiot relative...the one you shunned.” and further noting “your own self esteem gets lost with this.” [EAD] Later, Ms. A. stated that she has the ability to be accepting of her self, even with EML but believes if others knew of it, they would label her “nuts.” Mr. M.. vehemently disagreed with the “nut” label for EML, but all commented on the negative connotation of the word senile. Another consequence of forced disclosure of EAD for the participants was to express irritation with themselves, and embarrassment in interaction with others. Ms. J. admitted that the most difficult part

of EML is that "you feel kinda desperate." Ms. A. cried as a reaction to the realization that she had forgotten she had attended our first meeting, and her forced awareness of this by others in the group. She also cried as she reacted to the fact that she had forgotten her deceased husband's birthday; she voiced with frustration "I have never done that before, what is wrong with me?" The emotional undertones that continually surfaced in these people's stories reflected the continuing Emotion work necessary for Disclosure work.

The following is an example of a participant who remained mired in the painful struggle of the disclosure process, and was never able to move on to an acceptance of his AD. During our initial interview, the Rev. V.'s diagnostic status was in limbo, since he had not been told definitively that he had AD. "My doctor didn't think my memory loss was so bad, he wants to wait and see if it worsens." This contributed to vacillation in his decision making, for example, should he retire from his consulting work or continue, and conflictual statements concerning his decline in functioning, for example, "I'm not as sharp," "I can't cope like I used to" vs "it doesn't overwhelm me," and "I'm pretty positive." He still presented himself well, and was very upbeat and confident in his manner. He admitted to an awareness of his memory changes and early functional problems, could discuss the implications of his EML, and was realistic in admitting that he should probably plan for a restricted future.

Rev. V. had agreed to a follow up interview on his next visit to Jacksonville, but on his return one year later, he refused to honor that promise. He did consent to allowing his daughter (a nurse in the PhD program) to dialogue with him and share the information with me. He admitted that he was not willing to talk with me because he was "too embarrassed, and not the same" as he used to be. His statements revealed a much

changed individual, a man wracked with worry about the future, and frustration with the present. The issues that he now disclosed reflected the consequences of his continuing memory changes. He shared his "embarrassment with the inability to remember simple things, like names of people in church," and his constant worry that he would appear "old and stupid" to others, for example, not remembering how much money he gave someone, thus unsure of how much change to expect. He also expressed frustration with his decline in problem solving and functional abilities. Many of the experiences that he now shared reflected the loss of face that was occurring with continual forced disclosure, and few opportunities for positive reinforcement. He spent much time sharing with his daughter how he felt he was losing himself, that he is not what he used to be, and that since so much of him was about relating to others, he felt part of that was now gone. This statement is significant for him recognizing that his losses due to AD impact and diminish his interactional opportunities. He had made the decision to retire, and he poignantly gave his daughter copies of his sermons and books, seeming to symbolically give up the piece of himself that was most precious to him and that he sensed he was losing.

He acknowledged his memory was now worse, and because of this certainty, he was refusing further evaluation or retesting, stating "why spend the time and money when there is nothing that can be done." He stated that he was not anxious to do something that was really for someone else, of no benefit to him, and would only make him feel worse. His comments reflected his sense of despondency, and also an acute realization of his changes. She asked him if he was worried that God would forget him; he smiled and said no, but he was afraid that he would forget God, and he only hoped God would understand. His daughter reported that he was now "self isolating, and irritating to be

around.” He was able to discuss that his EML was getting worse; his reaction was negative and fatalistic. The effects of the disease progression reflected a very different person than the man I had met just one year earlier.

### Interactional problems

Forced disclosure, the last phase of Disclosure work, can be high risk for interactional problems, leading to feelings of devastation and alienation, and furthering feelings of decreased self worth in the person with EAD. Both Ms. A. and Ms. W. reached the stage of EAD where they intermittently experienced symptoms of paranoia. Ms. A. misplaced personal items, and then accused the housekeeping staff of theft; Ms. W. accused her son of saying “hurtful things” to her. Resultant interactional problems occurred with staff, family, and neighbors; as one neighbor stated “we are tired of hearing about it.” Ms. W. described in vivid detail her situational event, “I took offense to something that my son said and I worked myself up to a terrible pitch and I had a completely sleepless night over it and when I woke up in the morning, I didn't expect to see the same face in the mirror because I had been up all night long ...I realized I was being completely irrational. And that scared the hell out of me. I looked up the word paranoid. And I think that was a paranoid event because my son, if he did say something, certainly never intended to wound me, because he is a very good man.” Ms. A often gave her account of how “someone comes into my apartment when I am not there and takes my hose, my sweater, and things out of my refrigerator. This place is not safe.” Staff responded by either ignoring or disputing her claims; she then would storm around the front desk and proclaim “I'm moving out of this place, nothing is safe.” The poignant part was that both of these women would later realize their miscalculations, and then

express profuse apologies. One day Ms. A. admitted to me "I found my things you know, and I apologized to the girls, but I'm tired of eating crow."

### Exclusion

With the transitioning of EAD, strategies such as covering and hiding began to fail, forcing disclosures and even creating a strain in the support system of friends. People were "outed" by their failures in memory and behavior if they no longer could cover and perform. A social leader of the retirement community came to me one day "with a dilemma to discuss." She elaborated that although she was a friend of Ms. G.'s, she was concerned about an incident that had occurred when Ms. G. had recently appeared at a canasta card game and stated to the group, "What is this all about, I have never played this before." The group members were "shocked, because she had played well for years." Some in the group were becoming quite intolerant of her inability to play, since it disrupted their weekly card game. The dilemma was whether to choose to protect their friend and attempt to still include her in the card games, or to find a way to exclude her from the group. The leader eventually opted to ask Ms. G. to leave the group, "to protect her from hurt feelings from others" but assured her she was welcome back into the group "when she was feeling better, which of course I know will not happen because of her memory problem." EAD led to exclusion in other ways also. Ms. A. shared with the group her feelings when she was left out of a meeting between administration and her family concerning her "recent fiascos" of leaving the water running in the sink and a pot to boil dry on the stove. Although she understood the need for the meeting, she was angry at being excluded and marginalized. "She [administrator] called all three of my boys in for a meeting after I burned things up. I wouldn't have been so mad if I had been included. I

felt so hurt about that ...” Wood (1999) discussed Kitwood’s belief on personhood in AD being created (or diminished) in social relationships. As presented in these interactions, it was evident that friends’ supportive endeavors in the selective disclosure phase allowed for a preserved sense of self, while many of the interactions in this phase led to diminished feelings of self worth.

Charmaz’s (1983) classic study on suffering in the chronically ill identified loss of self as a fundamental form of suffering, with consequences of them leading restricted lives, experiencing social isolation, and being discredited. In a similar fashion, the above stories of forced disclosure reveal that some person’s at this stage of their AD experience a type of suffering from changes in self concept, interactional problems, and the resultant exclusion discussed above. If the person with EAD continues to experience interactional problems, fewer opportunities for positive reinforcement of self are presented. If the participants with EAD remain stalled in ambivalence about the disclosure process, their ability to progress to the next stage of Identity work is impaired.

#### Summary

This chapter focuses on Disclosure work, the third stage of Identity work. Disclosure work involves a continuum, beginning with nondisclosure, then progressing to selective disclosure and finally forced or open disclosure. Covering strategies to maintain nondisclosure are described, as well as conditions necessary for selective disclosure. Emotion work was found to be pervasive throughout disclosure work, as both participants and their families yielded to the progressive changes of EAD. It is proposed that the changes discussed in this chapter resulting from disclosure work provide a type of reality

testing for people with EAD, assisting them to begin the next stage of work, which for some becomes the process of Confirmation work.

## CHAPTER 6 CONFIRMATION WORK

The core process of Identity work, and the stages of Explanatory work, Recognition work and Disclosure work have been discussed in Chapters 4 and 5. In Explanatory work and Recognition work, the individual's sense of self was challenged as he/she experienced an increasing self awareness of EAD changes and gave meaning to these changes; in Disclosure work, they progressed through the stages of saving face and losing face, and for some, admitting to EML changes. This chapter focuses on how persons with EAD view their changing sense of self as they continue on their path of discovery integral to completing their Identity work in the early phase of AD. This fourth stage, confirmation work, requires the person to confirm or validate their EAD as the reason for their changing self, and to be able to verbalize this realization over time. As discussed in the literature review, many researchers have expressed the belief that the sense of self can be maintained in AD (Kitwood & Bredin, 1992; Kitwood, 1993; Sabat & Harre, 1992), if the person remains connected to others. Since these authors were discussing AD in its later stages, maintenance of self was frequently accomplished through the agency of others and a supportive social psychological environment, while placing less emphasis on neurological diagnosis and decline. A sense of individuality or sense of self is fundamental to positive interaction and relationships, and since the persons interviewed for this research were in the early stages of their AD, they expressed experiencing not so much a loss of self, but a changing self, since they still retained the ability to initiate and

maintain interaction. Many discussed their difficult and traumatic experiences, but they were then able to regain their sense of well being and persist in their Identity work. By doing the Emotion work required for the Recognition and Disclosure stages, some individuals came to a sense of understanding about their AD, and accepted and confirmed their EAD status. Not all individuals, however, were able to progress to this last stage of confirmation work, and thus were not able to complete their Identity work and the experience of viewing themselves as a person with EAD.

