AN INVESTIGATION OF COGNITIVE AND FUNCTIONAL DEFICIT AWARENESS AND SATISFACTION WITH CARE AMONG CLIENTS WITH DEMENTIA

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AWARENESS AND SATISFACTION WITH CARE

AMONG CLIENTS WITH DEMENTIA

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ABSTRACT

Dementia is a devastatingly debilitating disease that impacts not only the individual, but also the caregivers and professionals that provide care for that individual. There is a vast amount of research based on caregiver reports and doctor reports as well as some qualitative research conducted on individuals with dementia. However, there is a dearth of research conducted comparing awareness of deficits among individuals with dementia and their caregivers. Also missing is comparisons of beliefs of satisfaction with care among individuals with dementia. The purpose of this study was to investigate how perceptions of symptomatology (deficit awareness) relate to satisfaction with care, and whether there is a correlation between clients’ and caregivers’ evaluations of memory deficits. A total of 180 dyads were selected to complete several rating scales taken from the Chronic Care Network for Alzheimer’s disease (CCN/AD) study to compare results. These include the Personal Self-Maintenance, the Functional Activities Questionnaire, the Quality of Care Scale, the Blessed Memory Scale, and The Mini Mental State Exam. A multiple regression analysis showed that clients’ satisfaction with care was not dependent upon their perceived level of impairment, except for Doctors’ reports on the PSM. A one-way multivariate analysis of variance showed that there are significant differences between clients’ and caregivers’ perceptions of symptomatology of dementia. Implications and recommendations for clinical practice, counselor education, and supervision, and future research are outlined.
DEDICATION

This dissertation is dedicated to all the individuals who are suffering from dementia and their caregivers. The hope is that this research and more to follow help to bring a better understanding to treatment and the effects of dementia on the individual as well as their caregivers. To those individuals who have let me into their lives and for those in the future who will allow me to understand their experiences, thank you. Finally, to my wife Timia, without your support and constant belief in me, I could not have accomplished this.
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CHAPTER I

INTRODUCTION

Introduction to Dementia

Of all the illnesses that clinicians encounter, dementia is perhaps the most confusing and distressing to clients. Unlike other illnesses with a clear organic basis, dementia seems to erode the very essence of a client’s being. Dementia is somewhat unique in that it is a disease of late life and it retains its potential to affect clients and loved ones until death. Cognitive deficits in dementia occur in several different spheres including memory impairment, aphasia, agnosia, apraxia, and loss of executive functions. Memory loss is inclusive of loss of ability to communicate through verbal or written language, and an inability to recognize familiar objects by sight, smell, touch, taste, or sound. The physical limitations of dementia present enormous challenges for the clients and their caregivers, spouses, or friends.

Dementia is a progressive, debilitating disorder affecting increasing numbers of clients worldwide. Alzheimer’s disease is the most prevalent type of dementia, and an estimated 4 million Americans are affected by it. The number will continue to grow and by 2050, where 1 in 45 Americans may develop Alzheimer’s disease unless a cure is found (Klein & Kowall, 1998). Dementia is a generic term that refers to a group of symptoms that reflects the loss of intellectual capabilities and interferes with daily functioning (Loring, 1996). According to the Diagnostic and Statistical Manual of
dementia is defined as “The development of multiple cognitive deficits manifested by memory impairment as well as one or more of the following: aphasia, apraxia, agnosia, and disturbance in executive functioning” (p. 88).

Dementia is a chronic disease that is characterized by a decline in cognitive skills over many years at rates that vary depending on the stage of disease (Galasko, Corey-Bloom, & Thal, 1991; Morris, Edland, Clark, Galasko, & Koss, 1993). The rate of decline is generally highest during the moderate stage and is reduced in the early and late phases of the disease (Brooks, Kraemer, Tanke, & Yesavage, 1993). The most influential representation of dementia is as a disease of the brain, and using this understanding clinical interventions locate people with dementia as dysfunctional learners whose cognitive capacity can be increased through psychological and pharmacological means.

A second perspective of dementia is as a personal experience in which the client struggles to establish meaning in the context of their lifetime experiences. The most widely adopted descriptions of dementia identify the general syndrome as impairments in cognitive functioning, such as short-term memory loss and a reduction in verbal fluency. Within these definitions, the ‘thing’ that is lost in dementia is defined in terms of intellectual, linguistic, and cognitive functioning arising directly from neurological impairments. This is a representation of dementia in terms of a disease of the brain, with the clinical changes represented as the psychiatric and psychological equivalents of the activities of specific parts of the brain. Our response to people with dementia, both as service providers and as individuals, reflects our abilities to conceptualize such potential personal loss.
Dementia and Its Affect on Clients’ Lives

Dementia poses a number of fundamental challenges, not the least of which is that the caretaker can no longer be sure whether the care delivered is as the individual would have wished. The way in which dementia undermines personhood is through an attack on the individual’s identity, as it strikes at the very nature of personhood. For example, dementia has frequently been identified with a loss of self, mainly through the deterioration of memory and the increasing difficulty of communication. Many persons suffering from advanced dementia experience significant and frequent distress as they feel their sense of identity is slipping away. Persons with dementia describe this loss of identity in poignantly articulate terms (Cohen & Eis dorfer, 1986; McGowin, 1993), and family members and other loved ones experience their own unique painful reactions.