Confirmation work in this study is a social process achieved daily in interaction with self and others, and it has three phases: facing, naming, and accepting the EAD. Facing requires confronting the changes; naming involves validating the EAD as the causation of the changing self; acceptance requires verbalizing this realization. For the person to face the EAD, an open awareness context remained an essential component in this phase of Identity work, and is discussed further in this chapter. Emotion work also continued as integral because the person was adjusting to the emotional upheavals of living with the diagnosis. The emotional reaction to EAD changes caused some people to become despondent and emotionally bereft, but the ability to struggle with these changes and then move on to the acceptance process was central to Confirmation work. This emotional process was actualized in a variety of ways, all of them cathartic for the individuals; some talked with another person about their condition, some used the group process to assist them through Confirmation work, and a few of the more articulate and educated wrote and published their experiences in order to share with a larger audience their experience with EAD.

Knowledge of persons perspective of their changing self at this juncture in their EAD process was predictive of reactions to the progression of the disease. Depending on the meaning of the EAD changes to the person, there can be various responses to the changes. Wood (1999) discussed how the interaction of the person and the disease come to the fore in their accounts of how they cope with and manage their AD. Harris and Sterin (1998) interviewed people with EAD with a focus on examining the concept of self; one of these authors was in the early stages of AD. They described various typologies, which included "I'll live until I die", "I accept what I have", "there is nothing wrong with me" and "I'm just struggling to get through the day." Snyder (1999) named the responses she obtained in her interviews with people with EAD their "personal definitions" of the disease. The present study also revealed various responses of participants with EAD, reflecting differing paths towards or away from the Confirmation work.

#### Accounts of Confirmation Work

My methodology did not plan for routine follow up interviews, and it is unusual in this type of research, because of the time required, to be afforded an opportunity to witness person's with EAD progress through Recognition work, to Disclosure and Confirmation work. Fortunately, I was able to follow a few of the participant's EAD progression, due to their continued interaction with me at my place of employment. Also, personal accounts or narratives of people with EAD exist in the literature, and they include insights gleaned at progressive stages of the person's disease. Anecdotal in nature, they are first hand accounts, written in an attempt to inform the world of their unique insight into their EAD experience. In telling their story and sharing their experiences in their own voices, they sought to understand their changing world. The

writing process itself can be considered therapeutic in this endeavor, as the printed word acted to confirm their awareness of their changing condition. The three phases of Confirmation work - facing, naming, and accepting were revealed in each of these narratives. As stated previously, stages and phases occur over time, often simultaneously, and may not be sequential in nature.

### Facing the Darkness

One autobiographical account (Davis, 1989), written by the pastor of a large Miami congregation (and his wife), offers us an example of a person with EAD's journey through the stages of Identity work, towards the eventual facing and acceptance of his diagnosis. His is a story of experiencing the loss, fighting the changes, confirming his EAD diagnosis, and eventually finding a level of acceptance that was a comfort to him. He shares the story of his initial EAD changes, and the ensuing personal and spiritual journey through "devastation," "blackness" and "lost feelings." He is candid about his continuing struggle with facing the changes of EAD, and is forthright in naming his disease,

I am one of the younger people to be diagnosed as having Alzheimer's. I am also at one of the earliest stages of the disease to be diagnosed. This diagnosis, confirmed by literally hundreds of tests and those black spots on the sophisticated nuclear PET scan, means that now part of my brain is dead. This condition has an effect on me. (p. 21)

His descriptions of his initial darkness are palpable, as he shares the strategies that work and do not work to quiet his reactionary despair to his EAD. His story is embedded in his religious experiences, as he struggles to give an account of losing, and then regaining the thing most precious to him, his relationship with his God. He is eventually reconnected to his faith in God and his own peace only by letting go and allowing himself

to “rest in the Lord,” realizing that with his EAD, he is “sharing in the fellowship of the suffering.” He asked, “Why has God left me this little window of ability?” and eventually finds great comfort by realizing it is to “give others some insight into the devastation felt by the Alzheimer’s patient” by the writing of his book. His Confirmation work was possible because he continued to fight through his despair, doing the Emotion work necessary to come to an acceptance of his situation.

In comparing the account of the Rev. Davis above with that of the Rev. V. in Chapter 5, we see two ministers, both with deep and abiding faiths, both able to discuss their changes from EAD, yet reflecting different stages of Identity work. The latter, beset by shame and despair, was unable to find the strength necessary to endure the exposure required in Disclosure work; thus he stopped in his trajectory of Identity work, unable to continue forward towards Confirmation work and acceptance. Later discussions with Rev. V.’s daughter confirmed this immobilization status. Rev. Davis struggled mightily with the necessary Emotion work and then came to a level of reconciliation with his EAD, moving on towards an acceptance process, at peace with himself and his Lord.

#### Facing the Partial Self

Another insider’s view, titled Partial Viewpoint - An Alzheimer’s Journal was offered by Cary Henderson (1998), a retired history professor, written with the assistance of his wife and daughter. It is a narrative of his illness, highlighted with sensitive pictures that more fully reveal his world, written “for people with Alzheimer’s disease, to help them cope with the illness through the insight ... achieved by living with the disease (p.xxi).” Six years passed between his initial AD diagnosis and the beginning of the writing of his book, and this time period allowed for his progression through Recognition

work and Disclosure work, and to his eventual facing of his AD in the Confirmation stage. He considered it "one of my duties in trying to write this book, to sort of get people with Alzheimer's knowledgeable about what they can expect and what they can do, and of course, what they can't do. Perhaps I can help somebody else understand the world they are forced to live in." He called his book "my little Bible of Alzheimer's - the anecdotal career of an Alzheimer's patient." In the transcribed recordings of over 40 audio tapes, he gave his firsthand testimony of physical changes such as problems with reading and walking; and daily frustrations and fears such as fear of losing contact with people and places. These difficulties were balanced with the things that bring him comfort and pleasure, for example his dog, laughter and humor, the love and presence of family, and his "constant friend, music." Dr. Henderson was candid about his efforts at fighting, revealing the Emotion work necessary to face this stage, "it's a sincere effort to get it off my chest. I never was quiet. When I hurt, I yell, which is what I've been doing for several years now and it's food for thought, at least, an Alzheimer's picnic."

His Confirmation work, seen in his ability to name and accept his problem, was clear from the comments above. He accepted the realization of his condition, poignantly sharing, "but one thing is for sure, you never can be, never will be, what you once were. And that's hard to swallow." In a very proactive manner, he used the presence of his AD as an opportunity to continue in his lifelong career of teaching others by writing about his experience, which in itself was therapeutic and reality confirming. He continued his involvement in research by participating in the AD research trials at a large medical center, expressing pride in his contributory efforts, "I feel like something of a pioneer, ...and when I get to Durham, and I have something I like to do [the research], I'm kind of on a high.

It's something that I can do that not everybody can do, and it makes me feel very good about this. It makes me feel like I'm not going to just rot in my old age, helpless and stupid." His initial writings, published in the medical center newsletter, were the impetus to start one of the first patient support groups in his area, and finally, he "did not feel alone anymore." "I've been at this Alzheimer's thing for quite a while now, I don't enjoy Alzheimer's. I'll say that for you, for me - but there's something in it that I feel rather at home with people with Alzheimer's...I would like some exchange of views, some exchange of experiences,...this is a very important part of life." Actively engaging with others in the collaboration of the book, and participating in the group process allowed him to fully live with his EAD, honest with his reality and brave in his approach to fully involve himself and others. His shared experiences allow us a glimpse into the many facets of AD, and most importantly, a view of his strength and courage in continuing to be engaged, and not viewing AD as only a deficit. As he stated "the best thing to do about this is just not worry about it. Be happy with the partial view or whatever else is partial, everything is partial."

### Facing and Fighting

Don Baron, a 67 year old attorney diagnosed with EAD, had his experience documented in an international newsletter on Early Alzheimer's (Kuhn, 2000). Soon after he was given the AD diagnosis, he approached a counselor, named his problem, "I've been told I have Alzheimer's," and requested the counselor's assistance in exploring the meaning of these changes. He shared that his goal was to "make sense out of a disease that will eventually kill me." Mr. Baron made the choice to inform his clients of his AD (selective disclosure) and relinquish his law practice, a planned attempt to reorganize

priorities and use the time that was left for family and volunteer work. In an effort to share his new found expertise with AD, he proposed to the local that he become a member of their board, and he also offered to serve as a spokesperson for the national association; he was rebuffed by both groups. Somewhat perplexed by these refusals, (“After all, I’ve got real credentials, I’m the one with Alzheimer’s”) he eventually found an opportunity to share his story via an article written by him and his wife for a large city newspaper. With his counselor, he also was instrumental in starting an early AD support group, since he had remarked that he had never known anyone with AD, and wished a chance to share experiences and compare notes. As with the Rev. Davis and Dr. Henderson, Mr. Baron’s Confirmation work was evident in his ability to confront and face his disease, become involved in an EAD support group, and write his story. He was proactive in attempting to be involved with the AD organizational groups; their barriers to his involvement did not discourage him.

His counselor wrote that Mr. Baron often spoke “of the paradox of living with AD: the need to fight it, while at the same time accepting it.” This statement reflects that confirmation work can be two sided, analogous to reflecting both sides of a coin, or a two edged sword. Both aspects of this work, facing and fighting, can be valuable in propelling persons forward in their Identity work, as they engage in efforts to maintain their present status, while at the same time coming to a better sense of understanding about their AD. Similar to the narrative stories above, Mr. Baron experienced Emotion work by fighting through his despair to reach an acceptance of his condition, and he continued his Confirmation work with his proactive involvement. He continued to deal with his EAD from within, while at one point being realistic that “more and more, I’m becoming less and less.”

### Outcomes of Acceptance and Confirmation

Snyder's (1999) account of the subjective experience of seven individuals with EAD provided additive perspectives. By virtue of her work as a clinical social worker in a large AD research center, she was able to follow individuals over time, and thus was privileged to observe their response to the progression of AD. All the participants in this account were in an open awareness context and could speak of their EAD, although each person responded uniquely based on their experiences and personalities. A commonality of this group was that all were told their diagnosis and most attended an EAD support group. All were afforded an initial interview in their homes; a follow up interview occurred from 1 ½ to 4 years later. These lengthy interviews, and the group process itself elicited reflections about the impact of AD on their lives, their changing worlds, and their altered roles in those worlds. This process of dialogue allowed each of them the opportunity to work through the various stages of Recognition work and Disclosure work, and reach a level of acceptance in Confirmation work, thus validating the Confirmation work discussed in this research. All of the individuals were able to discuss their adjustments and adaptations to EAD, expressing the range from frustration and hope, to humor and acceptance.

Of those interviewed for this dissertation, the individuals able to share their experience with confirmation work included Ms. A., Ms. W., and Mr. M. By virtue of my continued contact with these people, we are able to have an ongoing dialogue about their experiences and concerns. Each of them has endured his/her struggles with EAD, done extensive emotion work (discussed in previous chapters,) but has managed to maintain a spirit of resilience in spite of their progressive diagnosis. Ms. A. told me that

even with her worsening memory problems, she is happy and can enjoy life; it is her “positive philosophizing” that assists her in coping most days. She shared her notion of the importance of “allowing the mind to rest [not worry] so that the body can also rest,” incorporating her personal belief system of a mind/body connection. She continues to practice her belief that effort and hard work are an antidote for facing her EAD problems, and she can be seen each day continuing to be engaged in life, visiting inpatients in the nursing home and checking books out of the library and “reading all night long.” She has often shared with me that her pleasant early life memories are compensation for any current losses from her EAD, stating that these long term memories are “something to hang onto.” She expresses few concerns about her AD progression now, and is often willing to discuss it with me; her personal philosophy is that people with EML “do not fear for the future and God allows this as self protection.” She most recently communicated that she has accepted the idea of remaining in her current apartment at a senior retirement community “even if I don’t like it.” For many months she had railed against her son’s advice, attempting to move back to her old family home, even going so far as to make independent inquiries of a moving company. After many months of arguing and the consternation of her family, she now admits, “I don’t need to be there all alone, what with my problems with my memory and all. I’d rather be back in my old home, but I accept I need to be here.” This phase of Emotion work propelled her towards her growing acceptance of her confirmation work. Her most recent example of resiliency was her announcement “hey, guess what, I am going to take up violin lessons.” She continued “why not, I already read piano music, so it can’t be that hard. I need a new challenge to keep my head going.” Her attitude of continued growth and focus on ability rather than

loss from EAD surely contributes to her positive view of herself as functional, rather than totally impaired.

Ms. W. is frank with me about her “good days, bad days” regarding her memory impairment. She tells me that she “works hard to beat this thing,” an example of her continued emotion work, often fighting her inclination to avoid social events and forcing herself to stay connected. “I don’t always feel like going on these outings, but my friends just insist, and I know I have to stay involved with things and not feel sorry for myself.” She makes great use of humor, often turning it on herself on the bad days, laughing and kidding about her problems with her memory. This is an extension of the social work discussed in the section on selective disclosure. Similar to Ms. A. above, Ms. W. confirmed the changes, “the problem is with my memory, as you know, and it’s not going to get better,” and focused on her strengths to deal with the decline. Her attitude of “we do the best that we can,” and “we have to try not to be negative - to be positive” has so far sustained her in her confirmation work and during her AD progression. Previously, she also had railed against her son for taking over in a perceived role reversal, “he’s like my father.” She is now more tolerant of their shared participation; remarking one day “my son is my partner,” now accepting that she needs increased monitoring with her EAD.

Mr. M. is still in the early stages of his AD, and has selectively disclosed his problems, dialoging with his neighbor, me, the EML support group, and his physician. One year after our EML support group, he now attends another support group that I lead for family caregivers (he cares for his wife with MS) and he frequently tells the group, “now remember, I have memory loss and I’m on aricept.” One of the members of this group, whose wife has late stage AD, often encourages Mr. M., reminding him of how well he is doing and supporting his efforts. If it was not for Mr. M.’s ability to accept and

confirm his condition, he would be denied the positive feedback and support that this group now offers him. Confirmation work has allowed him to reach out and be connected with a new support group, one able to offer him support at a crucial time in his life. By admitting to himself and those close to him the reality of his situation, the group allows him the opportunity to confirm his EAD diagnosis through the process of continued disclosure; in turn he is supported through his changes by understanding group members.

As detailed above, the acceptance phase of confirmation work involved not only acceptance of their EAD, but also its implications. For Ms. A., it meant acceptance of the need for environmental changes in her place of living. For Ms. W., it meant accepting the vagaries of her illness with her “good days, bad days,” and also her need to push herself to maintain her motivation to stay involved. Both of these ladies accepted their disease trajectory, and the need for increased family assistance. Mr. M., with the acknowledgment of his EAD, has also accepted the advice and support of a caregiver group to assist him in his Identity work journey.

#### Confirmation Work and Open Awareness Context

Open awareness context, initially discussed in Chapter 4 as a condition for Identity work, continues its relevance in this phase, since it was noted that those able to do the work of confirmation all were in an Open Awareness Context from the beginning. More importantly, if their AD was discussed, validated or in any way confirmed by their physician, then they were able to work through to an acceptance in their confirmation work. Ms. W. had discussed her condition with her son, and remained open to discussions with myself and eventually, others. She shared that she and her son had been dialoging since the changes in her memory were first noted. During our initial interview,

she produced the letter she received after her evaluation at a large speciality diagnostic center, and it clearly discussed her EML and probable EAD. While she was vague in her recollection of the actual discussion with the physician, she did relate a specific conversation with her son. "And I remember my son saying to me, 'Mama, I want you to know one thing. Whatever the treatment they give you, no matter what they promise, they can't give you back what you have lost. But they can help you for the future'." She was able to later discuss her condition with her primary doctor, even chiding him for not focusing on it enough.

Ms. A. also was able to discuss her EAD problems with her sons and her physician, although the discussion with the physician did not take place until after a series of catastrophic events forced the issue. She admitted at that time, "It's kind of a new thing. I'm aware of it. Maybe it's been going on longer than I realized, but after I did a few boo boos around the house, I thought I better kind of analyze what was going on with me ...". She was in an open awareness context with me from the very beginning. Mr. M. used his initial contact with me concerning the EML support group to turn his closed awareness context with his doctor into an open awareness context. With his permission, I contacted his physician, telling him that Mr. M. wished to speak with him concerning his EML. Mr. M. told me this physician was "like an old family friend" and he was able to share with him his concerns, and begin treatment with Aricept. All of these individuals continue to use our frequent day to day contacts as opportunities to extend the dialogue regarding their EAD.

In the narrative accounts discussed earlier, the attorney Mr. Baron approached his counselor with the comment "I've been told I have Alzheimer's disease" (p.1). This impetus propelled him to seek guidance and counseling for support during this difficult

time, and he retained the relationship with his counselor until his death. The Reverend Davis was told directly by the neuropsychologist, who shared his remembrance of the encounter in the forward to the book, "We sat for a minute while he digested what I had told him. Then I asked him how he felt about this. He looked at me with a gentle smile. "I know that the Lord is with me ... I trust that this is part of that purpose" (p. 13). He also was told directly by his neurologist, who stated bluntly, "I wish I could tell you that you have cancer. There would be more chance for recovery..." (p.20). He began his narrative only six months later, "while I am still able to communicate, I want to share this incredible journey into Alzheimer's" in order to be "the voice for the voiceless people who suffer from this devastating disease."

Dr. Henderson had the unique experience of a confirmed AD diagnosis, due to a brain biopsy done during a shunt placement for an initial diagnosis of normal pressure hydrocephalus. The biopsy confirmed the telltale plaques and tangles typical of AD. When, two months later the early symptoms of his disease did not abate, he asked to return to the physician for follow up; it was then that he was told the truth of his AD diagnosis by his wife, which allowed him to make definite decisions about putting his life in order. He retired at the age of 57, two years post diagnosis, and they "traveled together, doing all the things we had planned for retirement." It was a full six years after diagnosis that he began the wonderful and poignant journal that allowed us insight into his journey with AD. This time period allowed ample opportunity to transition through the early stages of AD, thus affording us this rare glimpse of someone able to share the changes, from onset of symptoms, through "good days, bad days," to support group care, and finally the need for home care by his wife and daughter.