In an article by Menne, Kinney, and Morhardt (2002), individuals with dementia reported that they “wished to continue the lifestyle that they had become accustomed to” (p. 372). Other reported indicators of loss by individuals with dementia included not wanting to feel useless or unneeded, so they could continue to do “things properly and safely” (p. 379). Awareness of impaired cognition is more prevalent in mild dementia than others, which also leads to more reports of anxiety and depression due to their awareness (Dourado, Marinho, Soares, Englehardt, & Laks, 2007). Finally, Robertsson, Nordstrom, and Wijk (2007) reported that clients with mixed awareness were embarrassed and found it humiliating and hard to accept their inability to be aware of changes. They reported being ashamed and were aware of other people’s reactions to their behaviors. Losing the ability to perform the daily tasks that allow clients to live independently is devastating for the individual and their family. Individuals at the severe
stage of the disease usually also experience lack of insight and awareness of their deficits (and the implications of the disease) (Zanetti et al., 1999).

Dementia can also be seen within a social framework in which internal degradation interacts with external restrictions on social interaction. Alterations of the social environment are argued to maintain the person’s ability to establish a sense of social identity, value, and worth. In the social frame, understanding dementia involves understanding the dementia sufferer as a social being – as a person acting and reacting within a social context. Arguably this social context includes a political dimension whereby the establishment controls the even larger (and potentially subversive) ageing part of the population by identifying some form of behavior as deviant (Scull, 1995).

In the psychiatric realm, dementia has been seen as involving loss only on a neurological level and it was from this loss of brain functioning that behaviors that were frequently associated with dementia were said to emerge. The repositioning of dementia as involving both personal and social losses has meant that the behavior of people with dementia has acquired meaning in both personal and social frames. For example, Terri and Wagner (1992) have reported that depression has been the most commonly reported affective response of people with dementia.

Part of the reappraisal of dementia is reframed as a personal experience (Bender & Cheston, 1997; Kitwood, 1997b). Descriptions of this kind are clearly distinguishable from standard paradigm representations of brain functioning, but nevertheless concur that neurological deterioration impacts upon psychological functioning. This may affect the ability of that person to defend him or herself against the mental trauma caused by this deterioration. The clinical presentation of dementia within these personal accounts is
represented as a function not only of neurological deterioration, but of the person’s psychological health (Miesen & Jones, 1997).

The appraisal the person with dementia makes of his or her situation is likely to be interconnected with aspects of well-being such as mood and perceived quality of life. As stated above, a progressive decline in cognitive functioning is typical for people with dementia and Alzheimer’s disease. People who reach the severe stage of the disease have cognitive and functional loss that is so extensive that most cannot live independently. Deterioration in abilities to perform activities of daily living has also been found to be associated with lower awareness (Derousné et al., 1999; Migliorelli et al., 1995; Ott et al., 1996). The onset of dementia will give rise to a range of psychological responses including apparent unawareness of problems, as in denial or avoidant coping (Weinstein, Friedland, & Wagner, 1994). The manifestation of awareness or impaired awareness is likely to be affected by other factors related both to the dementia itself (such as accompanying depression, personality changes, or psychotic phenomenon), to its consequences, and to wider social factors and socio-cultural representations.

Sabat and Harre (1992) suggested that personal identity of clients with dementia persists far into the end stage of dementia. Social identity, on the other hand, which requires interaction with others in order to be materialized, can be diminished and even lost over the course of the illness. Tappen, Williams, Fishman, and Touhy (1999) cautioned that failure to recognize the person’s continuing awareness can lead to low expectations for therapeutic intervention, potentially resulting in mere task-oriented interaction. Bastings (2003) as well as others (Golander & Raz, 1996; Li & Orleans, 2002; Small, Geldart, Gutman, & Clarke-Scott, 1998; Vittoria, 1998) concluded that the
self is a continuum of memory and creativity that exists in a social context. Therefore, the person suffering from memory loss might suffer the gradual depletion of his or her personal control over identity, but not a total loss of self.

Some people with dementia who are often “written off” as helpless may, given proper environmental and social cooperation, demonstrate a degree of temporary reversal in symptoms, and perhaps with the proper creative activities the deterioration can be somewhat slowed (Kitwood & Bredin, 1992).

Caring is best construed not as the onerous supervision of decline, but rather as a process of helpful interaction. The subjectivity of persons with dementia must be acknowledged, gestures and utterances should be recognized as expansive of felt needs. It is wrong to underestimate what those with dementia can do with proper facilitation. (Kitwood, 1993, p. 89)

It is useful to realize that persons with a diagnosis of dementia seek meaning in the same way most people do, and their struggles to make sense of loss are common to others. People with dementia experience frustration, fear, loss of control, and anger. Accounts of dementia highlight individuals’ endeavors to retain hope and meaning. They remain persons, with their own unique gratifications and frustration, background, and destiny. There is a relatively benevolent point in the progression of dementia when anxiety and embarrassment are forfeited in favor of amnesia. People with progressive dementia come to forget that they forget. These people may experience a decline in quality of life and may display emotional reactions that clinicians should be aware of.

Gaugler, Kane, Kane, Clay, and Newcomer (2003) suggest that dementia has become a significant predictor of institutionalization. A study by Gruenewald, Karlamangla, Greendale, Singer, and Seeman (2007) suggests that feelings of usefulness to others is an important predictor for physical and mental health in older adults as well
as older adults who do not feel useful or participate in social activities often lead to more physical and psychosocial need for treatment. The key is what persons with dementia feel is quality of life, and we have to work at this level. One purpose of dementia care is therefore to maintain personhood in the face of failing mental powers.