### Summary

This chapter focuses on Confirmation work, the fourth and final stage of Identity work experienced by participants in this study. If people with EAD were able to successfully accomplish the Disclosure work, then they were strategically positioned to continue along the trajectory of Identity work and enter into Confirmation work. Confirmation work involved being able to respond to the changes of EAD, and included facing, naming and being able to acknowledge and accept their situation.

An open awareness context, begun with Explanatory work, was central to the continued Identity work process. Emotion work was also a crucial thread that continued as vital in the process of facing and experiencing Confirmation work. The crucial component deemed necessary for confirmation work was the disclosure, or the telling of the AD diagnosis. This disclosure was especially effective to Confirmation work if done by a physician, early in the AD process.

As these stories revealed, an open, honest, and direct approach with people regarding their probable EAD diagnosis afforded many the opportunity to experience an open awareness context and the confirmation process as they transitioned through the stages of EAD, finally coming to the acceptance phase that allowed them to positively experience their changing identity as a person with EAD. This acceptance completed the stage of Confirmation work, allowing the participant to experience the identity of a person with EAD, and complete the process of Identity work.

## CHAPTER 7 SUMMARY AND RECOMMENDATIONS

### Summary

This qualitative field research was an attempt to elicit the voices of persons with early memory loss due to a probable AD diagnosis, and to develop a substantive theory about what it is like to live with this condition. Eighteen individuals shared their experiences with EML through interviews and the support group process and five physicians contributed their perspective on the diagnostic process of EAD. Identity work emerged as the core process that explains people's experiences in their trajectory through EAD. The stages of identity work include explanatory work, recognition work, disclosure work and confirmation work. An open awareness context was the condition necessary for persons with EML to be able to begin the dialogue about their circumstances. A willingness to do the emotion work necessary to progress from a closed, mutual pretense or suspected awareness context into an open awareness context was requisite for identity work.

Explanatory work, the first stage of identity work, allowed people to make sense of their initial memory loss by identifying reasons for their memory changes. These early explanatory models included ideas such as normal aging, lack of paying attention, and even that memory loss can protect one from earlier life stresses and trauma. After exploring various explanatory models, persons with EML were able to attach a significance to their changes, and if they were willing to seek answers for these changes,

they progressed to the next stage of identity work, recognition work. Conditions for recognition work included an increasing self awareness of memory loss, which was especially troublesome if the person was still engaged in highly functional activities such as professional work. A second condition was the ability to monitor personal changes in functioning by the use of personal markers and comparative appraisals, using the gold standard of their previous performance level. A third condition was the willingness to seek answers via the diagnostic process, which for many required prompting and encouragement by family, friends and interested health professionals. Barriers to recognition work included the diagnostic process itself, including the attitude of health care professionals towards AD. Dialogue with the physician subsample revealed many problem areas that contributed to non diagnosis, including lack of medicine's diagnostic priority towards AD, lack of treatment options, lack of EAD diagnostic clues, temporal issues of lack of allotted time and the insidious nature of AD, and the social stigma of the AD diagnosis.

If, through recognition work, individuals were able to acknowledge to themselves the problematic meaning of their EML changes, they then could advance to disclosure work, which involved revealing their EML to others. Disclosure work included the phases of nondisclosure, or maintaining secrecy to save face; selective disclosure, or the revealing of the EML changes to a chosen few; and forced disclosure, resulting in increased disruption, exposure, and eventually loss of face. Compensatory strategies were especially important in the nondisclosure phase, with the goal of keeping the EML secret for as long as possible. Selective disclosure involved sharing with carefully chosen others, through use of the group process, interested professionals, and dialogue with close friends.

Forced disclosure was the most emotionally difficult period as people with EML discovered that they were unable to sustain their previous behaviors. This exposure, coupled with a perceived lack of familial support, led to decreased feelings of self worth, interactional problems and exclusion by friends and family.

Confirmation work, the last stage of identity work, involved the juncture of facing, naming and accepting the changes of EML and confirming their status as a person with EAD. Emotion work was inherent in both disclosure work and confirmation work, as the individuals with EML struggled to make sense of their progressive EAD changes, and sought the strength to finally confront and confirm their identity as someone with EAD.

This research revealed that when we as professionals initiate the dialogue, we can enter the world of the person who is experiencing EML changes that are often confusing and frightening. In this study, successfully initiating and completing confirmation work was possible only if the individuals had their diagnosis told to them by their physician or a close family member, indicating the centrality of an open awareness context. Only with an open awareness context between clinician and client can we offer the guidance that can lead to an informed and constructive period of time for the person with EAD, allowing them the opportunity to enter into and complete their identity work.

#### Recommendations for Practice

Dolinar, Eisdorfer, & Peterson (2001) state that clinical evaluation is “at the heart of the diagnostic strategy for identifying AD” (p.12). These authors offer many arguments concerning the importance of an early and accurate diagnosis, including the opportunity to use new medications that provide symptom relief and slow disease progression, increased time to consider medical and legal decisions about future care, and the occasion to provide

psychosocial assistance, such as detecting and treating concomitant depression and providing supportive services to caregivers

This research reflected the norm that routine screening for EAD is not done in clinical practice, nor was it advocated by the experts. But efforts towards early recognition are advocated (Doraiswamy, Steffens, Pitchumoni et al., 1998), thus it would behoove diagnosticians to become diligent in their practice to "ask the question" regarding an individual's change in early memory and functioning. Clinicians are urged to focus on subtle clues, such as vagueness in answering questions, and to especially pay attention to symptoms reflective of the warning signs published by the Alzheimer's Association; for example, has the client missed appointments, or misunderstood information about medications or follow up tests. They should be overt in asking the question about memory loss, or any changes in functioning, such as spatial perceptual problems (i.e. has the person gotten lost driving in familiar areas) and they should give patients permission to voice their concerns during routine office visits. They should take the time to talk and listen to their patients and to their family caregivers, making this dialogue a shared responsibility. They are also cautioned to interpret test results that measure mental and functional status in conjunction with the overall functional ability of the person with EAD, since data from the clients in this research indicated that people with EAD often function at a higher level than their test results might indicate.

As shown in this study, general practitioners diagnosed most of the persons with EAD, and these physicians made few referrals to AD speciality diagnostic centers. A full speciality evaluation should be offered to all clients with complaints of neurological symptoms, since AD can be misdiagnosed. A dramatic article in a recent Mayo newsletter

("When memory problems don't mean Alzheimer's," 2001) details the plight of a woman whose husband was persistent in obtaining for his wife a complete neurological workup after her general practitioner had diagnosed and treated her for AD. He stated "I knew something was wrong and I knew it wasn't Alzheimer's." His persistence in following his instincts paid off in a dramatic way; his wife was diagnosed with normal pressure hydrocephalus, a surgically treatable condition that can mimic the symptoms of AD and is correctable if diagnosed and treated in a timely manner. A full diagnostic workup can differentiate between the many kinds of dementia, for example, Alzheimers, Lewy Body, vascular or frontotemporal dementias, and a behavioral neurologist can offer clients and families strategies for dealing with problems specific to each type. However, even when the person with EML is evaluated by a specialty memory disorder clinic, the clinic's main focus is on diagnosis and research, with minimum opportunity for client follow up and support after the initial diagnostic visit; this followup is best offered by the primary care physician.

Disclosure of a diagnosis to a client is considered a fundamental right in our current climate of client rights and medical ethics, and the disclosure of a suspected EAD diagnosis should be no different. Persons with EAD have the same concerns as anyone given a devastating diagnosis, except that, because of the nature of their disease process, they are more limited in the time they might have available to discuss its implications. Few in this study received a direct disclosure of their EAD diagnosis, but for those who did, they clearly were better prepared to move along the continuum of identity work, and finally reach the stage of confirmation that allowed for acceptance of their changing identity. This acceptance process allowed individuals with EAD to face their future in an

open and honest manner, including facing the darkness, facing the partial self, and fighting to live with the disease, the stigma and the injustices it can evoke. Glaser and Strauss (1965), in discussing the impact of each type of awareness context between the client and the professional, noted that "people guide their talk and actions according to who knows what and with what certainty" (p.11). In this study, an open awareness context was central to people with EML being able to move forward in their process of identity work. In order to achieve this open awareness context, assistance from others was crucial, especially interested health professionals. Thus, it is imperative that health care practitioners recognize the important role they have in assisting persons with EAD towards an open dialogue about their changing condition and use every clinical opportunity to bring about this discussion.

A new practice paradigm could be created, one that offers a sensitive dementia caring community, is inclusive of a comprehensive dementia care support model of practice, and reflective of an person focused environment. The model developed during this study would be most useful for this paradigm, as each stage of the model offers an opportunity for client support and clinician intervention. During the stage of explanatory work, individuals can be encouraged to discuss their EML in an attempt to make sense of their changes. As shown in this research, the clinician has a crucial role in creating an open awareness context, and this dialogue could be useful in guiding the person with EML towards developing plausible ideas of causation, and leading the person towards recognition work.

During recognition work, the clinician can assist individuals with EML to develop the conditions that were deemed necessary for this stage of identity work. Increased self

awareness can be cultivated if the person with EML is questioning their changes or identifying changes evident of functional decline. Encouraging the use of personal markers and comparative appraisals could offer the person a way to evaluate their functional ability at a time of change and uncertainty. Assisting the person to seek answers for their changes, especially via the diagnostic process, could be the means to move the person towards the next stage of disclosure work. The astute clinician can also offer the person a suggestion of individual/ family counseling with knowledgeable dementia specialists to assist in the dialogue and diagnosis.

Specific support services should be initiated when the initial diagnosis is suspected or confirmed and individuals begin to navigate the area of disclosure work. The physicians in this study admitted they heard the frustration voiced by families, yet they were unaware of support resources available in the community. Individuals could benefit from participation in EML support groups, and the availability of day support centers (vs. day care centers) such as those described by Snyder (1999) that offer a sensitive social network where individuals could participate in meaningful activities, and receive ongoing advocacy and hope to sustain them on their AD journey. This supportive network would be especially useful during the stages of disclosure work and confirmation work, as these were the areas in this study where the turmoil of emotion work was most evident. Families and caregivers can be referred to family support groups that offer information and support, since findings in this study identified the need for tension management due to increased family criticism and enmeshed and changed roles.

During confirmation work, the clinician can continue to offer guidance, information and support, as this is the stage when persons with EML are facing and

accepting their change in status, transitioning from a person with EML to a person with EAD. An important component of this new practice model should be the inclusion of individuals with EAD as partners in the planning process, voices that can offer input into their future decisions and have their desires and needs heard and respected. Models that allow for continued independent living with the provision of supportive assist services would be most useful at this time in their AD, as currently persons in this transitional situation must move to an assisted living facility or move in with families in order to receive increased assistance. Services must of necessity stress the person's functional ability, as well as safety and minimal intrusion. Remembering that this was the period in their identity work when clients most often experienced loss of face, the opportunity for continuity in their living situation, with appropriate supports, should be most appreciated.

Advanced practice nurses are in a prime position to offer supportive services that can connect the medical and social needs of persons with EAD. Keady (1996) suggested that community mental health nurses have traditionally offered a family based system of interventions grounded in stress reduction and information giving, and the development of a supportive dementia care model of practice would continue this tradition. Education models for physicians and nurse clinicians must also be developed to include increased training to create knowledgeable health care practitioners that can offer appropriate information and encouragement to clients during each stage of identity work.

Practitioners can use the model described in this research to assess and evaluate individuals along the identity work continuum and use the interventions described above. Dialogue with the person with EML changes is of critical importance in order to develop and maintain the open awareness context that is so crucial to the initiation and completion

of identity work. Their stories allowed us a glimpse into their EAD journey; the clinicians role is to assist them in this ongoing passage, learning from their experiences and passing on this experiential learning to others with EAD that follow.

#### Recommendations for Research

Research should inform AD policies and practice (Goldsmith, 1996, p. viii). In the past, few researchers have attempted to dialogue with people with early AD, with a resultant dearth of knowledge in this area from the perspective of the "person with the problem." Yet, research into the person's subjective account of their EAD experience is precisely what is required to guide and direct our practice. Recommendations for research include the need for longitudinal qualitative research done over time, beginning early in the diagnostic process, with follow up at points in time to assess people's progression in their identity work. Future study designs should include planned opportunities for sequential interviews, in order to assess a person's progression through the stages of identity work discussed in this research. This study design should allow for increased opportunities for contact with persons with EML as they experience the stage of confirmation work, the area of this study based on the fewest interviews and thus the area in need of more research data. Also, research questions can be developed that seek specific details about the person with EML and their stage of identity work. The process of identity work identified in this study and the practice model that incorporates it described above can be translated into a model program for practice and evaluated for its effect on persons with EAD.

Based on the work of Robyn Yale (1991), and the results of the group process discussed earlier in this research, studies need to continue on the effectiveness of the use

of group process with people with EAD. Specifically, research should continue on the model of Identity work described in this study, and how the people fare who make use of this model. Accounts that include case studies with specific interventions would also contribute to our knowledge base about how to assist people with EAD to function more effectively as their disease progresses; observations of individual variation are essential.

There are many benefits that can be obtained from the EAD interventions described in this study, including the ability to foster independence for as long as possible, to keep people in the least restrictive environment for a longer period of time, and, most important, that of offering sensitivity and a hope for a better tomorrow for those with EAD. Research can provide the basis for improved practice tools; practitioners can provide the environment necessary to operationalize these practice models, and empower individuals with EAD to complete their identity work and experience the peace and hope shared by those in this research able to complete their identity work.

APPENDIX A  
SUBJECT INTERVIEW GUIDE

1. Tell me about your memory change.
2. Which of these changes is the most challenging to you?
3. How has the memory change affected your life [your interaction] with your family/friends/coworkers etc (get detail ie. church, work, family)
4. Tell me who you talk to about your early memory changes
5. What are the issues of most importance to you now?
6. What is the hardest thing about living with this memory change?
7. What advice would you give to someone else who is coping with this memory change?
8. Are there some things that you do that help you with this memory change?
9. What advice could you give to family members (or others) who are assisting you?
10. What advice could you give to other caregivers (e.g. nurses, doctors?)
11. Is there anything else that you want to tell me about your experience since this diagnosis / this change in your life?

APPENDIX B  
DEMOGRAPHIC FORM

Participant's Name:

Address:

phone number

Date of birth:

Diagnosis -

by whom \_\_\_\_\_

method of diagnosis \_\_\_\_\_

1. participant gender a) female  
b) male
2. Age
3. Relationship status a) single, never married  
b) married  
c) divorced or separated  
d) widowed  
e) other
4. Length of relationship in years
5. Time since 1st diagnosed w/ early memory loss/probable AD
6. Symptoms

(If appropriate) Caregiver name:

Relationship to participant:

Caregiver address (if different from above)

phone number

APPENDIX C  
FUNCTIONAL ACTIVITIES QUESTIONNAIRE (FAQ)

Ct Name \_\_\_\_\_ Referral Source \_\_\_\_\_ Family member \_\_\_\_\_

The FAQ is an informant based measure of functional abilities. Informants provide performance ratings of the target person on 10 complex, higher order activities. Individual items of the Functional Activities Questionnaire:

- |   |   |   |   |   |
|---|---|---|---|---|
| 1. writing checks, paying bills, balancing a checkbook                        | 3 | 2 | 1 | 0 |
| 2. assembling tax records, business affairs, or papers                        | 3 | 2 | 1 | 0 |
| 3. shopping alone for clothes, household necessities, or groceries            | 3 | 2 | 1 | 0 |
| 4. playing a game of skill, working on a hobby                                | 3 | 2 | 1 | 0 |
| 5. heating water, making a cup of coffee, turning off the stove               | 3 | 2 | 1 | 0 |
| 6. preparing a balanced meal  | 3 | 2 | 1 | 0 |
| 7. keeping track of current events  | 3 | 2 | 1 | 0 |
| 8. paying attention to, understanding, discussing a TV show, book or magazine | 3 | 2 | 1 | 0 |
| 9 remembering appointments, family occasions, holidays, or medications        | 3 | 2 | 1 | 0 |
| 10. traveling out of the neighborhood, driving, arranging to take buses.      | 3 | 2 | 1 | 0 |

\* dependent = 3

\* requires assistance = 2

\* has difficulty but does by self = 1

\* normal = 0

two other options

\* never did, but could do now = 0

\* never did and would have difficulty now = 1

**total score** computed by summing scores across the 10 items. Scores range from 0 - 30. Higher score = poorer function, impairment)

A cutoff of 9 is recommended (dependent in 3 or more activities)

Source: Pfeffer, R.I., Kurosaki, T.T., & Harrah, C.H. et al. (1982) Measurement of functional activities of older adults in the community. Journal of Gerontology, 37, 323-329.

APPENDIX D  
PHYSICIAN INTERVIEW GUIDE

1. How do you approach the issue of memory loss / memory changes with an older patient?
2. If you do, how do you assess a patient for a memory loss /problem/change. (ie are you looking for clues in their mannerisms? conversation?)
3. How do you think about memory changes/problems as compared with other medical conditions?
4. Under what conditions do you diagnose a person with memory problems? What diagnoses do you use?
5. How do you manage / treat early memory loss?
6. Under what conditions do you refer a patient for memory loss?
7. After giving a patient a diagnosis of probable Alzheimer's disease, what kinds of referrals or options do you offer your patients (and caregivers)

APPENDIX E  
Consent to Participate in Research  
(Patient Form)

University of Florida Health Science Center  
Jacksonville, Florida

Experiencing Early Memory Changes:  
The Client's Perspective

Susan Leger-Krall, ARNP, PhD(c)  
Principle Investigator  
Doctoral Student  
College of Nursing  
(H) 904-259-6568

You are being asked to participate in a research study. This form will give you information about this study and answer your questions. This study is being conducted within the community of Jacksonville and NE Fla and is part of a study for a nursing student's doctoral dissertation.