**Deficit Awareness in Dementia**

The capacity for self-awareness of deficits in persons with dementia has a substantial bearing on diagnosis, treatment, and safety issues. Impairment or loss of deficit awareness is often included in the description of dementia (McGlynn & Kaszniak, 1991). An estimated 20% of Alzheimer’s disease clients exhibit unawareness or misinterpretation of their illness (Migliorelli et al., 1995). Clinically, impaired deficit awareness impacts the management and treatment of individuals. Deficit awareness is the capability of a person to accurately evaluate and report about his/her ability and limitations. Deficit awareness, as a common symptom of dementia, may be the result of frontal lobe damage (Flashman, 2002).

The most serious effect of dementia is the loss of insight into the symptoms of the disease itself. David (1990) suggests that insight can be considered to have three related aspects: the ability to label (or re-label) various mental events as pathological, the recognition by the individual that he or she has a mental illness, and the extent to which the individual complies with the appropriate medical treatment for that intervention. Broadly speaking, levels of insight are related to levels of cognitive impairment, with those individuals suffering from the most severe impairment showing the least awareness of loss (Sevush & Leve, 1993). This tends to parallel the description of dementia as
progressing through a series of stages: the early stages of dementia are typically said to be characterized by intact levels of insight, which are then said to be lost as the disease progresses.

The concept of awareness has become recognized as an important subject of study in relation to a number of clinical areas including psychosis, brain injury, and particularly, dementia. It is important to remember, when dealing with individuals with dementia, understanding the subjective experience of clients is paramount. In relation to dementia, from a clinical point of view, understanding more about the awareness people with dementia have concerning their illness and its consequences is essential. Dementia needs to be placed within both social and personal frames. Within these accounts of the process of dementia, loss acquires both personal and social significance and consequently both psychological and social interventions are required to address these different representations of loss.

Dementia is a condition that cuts across clinical disciplines, including counseling, psychology, neurology, and psychiatry. It is likely that contributions towards the conceptualization and evaluation of awareness will be influenced by the conceptual framework carried by different disciplines. The circumstances of dementia are characterized by diverse symptoms as a result of organic, psychiatric, psychological, and functional changes. Objects of awareness similarly span a wide range of different kinds including specific cognitive impairments, affective changes, psychotic symptoms, neurological deficits, personality/behavioral changes, and functional disabilities as well as the experience of having the condition in general.
It is important to remember that the way in which both individual expression of awareness and judgment of another’s awareness may be influenced by social and cultural expectations. Despite the difficulties inherent in evaluating awareness, it is clear that our perception of the extent to which another is aware determines how we respond to that person. We all experience different states of awareness. At the simplest levels (sleep to wakefulness) and higher levels (goal-directive behavior, self-awareness), we all display biases in self-relevant judgments and have the capacity to engage in behavioral avoidance or to defend ourselves through denial. A degree of unawareness is a normal part of life. These tendencies are likely to be exacerbated under difficult circumstances such as the onset of serious illness or disability (Charmez, 1983; Coleman, 1996). But a person with dementia will arrive at a point where he or she is living more or less purely in the present, having lost the sense of connection between the past, present, and future that makes planning impossible. The fitting response to the increasing incidence of dementia in our ageing society is to enlarge our sense of human worth to include rather than exclude.

Apathy and psychosis are frequently present in people with less awareness, and may show common neuropathological substrates with awareness. People with unawareness may resist treatment intervention because they are not aware of their deficits. They can be at risk of harming themselves or others because they cannot judge situations adequately (Cotrell, Wild, & Bader, 2006).

Dementia and Satisfaction With Care

Another aspect of both dementia and awareness of symptomatology important to clients and caregivers alike is the individual’s satisfaction with care. As stated above,
individuals with dementia, if left alone or isolated, deteriorate much faster and in apathetic and riskier ways. So the question is, what are individuals’ experiences like and how do they make sense of their perceptions and experiences? To achieve better informed treatment and care it is necessary to consider the client’s experiences, therefore having a better idea of how to approach their condition. The majority of research in the area of clients’ perceptions of care was conducted in a qualitative manner. These studies mostly involved interviews with clients and their caregivers. However, to this point little if any research focused on satisfaction with care among dementia clients has included constructs such as awareness or insight.

Dementia treatment consists of two principle systems of care: formal and informal (Chappell, 1989). The formal care system refers to governmental and non-governmental service agencies, as well as to health professionals and paraprofessionals who work on clients’ behalf (Chappell, 1989). The informal care system describes family, friends, and neighbors who assume caregiving responsibilities. In its Guidelines of Care, The Alzheimer’s Society of Canada (1997) includes this introduction:

In addition to physical needs such as the need for safety, nutrition, and good health, people with Alzheimer’s disease have the same psychosocial needs as other individuals. They need stimulation and companionship; they need to feel secure, to feel they are unique and valued individuals, and to feel a sense of self-esteem. (p. 3)

Tom Kitwood (1997a) emphasized that a fuller attention to emotional and relational well-being may offset some of the behavioral impact of neurological impairment and that caregivers need to understand and appreciate the culture of dementia in order to establish therapeutic efficacy.
Menne et al. (2002) reported that “each individual wished to continue the lifestyle that they had become accustomed to over the years” (p. 372). Their overlying results indicated that individuals with dementia wanted to feel as if they “still . . . contributed to the world” (p. 379) and that they did not feel “useless and unneeded” (p. 379). Gillies (2000) conducted a study to offer individuals with dementia the opportunity to describe their experiences. She found that most reported frustrations of living with failing memories that contribute to the difficulties of ageing, as well as the effect of lowering self-esteem and brought on a sense of failure, incompetence, and “letting down” those that have been their closest companions.

Harris (2004) conducted interviews with individuals with dementia and found that there were eight common themes that were problematic for those individuals: trouble obtaining a proper diagnosis, marginalization, changing relationships with the family structure, work/retirement issues, dependency, lack of meaningful occupation, issues of self-esteem, and awareness of changes in self. These were also linked to decreased self-esteem and onset of depression and/or anxiety. In Gillies’ (2001) research, she found that most individuals felt their failing memory was irritating, horrible, and maddening. This ultimately affected self-esteem and feelings of being stupid, a nutcase, and daft.

What does all this mean in connection with satisfaction of care? Older adults suffering from dementia and residing in long-term care facilities receive physical and emotional benefit from family members and friends. Prior research suggests that pleasurable social experiences decreased behavioral problems among residents (McCallion, Toseland, & Freeman, 1999). A large portion of the population with dementia also has depression (Lee & Lyketsos, 2003; Terri & Wagner, 1992). Persons
with dementia complicated by agitation and depression have more frequent hospitalizations, have medical diagnoses in greater number and severity, receive more psychiatric mediations, and have higher pain prevalence (Bartels, Horn, & Smout. 2003). Results also indicate that persons suffering with dementia who also have other co-varying diagnoses, such as depression and anxiety, tend to not respond well with treatment. Therefore, these clients report dissatisfaction with care (Harris & Sterin, 1999; Lee & Lyketsos, 2003; McCallion et al., 1999; Terri & Wagner, 1992). Gillies (2001) poignantly stated that “more attention needs to be paid to those with dementia to understand and manage their condition so that services can be built . . . to retain abilities and maximize what remains of their self-esteem and dignity” (p. 112).

Statement of the Problem and Need for the Study

Although a literature review has revealed that there is an abundance of research surrounding dementia as a medical condition, as well as research about the clients’ perceptions and caregivers’ perceptions or life with the illness, there is very little comparing both client and caregiver illness-related awareness. To date, there has been minimal research comparing subjective (client) and objective (caregiver/professional) measurements. There is also minimal research examining the difference in self-perception of symptoms and self-perception of care received. Furthermore, does the difference in self-perception of care and objective measurement lead to differences in satisfaction of care? If research on self-perceptions of dementia, symptoms, and quality of care improved, this would help practitioners in the application of more appropriate treatment and intervention strategies. This may also lead to fewer consumers of mental
and medical health services, as well as fewer consumers with dementia becoming unattended to. In addition, this would most likely reduce the amount of care burnout, as appropriate treatments could be offered. Perhaps clients could also be more effectively placed in the least restrictive treatment environment.

The limited amount of research on the differences of client and caregiver perceptions, including symptom identification and perception of care, hinders discussion of the importance of the factors described above as they relate to quality client care. Researchers and clinicians need to find innovative ways of managing the dementing process that sufferers and their caregivers experience. In particular, there is a pressing need to find interventions that increase the likelihood of the dementia sufferer continuing to live and be cared for within their own homes or the least restrictive environment. We can only do this by continuing to develop a new understanding of the dementing process through focusing on dementia both as an activity within a social world and a personal experience. We need to focus on symptoms and their psychosocial significance as well as on syndromes and their neuropsychiatric origins. Caregivers in particular often need space in which others can help them to listen to their own story of grief, guilt, and anger (Hettiaratchy & Manthorpe, 1992).

Similarly, clinical ratings are a widely used method of assessing awareness. Essentially these evaluations seem related to the assumption that unawareness is in itself a kind of symptom which may form a part of the disease process. Procedures for assessing awareness do vary, including interviews with the person (Weinstein et al., 1994), interviews with the informant (Loebel, Dager, Berg, & Hydes, 1990), case record reviews (Reed, Jagust, & Coulter, 1993), structured questioning (Verhey, Rozendal,
Ponds, & Jolles, 1993), standardized interview techniques (McDaniel, Edland, Heyman, and the CERAD clinical investigators, 1995), and use of single-item rating scales (Harwood, Sultzer, & Wheatley, 2000).

The object of awareness assessment is variable, with some studies focusing closely on memory functioning and others on broader domains of cognitive functioning, while a few also include activities of daily living (Zanetti et al., 1999). Other methods place more emphasis on perceived current functioning, while others focus in more detail on perceptions of the impact of difficulties and their likely progression.

Assessing awareness in the context of an interview might allow for comprehension to be checked and answers to be explored in more detail (Sevush & Leve, 1993). The problem is that there has not been a comprehensive effort to research the differences of caregivers’ and clients’ perceptions of illness. In order to identify whether differences exist, and thereby whether researchers can better understand lack of symptom-related insight among persons with dementia, this research is necessary. If this were accomplished, a more focused effort could be applied toward the creation of appropriate and useful interventions for the afflicted.