What is the purpose of the study?

The purpose of this study is to talk to people who are experiencing some early memory change problems. It is hoped that your sharing of this information will help nurses and others better understand this experience, and help us better plan for future needs of these clients.

What will be done if you take part?

If you agree, Ms. Krall will ask you some questions about your experience with early memory changes. The conversation will be recorded on an audio tape recorder. The interview will be between Ms. Krall and yourself, and should take approximately 45 minutes to 1 hour. Ms. Krall might also review your medical record for purposes of diagnosis verification.

What are the discomforts and risks you might expect?

There are no risks from participating. If you become tired or uncomfortable, you may end the interview at any time. The information is considered private and will not be shared with your doctor or your family. Information from this interview might be shared in a general manner with other doctoral nursing students who participate in a research seminar.

Will the study cost you anything?

You will not be charged for taking part in this study.

What are the potential benefits of the study?

The interview will give you an opportunity to discuss any issues you might have concerning early memory loss. The information you share could assist nurses and other people caring for early memory loss clients.

What alternatives do you have?

There are no alternative treatments.

Will your privacy be respected?

Your participation in this research will be kept confidential and your name will not be known by anyone other than Ms. Krall. Your name will not be included in any publications that might result from this study.

What if there is an injury from the study?

This interview should not cause any injury. If you become ill, appropriate medical care will be summoned.

How can you get answers to questions?

Ms. Krall, ARNP will be glad to answer any questions you may have about this research. You may reach her by calling the College of Nursing office in Jacksonville at 904-549-3245 and ask to speak / or leave a message with the secretary, who can contact Ms. Krall. In addition, if you have any questions about your rights as a research subject, you may contact the Institutional Review Board, University Medical Center, 655 W 8th Street, Jacksonville, FL 32205, through Ms. Shari Shreve, IRB Secretary, at 549-3136.

Can you quit at any time?

You may decide to withdraw from this study at any time. Your participation is voluntary at all times, and refusal to participate will cause you no penalty or loss of benefits in receiving care.

Are there any conflicts of interest?

Ms. Krall will not receive any benefit from your decision to take part in this research.

Consent

You are free not to take part in this study. If you choose to participate, you are free to withdraw your consent and stop at any time without the decision affecting your medical care. Before giving your consent by signing this form, you have had a chance to have your questions answered about the study procedures, their inconveniences, risks, and available alternatives. Based on this information, your signature below shows that you voluntarily agree to participate in this research. A copy of the entire consent form will be given to you.

I, \_\_\_\_\_, hereby agree to participate in a research study entitled " Early Memory Changes: The Client's Perspective".

\_\_\_\_\_  
Patient Signature

\_\_\_\_\_  
Date

I have fully explained to \_\_\_\_\_ the nature, purpose and risks of this study, and have answered all questions to the best of my ability. To the best of my knowledge, the patient signing this consent has had the study fully and carefully explained and clearly understands the nature, risk, and benefits of participation in this project.

\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Date

\_\_\_\_\_  
Person providing information to pt

\_\_\_\_\_  
Date

APPENDIX F  
Consent to Participate in Research  
(Physician Form)

University of Florida Health Science Center  
Jacksonville, Florida

Experiencing Early Memory Changes:  
The Client's Perspective

Susan Leger-Krall, ARNP, PhD(c)  
Principle Investigator  
Doctoral Student  
College of Nursing  
(H) 904-259-6568

You are being asked to participate in a research study. This form will give you information about this study and answer your questions. This study is being conducted within the community of Jacksonville and NE Fla and is part of a study for a nursing student's doctoral dissertation.

What is the purpose of the study?

The purpose of this study is to talk to people who are experiencing early memory change. I would also like to obtain information from physicians caring for these patients regarding their experience with people with early memory changes /loss and the diagnostic process.

What will be done if you take part?

If you agree, Ms. Krall will ask you questions about your experience with patients with early memory changes, how you recognize the problem and your diagnostic process. The conversation will be recorded on an audio tape recorder. The interview will be between Ms. Krall and yourself, and should take approximately 30 minutes.

What are the discomforts and risks you might expect?

There are no risks from participating. You may end the interview at anytime. The information is considered anonymous and confidential and will be shared only with my faculty advisor. Tapes will be erased after they are transcribed.

Will the study cost you anything?

You will not be charged for taking part in this study.

What are the potential benefits of the study?

The interview will give you an opportunity to discuss any issues you might have concerning persons with early memory changes. The information you share could assist nurses and other people caring for patients with early memory changes.

What alternatives do you have?

There are no alternative treatments.

Will your privacy be respected?

Your participation in this research will be kept confidential and your name will not be known by anyone other than Ms. Krall. Your name will not be included in any publications that might result from this study.

What if there is an injury from the study?

This interview should not cause any injury.

How can you get answers to questions?

Ms. Krall, ARNP will be glad to answer any questions you may have about this research. You may reach her by calling the College of Nursing office in Jacksonville at 904-549-3245 and ask to speak / or leave a message with the secretary, who can contact Ms. Krall. In addition, if you have any questions about your rights as a research subject, you may contact the Institutional Review Board, University Medical Center, 655 W 8th Street, Jacksonville, FL 32205, through Ms. Shari Shreve, IRB Secretary, at 549-3136.

Can you quit at any time?

You may decide to withdraw from this study at any time. Your participation is voluntary at all times, and refusal to participate will cause you no penalty or loss of benefits in receiving care.

Are there any conflicts of interest?

Ms. Krall will not receive any benefit from your decision to take part in this research.

Consent

You are free not to take part in this study. If you choose to participate, you are free to withdraw your consent and stop at any time. Before giving your consent by signing this form, you have had a chance to have your questions answered about the study procedures, their inconveniences, risks, and available alternatives. Based on this information, your signature below shows that you voluntarily agree to participate in this research. A copy of the entire consent form will be given to you.

I, \_\_\_\_\_, hereby agree to participate in a research study entitled " Early Memory Changes: The Client's Perspective".

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

I have fully explained to \_\_\_\_\_ the nature, purpose and risks of this study, and have answered all questions to the best of my ability. To the best of my knowledge, the person signing this consent has had the study fully and carefully explained and clearly understands the nature, risk, and benefits of participation in this project.

\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Date

\_\_\_\_\_  
Person providing information

\_\_\_\_\_  
Date

## REFERENCES

Altheide, D.L., & Johnson, J.M. (1994). Criteria for assessing interpretive validity in qualitative research. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 485-499). Thousand Oaks, CA: Sage Publications.

Alzheimer's Association. (1995a). Alzheimer's Disease: Inside looking out [Videotape]. (Available from the Cleveland chapter of the Alzheimer's Association).

Alzheimer's Association. (1995b). The diagnosis of Alzheimer's Disease: Today's capabilities, tomorrow's expectations. [Webmaster@alz.org](mailto:Webmaster@alz.org)

Alzheimer's Association. (1998, March 9). News Alert: Possible new dementia screening test. [On line]. Available Internet: [www.alz.org/private/](http://www.alz.org/private/).

Alzheimer's Association. (2001). Physicians and health care professionals: General statistics/ demographics [On line]. Available Internet: [www.Alz.org/hc/overview/stats/.htm](http://www.Alz.org/hc/overview/stats/.htm)

Alzheimer's Disease and Other Dementias: Guidelines for Detection and Diagnosis. (2001). Consultant, 41, 105-1056.

American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4th ed.). Washington, DC: Author.

Anthony, J.C., LeResche, L., Niaz, U., Von Korff, M.R., & Folstein, M.F. (1982). Limits of the "Mini - Mental State" as a screening test for dementia and delirium among hospital patients. Psychological Medicine, 12, 397-408.

Arkin, S. (1991). Memory training in early Alzheimer's disease: An optimistic look at the field. The American Journal of Alzheimer's Care and Related Disorders & Research, 6(4), 17-25.

Baker, F.M., (1989). Screening tests for cognitive impairment. Hospital and Community Psychiatry, 40, 339-340.

Beck, C.T. (1993). Qualitative research: The evaluation of it's credibility, fittingness and auditability. Western Journal of Nursing Research, 15, 263-266.

- Berg, L. (1990). Detection of early (very mild) Alzheimer's disease. In J.E. Morley, R.M. Coe, R. Strong, & G.T. Grossberg (Eds.), Memory functioning and aging related disorders (pp.223-236). New York: Springer Press.
- Blumer, H. (1969). Symbolic interactionism: Perspective and method. Berkeley, CA: University of California Press.
- Boise, L., Camicioli, R., Morgan, D., Rose, J., & Congleton, L. (1999). Diagnosing dementia: Perspectives of primary care physicians. The Gerontologist, 39, 457- 464.
- Bok, S. (1989). Secrets: On the ethics of concealment and revelation. New York: Vintage Books.
- Bould, S., Sanborn, B., & Reif, L. (1989). Eighty-five plus: The oldest old. Belmont, CA: Wadsworth Publishing Co.
- Bowers, B.J. (1988). Grounded theory. In B. Sartar (Ed.), Paths to knowledge (pp. 33-56). New York: NLN Press.
- Boyd, C.O. (1993). Philosophical foundations of qualitative research. In P.L. Munhall & C.O. Boyd (Eds.), Nursing research : A qualitative perspective (pp. 66-93). New York: NLN Press.
- Callahan, C.M., Hendrie, H.C. & Tierney, W.M. (1995). Documentation and evaluation of cognitive impairment in elderly primary care patients. Annals of Internal Medicine, 122, 422-429.
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. Sociology of Health and Illness, 5(2), 168-195.
- Coenen, H. (1991). Wandering through the caves: Phenomenological research in a social world of dementia. In D. Maines (Ed.), Social organization and social process (pp.310-320). New York: Aldine de Gruyter.
- Cohen, D. (1991). The subjective experience of Alzheimer's disease: The anatomy of an illness as perceived by patients and families. The American Journal of Alzheimer's Care and Related Disorders & Research, 6(3), 6-11.
- Cohen, D. & Eiserdorfer, C. (1986). The loss of self: A family resource for the care of Alzheimer's disease and related disorders. New York: Norton.
- Corcoran, M. (1993). Management decisions made by caregiver spouses of persons with Alzheimer's disease. The American Journal of Occupational Therapy, 48(1), 38-45.

Cotrell, V. & Schultz, R. (1993). The perspective of the patient with Alzheimer's Disease: A neglected dimension of dementia research. The Gerontologist, 33, 205-211.

Cromwell, S.L. (1994). The subjective experience of forgetfulness among elders. Qualitative Health Research, 4, 444-462.

Cromwell, S., & Phillips, L. (1995). Forgetfulness in elders: Strategies for protective caregiving. Geriatric Nursing, 16(2), 55-59.

Crum, R.M., Anthony, J.C., Bassett, S.B., & Folstein, M.F. (1993). Population based norms for the Mini-Mental State Exam by age and educational level. Journal of the American Medical Association, 269, 2386- 2391.

Cummings, J.L.(1993). Mini-mental state examination - norms, normals and numbers. Journal of the American Medical Association, 269, 2420- 2421.

Davis, R. (1989). My Journey into Alzheimer's Disease. Wheaton, IL: Tyndale House.

Dolinar, T., Eisdorfer, C., & Petersen, R. (2001). Strategies for early diagnosis. Patient Care for the Nurse Practitioner, 4, 12-22.

Doraiswamy, P.M., Steffens, D.C., Pitchumoni, S. & Tabrizi, S. (1998). Early recognition of Alzheimer's Disease: What is consensual? What is controversial? What is practical? The Journal of Clinical Psychiatry, 59, 6-18.

Doyle, G.C., Dunn, S.I., Thadani, I., & Lenihan, P. (1986). Investigating tools to aid in restorative care for Alzheimer's patients. Journal of Gerontological Nursing, 12(9), 19-24.

Eisdorfer, C., Cohen, D., Paveza, G.J., Ashford, J.W., Luchins, D.J., Gorelick, P.B., Hirshman, R.S., Freels, S.A., Levy, P.S., Semla, T.P., & Shaw, H.A., (1992). An empirical evaluation of the global deterioration scale for staging Alzheimer's Disease. American Journal of Psychiatry, 149, 190-194.

Estes, C., & Binney, E. (1989). The biomedicalization of aging: dangers and dilemmas. The Gerontologist, 29, 587-596.

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research, 12, 189-198.

Ganguli, M. (1997). The use of screening instruments for the detection of dementia. Neuroepidemiology, 16, 271-280.

Germain, C. (1993). Ethnography: The method. In P.L. Munhall & Boyd, C.O. (Eds.), Nursing research: A qualitative perspective (pp. 237-268). New York: NLN Press.

Gilhooly, M.L.M., & Birren, J.E. (1986). Introduction. In M.L.M. Gilhooly, S.H. Zarit, & J.E. Birren (Eds.), The dementias: Policy and management (pp. 1-12). Englewood Cliffs, NJ: Prentice-Hall.

Glaser, B.G. (1978). Theoretical sensitivity. Mill Valley, CA: Sociology Press.

Glaser, B.G. (1992). Basics of grounded theory analysis: Emergence vs forcing. Mill Valley, CA: Sociology Press.

Glaser, B.G. & Strauss, A. (1965). Awareness of dying. New York: Aldine Publishing Company.

Glaser, B.G. & Strauss, A. (1967). The discovery of grounded theory. New York: Aldine De Gruyter.

Goffman, E. (1959). The presentation of self in everyday life. New York: Doubleday

Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. New York: Simon & Schuster Inc.

Golander, H. & Raz, A.E. (1996). The mask of dementia: Images of "demented residents" in a nursing ward. Ageing and Society, 16, 269-285.

Goldsmith, M. (1996). Hearing the voice of people with Dementia. Bristol, PA: Jessica Kingsley Publishers

Groups offer support for newly diagnosed. (1995, Spring). Advances in Alzheimer Research, 5, 4.

Gubrium, J.F. (1975). Living and dying at Murray Manor. New York: St. Martin's.

Gubrium, J.F. (1986). Oldtimers and Alzheimer's: The descriptive organization of senility. Greenwich, CT: JAI Press.

Gubrium, J.F. (1993). Speaking of life: Horizons of meaning for nursing home residents. Hawthorne, NY: Aldine de Gruyter.

Gubrium, J.F., Holstein, J.A. & Buckholdt, D.R. (1994). Constructing the life course. Dix Hills, NY: General Hall, Inc.

Harris, P.B. & Sterin, G.J. (1998, November). Insider's perspective: Defining and preserving the self in dementia. Paper presented at the 51<sup>st</sup> annual scientific meeting of the Gerontological Society of America, Philadelphia.

Henderson, C.S. (1998). Partial view: An Alzheimer's journal. Dallas, TX: Southern Methodist University Press.

Henderson, A.S. & Huppert, F.A. (1984). The problem of mild dementia. Psychological Medicine, 14, 5-11.

Herskovits, E. (1995). Struggling over subjectivity: Debates about the "self" and Alzheimer's Disease. Medical Anthropology Quarterly, 9, 146-164.

Hutchinson, S.A. (1993). Grounded theory: The method. In P. L. Munhall & C. O. Boyd (Eds.), Nursing research: A qualitative perspective (pp. 180-212). New York: NLN Press.

Hutchinson, S.A., Leger-Krall, S., & Wilson, H.S. (1997). Early probable Alzheimer's Disease and awareness context theory. Social Science and Medicine, 45, 1399-1409.

Jaffe, D.J., & Miller, E.M. (1994). Problematizing meaning. In J.F. Gubrium & A. Sankar (Eds.), Qualitative methods in aging research (pp. 51-64). Thousand Oaks, CA: Sage Publishing.

Katz, S. (1983). Assessing self-maintenance: Activities of daily living, mobility, and instrumental activities of daily living. Journal of American Geriatric Society, 31, 721.

Katzman, R., Brown, R., Fuld, P., Peck, A., Schechter, R., & Schimmel, H. (1983). Validation of a Short Orientation- Memory -Concentration Test of cognitive impairment. American Journal of Psychiatry, 140, 734-739.

Kaufman, S. (1986). The ageless self: Sources of meaning in late life. New York: Meridian.

Keady, J. (1996). The experience of dementia: A review of the literature and implications for nursing practice. Journal of Clinical Nursing, 5, 275-288.

Keady, J. & Nolan, M. (1994). Younger onset dementia: Developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers. Journal of Advanced Nursing, 19, 659-669.

Keady, J. & Nolan, M. (1995a). IMMEL: Assessing coping responses in the early stages of dementia. British Journal of Nursing, 4, 309-314.

Keady, J. & Nolan, M. (1995b). IMMEL 2: Working to augment coping responses in early dementia. British Journal of Nursing, 4, 377-380.

Keady, J. & Nolan, M. (1996). The experience of dementia: A review of the literature and implications for nursing practice. Journal of Clinical Nursing, 5, 275-288.

Kitwood, T. (1993). Towards a theory of dementia care: The interpersonal process. Aging and Society, 13, 51-67.

Kitwood, T. & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. Aging and Society, 12, 269-287.

Kluger, A., & Ferris, S. H. (1991). Scales for the assessment of Alzheimer's disease. The Psychiatric Clinics of North America, 14, 309-326.

Kokmen, E., Naessens, J. M., & Offord, K.P. (1987). A short test of mental status: Description and preliminary results. Mayo Clinic Proceedings, 62, 281-288.

Kuhn, D. (2000). Fighting and accepting Alzheimer's disease. Early Alzheimer's: An international newsletter on dementia, 3, 1-5.

Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. Gerontologist, 9, 179-186.

Lee, H., Swanwick, G.R., Coen, R.F., & Lawlor, B.A. (1996). Use of the clock drawing task in the diagnosis of mild and very mild Alzheimer's disease. International Psychogeriatric, 8, 469-476.

Loreck, D.J., Bylsma, F.W. & Folstein, M.F. (1994). The dementia signs and symptoms scale. The American Journal of Geriatric Psychiatry, 2, 60-74.

Lucca, U., Comelli, M., Tettamanti, M., Tiraboschi, P. & Spagnoli, A. (1993). Rate of progression and prognostic factors in Alzheimer's disease: A prospective study. Journal of the American Geriatric Society, 41, 45-49.