Purpose of the Study

The purpose of this study was to investigate the difference between subjective (client-related) and objective (caregiver-related) awareness of disease-related symptomatology among persons with dementia. Comparing standardized measurements of mental status among dementia clients is used to achieve this purpose. Specifically, the researcher studied whether there is a correlation between clients’ and caregivers’
evaluations of memory-related deficits (and related symptoms) and how perceptions of symptomatology relate to satisfaction with care. The researcher gathered archival data using individuals involved in a study conducted by the Chronic Care Network for Alzheimer’s disease, which employed standardized instruments to measure level of cognition and awareness in individuals with dementia. Results of research showed that there are significant differences between clients’ and caregivers’ perceptions (i.e., awareness) of dementia-related symptomatology, and the following implications are:

- With better understanding of deficit awareness/unawareness among clients with dementia (particularly at different stages), clinicians could be better suited to choose specific strategies tailored to the willingness of clients to participate in treatments matching their level of awareness.

- Because awareness is significantly different between clients and caregivers, it should help professionals understand the progression of dementia.

- Because awareness is significantly different between clients and caregivers, an enhancement of the understanding of dementia will occur and possibly ease caregivers’ mental burdens, feelings of helplessness, and overall burden of care giving.

- Because significant results are found, there is an enhancement of the understanding of awareness/unawareness of dementia by including data related to caregivers’ and clients’ perceptions of illness, a correlation that has not been studied to date.
• Because significant results are found, an enhancement of the understanding of how satisfaction of care by clients relates to better or poorer awareness of illness is presented, a relation to date that has not been studied.

Research Questions

This study answers the following research questions:

• Is there a relationship between dementia clients’ self-reported perceptions of memory deficits, professional reports, and clients’ satisfaction with care?
• Is there a difference between dementia clients’ and their caregivers’ perceptions of the clients’ dementia-related deficits, based on three groupings of severity of symptomatology?

Definition of Terms

The most frequently used terms of this study are defined within this section. These words and phrases help provide a better understanding of technical terms used in this research study.

Agnosia: Impairment of the ability to recognize or comprehend the meaning of, various sensory stimuli, not attributable to disorders of the primary receptors or general intellect; agnosias are receptive defects caused by lesions in various portions of the cerebrum (WebMD.com).

Alzheimer’s disease: A progressive neurological disease of the brain that leads to the irreversible loss of neurons and dementia. The clinical hallmarks of Alzheimer’s disease are progressive impairment in memory, judgment, decision making, orientation to physical surroundings, and language. Alzheimer’s disease is the most common of all
neurodegenerative diseases. It accounts for about two thirds of cases of dementia with vascular causes and other neurodegenerative diseases making up most of the rest (http://www.medterms.com/script/main/art.asp?articlekey=2213).

Anosognosia: Unawareness of cognitive or functional impairment (Cosentino & Stern, 2005).

Aphasia: An impairment in the understanding or transmission of ideas by language in any of its forms . . . that is due to injury or disease of the brain centers involved in language (APA, 2000).

Apraxia: A disorder of voluntary movement consisting of impairment of the performance of skilled or purposeful movements, notwithstanding the preservation of comprehension, muscular power, sensibility, and coordination in general; results from acquired cerebral disease. A psychomotor defect in which the proper use of an object cannot be carried out although the object can be named and its uses described (WebMD.com).

Awareness: Ability to realistically appraise their existing abilities and the limitations of those abilities.

Blessed Memory Test: Also known as the Information Memory-Concentration Exam has been used to screen client populations to document interval changes in clients with known dementia and to define the severity of dementia (Blessed, Tomlinson, & Roth, 1968).
Deficit Awareness: Ability to realistically appraise existing limitations to abilities.

Dementia: Dementia is a generic term that refers to a group of symptoms that reflects the loss of intellectual capabilities and interferes with daily functioning (Loring, 1999).


Executive Functioning: Term used to describe higher brain functioning including cognitive thinking and decision-making.

Insight: This refers to an individual’s awareness of their mental disorder (Schwartz, 1998).

Least Restrictive Environment: This defines the environment that a person can receive treatment which has the fewest necessary limitations.

Mini Mental State Exam (MMSE): The MMSE is an instrument commonly used to assess cognitive status in both clinical and community settings. Originally designed as a screening tool for dementia, the instrument has been widely used and well documented in dementia-related research (Algase, Beattie, & Therrien, 2001).

Overview of the Remainder of the Study

This paragraph explains what occurs in the remainder of this dissertation. Chapter II includes a thorough review of the literature related to dementia, screening tests, and methods used to identify dementia in clients, deficit awareness, and
associations with other disorders. This review includes a comparison and critique of related research conducted by mental health professionals. Chapter III describes the methodology of this study including the general research design, null and directional hypotheses, participants, instruments, and data analysis. Chapter IV provides the results of statistical analyses used in the study as well as descriptive and inferential statistics. Finally, Chapter V includes a conclusion and summary of statistical results found, a comparison of these results to the previous studies in the area, and a discussion of the results related to theory. Implications to future research as well as current practices are presented.
Chapter II describes the literature relevant to dementia, insight and/or awareness of dementia, and assessment measures used in assessing dementia and awareness. Specifically, this chapter examines the literature pertaining to examining individuals with dementia, their experiences and satisfaction, as well as caregivers involved with individuals coping with dementia. The literature review is divided into different sections. The first section is a review of general research on dementia. Other sections include information on topics related to dementia, including client satisfaction, individuals’ experiences, and caregiver research. Finally, a critique on the research is presented and rationale for the proposed research is offered.

Review of Empirical Literature Related to Dementia

Dementia is technically a syndrome, or set of symptoms, that can be caused by any number of physical diseases. Defined as a precipitous decline in mental function from a previous state leading to significant disability, dementia can occur in all ages and may or may not be irreversible. Dementia is also defined as “the development of multiple cognitive deficits . . . due to the direct effects of a general medical condition, to the persistent effects of substance abuse, or to multiple etiologies” (APA, 2000, p 147).
Dementia includes memory impairment, deterioration of language abilities, apraxia (impaired ability to execute motor activities), and disturbance of executive functioning.

Dementia includes several categories including dementia of the Alzheimer’s Type, Vascular Dementia, Substance-Induced Persisting Dementia, Dementia Due to Multiple Etiologies, and Dementia due to several medical conditions (APA, 2000). When discussing dementia, authors and researchers often will “switch” using dementia and Alzheimer’s disease, as well as dementia of the Alzheimer’s Type when discussing dementia.

In the DSM-IV TR (APA, 2000), the different types of dementia are described. It is reported that “the presumed etiology determines the specific dementia diagnosis” (p. 152). Vascular Dementia includes neurological signs and evidence of vascular disease related to dementia being present. Dementia Due to Other General Medical Conditions (e.g., Pick’s Disease, HIV) must have history of the medical disease and causal factors of that disease to dementia. Dementia of the Alzheimer’s Type must have other cognitive deficits ruled out first and there must be a gradual onset and continuing cognitive decline. Dementia of the Alzheimer’s Type (DAT) is the same as what is termed Alzheimer’s disease (APA, 2000). Overall, any dementia diagnosis includes cognitive deficits, including any of the following: apraxia, aphasia, agnosia, or disturbance of cognitive functioning.

Over the past 15 years there has been an increased interest in the empirical study of insight/awareness in a number of clinical areas including mental illness (Amador & David, 1998), brain injury (Prigatano & Schacter, 1991), and dementia (Marková & Barrios, 2000). These studies have focused on the relationship between individuals’
awareness or understanding of their condition and clinical variables such as severity of their condition, the stage of the illness, level of intellect, and so forth.

Debate has been raised concerning what approach to use when investigating poor awareness in individuals with dementia. A study by Robertsson et al. (2007) presented various research approaches for investigating poor insight in individuals with Alzheimer’s disease. They conducted a literature review using the search engines Cinahl and PsychInfo from 1993-2003 and analyzed the approaches from neuropsychological, psychological, socio-psychological, and sociological/anthropological/ethnological research perspectives. The authors found that various studies of poor insight in Alzheimer’s disease clearly show that the concept has been investigated in detail from different perspectives. Each of the perspectives has its merits, but none of them produced results that clearly provide understanding of what poor insight implies and involves.

In the neurological and neuropsychological conceptualization of awareness, the framework has developed predominantly along neurocognitive lines. Awareness has been conceived in modular terms, in a similar way to other “neuropsychological” functions such as memory, speech, perception, etc. Schacter (1992) reported that different degrees of awareness are equated with awareness of different aspects or types of the impairment rather than qualitative differences in awareness itself.

Prigatano et al. (1986) reported that individuals’ awareness could be assessed according to their judgment of severity of impairment; whereas Sherer, Bergloff, Boake, High, and Levin (1998) believed that awareness could be measured by comparison with previous functioning. Schacter (1992) reported that awareness can be predicted by their performance on specific tests assessing the level of impairment and how this compares to
objective test scores. Thus, the conceptualization of awareness is very closely linked with, and to some extent determined by, the neurological/neuropsychological impairment itself.

The concept of awareness or insight has been conceived more broadly with two main concepts: (1) awareness of change (i.e., awareness of abnormal mental/behavioral phenomenon) and (2) judgment concerning the nature of this change (Jaspers, 1948). The latter component gives rise to much of the broad conceptualization of insight in that it can variously include not just knowledge that the experienced change can represent a particular illness but also the assorted consequences to the self of experiencing the illness. In the general psychiatric conceptualization of awareness, Berrios and Marková (1998) cited that individuals with mental disorders often show little awareness or insight into having a mental disorder. In general psychiatry, unawareness of mental illness was inherent to the conceptualization of having a mental illness. It was when individuals were observed to show degrees of awareness into their mental illness that this became a focus of interest, and conceptualization of the notion was developed along different lines.

In the Psychoanalytic conceptualization of awareness, insight has been conceived as a much deeper knowledge of change in self. The concept of insight within this particular framework is broad, incorporating awareness not just of experience but of the way in which the self relates to them and reasons for this (Reed, Jagust, & Coulter, 1993). However, the concepts for this framework are blurred and difficult to define (Lamar, Lasarev, & Libon, 2002).

Most studies examining awareness in dementia tend not to specifically define the construct of awareness/insight used. The terms themselves therefore seem to be used
 interchangeably. The conceptual framework in which awareness has been based within the neurosciences seems to have developed following interest taken in the apparent loss of awareness observed in clients with prominent neurological or neuropsychological impairments (Rubens & Garrett, 1991). In this sense, awareness is conceived in modular terms where different degrees of awareness are equated with awareness in different types or aspects of impairment. In the general psychiatric sense, insight or awareness is associated with clients with mental disorders and recognition on the part of the client that they have a mental illness and need treatment (McEvoy et al., 1989). It is in this sense that this study is necessary. Understanding the level and nature of awareness or unawareness as it is related to caregivers and clinicians will land advancements into treatment needs and institutionalization of best practices for these suffering individuals.