Lyman, K.A. (1989). Bringing the social back in: A critique of the biomedicalization of dementia. The Gerontologist, 29, 597-605.

Lyman, K.A. (1993). Day in, day out with Alzheimer's : Stress in caregiving relationships. Philadelphia: Temple University Press.

MacRae, H. (1998). Managing feelings: Caregiving as emotion work. Research on Aging, 20, 137-160.

Mahoney, F.L., & Barthel, D.W. (1965). Functional evaluation: The Barthel index. MD State Medical Journal, 14, 61-65.

Maines, D.R. (1993). Forward (xii). In J.F. Gubrium, Speaking of life. New York: Aldine de Gruyter.

Mathieson, C.M., & Stam, H.J. (1995). Renegotiating identity: Cancer narratives. Sociology of Health and Illness, 17, 283-306.

McCormick, W., Kukull, W., van Belle, G., Bowen, J., Teri, L. & Larson, E. (1994). Symptom patterns and comorbidity in the early stages of Alzheimer's disease. Journal of the American Geriatric Society, 42, 517-521.

McDougall, G. (1995). Memory strategies used by cognitively intact and cognitively impaired older adults. Journal of the American Academy of Nurse Practitioners, 7, 369-376.

McGowin, D. F. (1993). Living in the labyrinth: A personal journey through the maze of Alzheimer's Disease. New York: Delacourte Press.

McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., Stadlan, E.M. (1984). Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. Neurology, 34, 939-944.

McSweeney, J., Allan, J. & Mayo, K. (1997). Exploring the use of explanatory models in nursing research and practice. Image: Journal of Nursing Scholarship, 26, 177-180.

Moody, H.R. (1988). From informed consent to negotiated consent. The Gerontologist, 28, (Suppl.), 64-70.

Morse, J.M. (1986). Quantitative and qualitative research: Issues in sampling (pp. 181-193). In P.Chinn, Nursing Research Methodology, Rockville, MD. Aspen Publications.

Morse, J.M. (1994). Designing funded qualitative research. In N. Denzin & Y. Lincoln (Eds.), Handbook of Qualitative Research (pp. 220-235). Thousand Oaks, CA: Sage Publications.

Munhall, P.L. (1993). Ethical considerations in qualitative research. In P.L. Munhall & C.O. Boyd (Eds.), Nursing research: A qualitative perspective (pp. 395-408). New York: NLN Press.

- O'Connor, D.W., Pollit, P.A., Hyde, J.B., Brook, C.P.B., Reiss, B.B., & Ross, M. (1988). Do general practitioners miss dementia in elderly patients? British Medical Journal, *297*, 1107-1110.
- Orona, C. (1990). Temporality and identity loss due to Alzheimer's Disease. Social Science and Medicine, *30*, 1247-1256.
- Petersen, R.C., Smith, G.E., Waring, S.C., Ivnik, R.J., Tangalos, E.G., & Kokman, E. (1999). Mild cognitive impairment in clinical characterization and outcome. Archives of Neurology, *56*, 303-308.
- Pfeffer, R.I., Kurosaki, T.T., Harrah, C.H., Chance, J.M., & Filos, S. (1982). Measurement of functional abilities in older adults in the community. Journal of Gerontology, *37*, 323-329.
- Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. Journal of the American Geriatrics Society, *23*, 433-441.
- Pinnick, N. (1984). The work of chronically ill children on a hospital unit. Children's Health Care, *12*, 113-117
- Rapp, C., Topps-Uriri, J. & Beck, C. (1994). Obtaining and maintaining a research sample with cognitively impaired nursing home residents. Geriatric Nursing, *15*(4), 193-196.
- Reisberg, B., Ferris, S.H., & de Leon, M.J. (1988). The Global Deterioration Scale (GDS). Psychopharmacological Bulletin, *24*, 661.
- Reynolds, L.T. (1990). Interactionism: Exposition and critique. Dix Hills, NY: General Hall.
- Rodgers, B.L., & Cowles, K.V. (1993). The qualitative research audit trail: A complex collection of documentation. Research in Nursing and Health, *16*, 219-226.
- Rouleau, I., Salmon, D.P., & Butters, N. (1996). Longitudinal analysis of clock drawing in Alzheimer's disease patients. Brain Cognition, *31*, 17-34.
- Sabat, S.R., & Harre, R. (1992). The construction and deconstruction of self in Alzheimer's disease. Aging and Society, *12*, 443-461.
- Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. Advances in Nursing Sciences, *16*, 1-8.

Sandelowski, M., Davis, D. H., & Harris, B. G. (1989). Artful design: Writing the proposal for research in the naturalist paradigm. Research in Nursing and Health, 12, 77-84.

Saunders, P.A.(1998). "My brains on strike": The social construction of identity through the memory accounts by dementia patients. Research on Aging, 20, 65-90.

Schulzer, M., Calne, D. B., Snow, B., & Mak, E. (1993). A scoring error in the mini-mental state test. Canadian Journal of Psychiatry, 38, 603-605.

Seymour, J., Sauders, P., Wattis, J. P., & Daly, L. (1994). Evaluation of early dementia by a trained nurse. International Journal of Geriatric Psychiatry, 9, 37-42.

Small, G.W., Rabins, P.V., & Barry, P.P. (1997). Diagnosis and treatment of Alzheimer's disease and related disorders. Consensus statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society. Journal of the American Medical Association, 278, 1368-1371.

Snyder, L. (1999). Speaking our minds - Personal reflections from individuals with Alzheimer's. New York: W.H. Freeman.

Soloman, P. R., Hirschhoff, A., Kelly, B., Relin, M., Brush, M., DeVeaux, R.D., & Pendlebury, W.W. (1998). The 7 minute neurocognitive screening battery highly sensitive to Alzheimer's Disease. Archives of Neurology, 55, 349-355.

Soloman, P. & Pendlebury, W. (1998). Recognition of Alzheimer's Disease: The 7 minute screen. Family Medicine, 30, 265-269.

Starr, P. (1982). The social transformation of American medicine. New York: Basic Books.

Stern, P. N., Allen, L. M., & Moxley, P. A. (1982). The nurse as grounded theorist: History, process and uses. The Review Journal of Philosophy and Social Sciences, 7, 200-215.

Storandt, M., & Hill, R. (1989). Very mild senile dementia of the Alzheimer type. II. Psychometric test performance. Archives of Neurology, 46, 383-386.

Strauss, A., & Corbin, J. (1994). Grounded theory methodology: An overview. In N. Denzin & Y. Lincoln (Eds.), Handbook of qualitative research (pp. 273-285). Thousand Oaks, CA: Sage Publications.

Strauss, A., Corbin, J., Fagerhaugh, S., Glaser, B., Maines, D., Sucek, B., & Wiener, C. (1984). Chronic illness and the quality of life. St. Louis, MO: C.V. Mosby Co.

Tappen, R.M. (1994). Development of the refined ADL assessment scale for patients with Alzheimer's and related disorders. Journal of Gerontological Nursing, 20(6), 36-42.

Timko, C. & Moos, R.H. (1991). A typology of social climates in group residential facilities for older people. Journal of Gerontology, 46, 160-169.

U.S. Department of Health and Human Services. (1996). Recognition and initial assessment of Alzheimer's disease and related dementias (AHCPR Publication No. 97-0702). Rockville, MD: Author.

Vittoria, A.K. (1998). Preserving selves: Identity work and dementia. Research on Aging, 20, 91-136.

Weiler, P.G., Chiriboga, D.A., & Black, S.A. (1994). Comparison of mental status tests: Implications for Alzheimer's patients and their caregivers. Journal of Gerontology, 49, (Suppl.) S44-S51.

West, M., Bondy, E. & Hutchinson, S. (1991). Interviewing institutionalized elders: Threats to validity. Image: Journal of Nursing Scholarship, 23, 171-176.

When memory problems don't mean Alzheimer's. (2001, August). The Mayo Clinic Checkup, 8, 1,6.

Wilson, H.S., & Hutchinson, S.A. (1996). Consumer's guide to nursing research: Exercises, learning activities, tools and resources. Albany, NY: Delmar.

Wood, B. (1999). The person in dementia care. Generations. The Journal of the American Society of Aging, 23, 35-39.

Yale, R. (1991). A guide for facilitating support groups for newly diagnosed Alzheimer's patients. Palo Alto, CA: Alzheimer's Association of Greater San Francisco Bay Area.

Zarit, S. H. & Downs, M.G. (1999). Center stage for the people who live with the condition. Generations. The Journal of the American Society of Aging, 23, 35-39.

### BIOGRAPHICAL SKETCH

Susan Leger-Krall received her BSN from the University of North Florida, Jacksonville, Florida in 1977, and her MSN from the University of Texas, San Antonio, Texas in 1978. She has been a geriatric nurse practitioner in Florida since 1992. She has many years of experience in nursing education and practice, and currently functions as an advanced practice nurse in long-term care.

IDENTITY WORK IN INDIVIDUALS WITH EARLY ALZHEIMER'S DISEASE

BY  
SUSAN LICER-KRALL

UNIVERSITY OF FLORIDA



3 1262 08555 2627

2011