The appraisal the person with dementia makes of his or her situation is likely to be interconnected with aspects of well-being such as mood and perceived quality of life. Some aspects of dementia may exert an influence on treatment outcome. For example, one retrospective study found that clinician-rated insight into memory difficulties appeared to be associated with greater gains from participating in memory therapy groups (Koltai, Welsh-Bohmer, & Schmechel, 2001).

There is an expectation that people with dementia will overestimate their level of functioning, but in fact that is not always the case (Michon, Deweer, Pillon, Agid, & Dubois, 1994), and some people with dementia rate their own functioning as much worse than do their relatives. Although there is some support for the validity of caretaker ratings (Jorm et al., 1994; Tierney et al., 1996), it is clear that factors such as depression or strain can exert an influence (de Bettignies, Mahurin, & Pirozzolo, 1990; Jorm et al.,
and a number of investigators acknowledge concerns about the assumption that caretaker ratings are a reliable standard (Green, Goldstein, Sirockman, & Green, 1993; Mangone et al., 1991).

A small number of studies have adopted a phenomenological approach to understanding awareness. In this approach, expressed awareness is explored in its social and psychological context, and there is often a theoretical assumption that awareness is in some way related to the experience of self and identity, whether understood from a social cognitive, material-discursive, or social constructionist perspective. Therefore, awareness is likely to be seen more as a fluctuating and dynamic construction than as a fixed attribute (Clare, 2002a, 2002b, 2003; Elliot, Fischer, & Rennie, 1999; Mayhew, Acton, Yauck, & Hopkins, 2001; Phinney, 2002).

Subjective complaints of memory loss are common in the elderly, with a reported frequency of 22% to 56% in community-based studies (Jonker, Geerlings, & Schmand, 2000). These memory complaints have been associated with a host of psychological factors. Concerning depression, Comijs, Deeg, Dik, Twisk, and Yonker (2002) found that clients suffering from dementia often have symptoms of depression that are co-morbid, and that depressive symptoms often occur more predominantly during the mild stage and decreases during the moderate stage, and ultimately disappear during the severe stage. Studies by Grut et al. (1993) and O’Conner, Pollitt, Roth, Brook, and Reiss (1990) have also supported these results. Anxiety is another form of psychological factor that is associated with memory complaints. A study by Clarnette, Almeida, Forstle, Paton, and Martins (2001) as well as Comijs et al. (2002) supported findings by Hanninen, Reinikainen, and Helkala (1994) that anxiety in its own right can cause memory
difficulties during an anxiety crisis. Clarnette et al. (2001) found that clients suffering psychosis have severe memory difficulties ranging from black-outs to amnesia. Hanninen et al. (1994) conducted a study concerning somatic complaints and found that clients with severe somatic problems often have memory complaints mirroring dementia symptoms. A study conducted by Comijs et al. (2002) found that personality factors such as low self-esteem and low perceived self-efficacy often restrict a client’s ability to maintain good memory. In the same sense, a study by Hanninen et al. (1994) found that neuroticism personality factors significantly cause poor memory results. Jorm et al. (1994) completed a study as well that indicated the above named personality factors significantly decreased one’s memory capabilities as well as performance on memory tests. These findings suggest the need to control these aspects in relation to research concerning dementia.

Although the clinical relevance of memory complaints in individuals with dementia appears negligible in relation to objective cognitive functioning, an emerging body of literature has indicated that poorer memory appraisals may predict developing dementia or Alzheimer’s disease in older adults with assumed normal cognition (Geerlings, Jonker, Bouter, Ader, & Schmad, 1999; Schmand, Jonker, Geerlings, & Lindeboom, 1997; Schmand, Jonker, Hooijer, & Lindenboom, 1996; Tobiansky, Blizard, Livingston, & Mann, 1995).

It should be understood that the findings in this area remain generalized, with some studies showing a lack of relationship between subjective memory deficits and future neurocognitive decline or dementia in elderly persons followed from one to several years. Flicker, Ferris, and Reisberg (1993) conducted a longitudinal study of cognitive
function in elderly persons with subjective memory complaints. They found no relationship between reported memory issues and cognitive decline following the clients 3 years later. Jorm et al. (1994) and Schofield et al. (1997) conducted a similar study where they also did not find any significant correlation between memory difficulty and cognitive decline over several years. However, they were not able to control for a diagnosis of dementia versus “healthy” individuals. Thus the clinical importance of appraised memory dysfunction among elders without objective cognitive impairment remains unclear. This study is aimed at being able to identify cognitive impairment through objective measures to control for dementia diagnoses.

Review of Empirical Literature Related to Awareness in Dementia

The capacity for self-awareness in persons with dementia has bearing on client diagnosis, treatment, and safety issues. Impairment or loss of deficit awareness is often included in the description of dementia (McGlynn & Schacter, 1989), and an estimated 20% of Alzheimer’s disease clients exhibit unawareness or misinterpretation of their illness (Migliorelli et al., 1995). Clinically, impaired deficit awareness impacts the management and treatment of clients (McGlynn & Schacter, 1997). For example, such persons may refuse needed interventions because they are unaware that a problem exists (Seltzer, Vasterling, Yoder, & Thompson, 1997). Furthermore, patients unaware of their deficits may engage in unsafe tasks (cooking, driving), placing themselves at risk and distressing caregivers (deBettignies et al., 1990).

A study by McGlynn and Kaszniak (1991) found that AD patients showed inaccuracy in predicting their performance in most cognitive tasks when compared to
both their actual performance and relatives’ predictions, despite generally accurate prediction of their relatives’ performance on the same tasks. The investigators theorized that people with dementia are unable to update their perception of how they perform based on actual performance. Such an inability could prevent affected individuals from adopting new strategies for safely coping with difficult tasks (LaBuda & Lichtenberg, 1999).

A study by Graham, Kunik, Doody, and Snow (2005) tested the theory that people with dementia do not update their self-perception based on actual performance and actually have an increased level of deficit awareness due to their inability to update their self-perceptions. Their results indicated that individuals with dementia had similar perceptions of performance when compared to control groups but performed worse on cognitive tests than the control group. Also, individuals with dementia over-estimated their performance on specific cognitive tests as well as did not update their self-perceptions of, and may not be aware of, their actual performance on cognitive tasks. One interesting result also showed that normal individuals often perceived their performances on tasks inaccurately as well.

A study conducted by Derousne et al. (1999) looked into unawareness of cognitive deficits in individuals with mild Dementia of Alzheimer’s type (DAT). Their results indicated that awareness of cognitive deficits varied greatly between the individuals studied, most individuals with DAT were intellectually aware of their cognitive deficits but were unable to or failed to evaluate the severity or consequences the deficits have on their everyday life, and that decreased awareness positively correlated with age (i.e., older individuals evidenced poorer awareness).
Snow et al. (2005) investigated factors contributing to increased discrepancies between self-report and proxy report of deficits. In addition, they examined how these factors varied by diagnostic status (presence or absence of dementia and depression), measurement method (individual report compared to clinician report versus informant report), and deficit awareness dimensions (cognitive, functional, emotional, and general awareness). Results indicated that people with dementia had significantly higher cognitive impairment and functional disability scores than non-demented individuals. Also, caretakers of dementia individuals had higher scores for feeling burdened and there was a greater discrepancy between patient and informant in awareness found with non-demented clients. Their results also indicated that fewer deficits were identified by individuals with dementia than their informants and that more impairment in deficit awareness was associated with higher levels of burden and presence of dementia. Finally, the presence of dementia positively predicted cognitive deficits and that impairment in deficit awareness was associated with the presence of dementia and absence of depression.

A study by Dourado et al. (2007) assessed awareness of disease of client/caregiver dyads and the relationship between unawareness on various domains and sociodemographic variables among elderly Brazilians with Alzheimer’s Disease (AD). They found that mild AD groups scored significantly better on cognitive tests than moderate dementia patients as well as a positive relationship between age and impaired awareness of disease. They also found that the awareness of impaired cognition was more prevalent in mild AD dyads. Finally, they found a significant difference in awareness of disease in a sample of mild and moderate AD patients as well as older
patient dyads showed more severe level of unawareness and more impairment than younger dyads.

A study by Cotrell, Wild, and Bader (2006) investigated the relationship between individual’s cognitive status, deficit awareness, medication management skills, and actual medication adherence. They also investigated caregivers for their prediction of the care recipient’s management abilities. They found that there was no significant difference between individuals with AD and non-impaired individuals when it concerned medication management and that the higher level of assistance led to a higher level of deficit awareness.

Zanetti, Vallotti, Frisoni, et al. (1999) evaluated insight in a group of individuals with dementia with two assessment scales and assessed their relationship with the cognitive level of disease severity. Their results showed that the association between insight and cognitive status reflects more closely the observable decline of insight and can provide estimates of when the decline of insight begins and ends.

Howorth and Saper (2003) attempted to characterize the factors determining the retention or loss of insight in dementia. They posited that insight in dementia is a complex, multi-dimensional, and value-laden concept. Emotional and behavioral aspects need to be considered as well as cognitive, which is emphasized by traditional methods of assessment based on quantitative ratings. Implicit awareness may be accessible through subjects’ predictions on performance. An adequate account of insight in dementia should incorporate both objective and subjective measures in order to determine the interrelationships between organic changes, personality factors, and psychological mechanisms.
Snow, Graham, et al. (2005) examined factors affecting deficit awareness (DA) and the effects of diagnostic status (dementia and depression), measurement method and DA dimension on these relationships. They concluded that DA measurement method was an important moderating variable and that clinicians may be better at evaluating cognitive deficit awareness whereas informants may be better at evaluating functional and emotional/behavioral deficit awareness.

Vogel et al. (2004) also investigated impaired awareness of cognitive deficits in individuals with mild cognitive impairment and Alzheimer’s disease. They found no significant difference in levels of awareness between the two groups and concluded that subjective memory problems should not be a mandatory prerequisite in suspecting dementia. This conclusion, they state, makes reports from informants together with thorough clinical interviews and observation central when assessing suspected dementia disorders.

O’Keefe et al. (2007) studied Frontal Temporal Dementia (FTD). Their aim was to investigate awareness of cognitive deficits in FTD, Corticobasal Degeneration (CBD), and Progressive Supranuclear Palsy (PSP) using a multidimensional approach to assessments. They identified that there are different patterns of neuropsychological performance and behavioral rating scores predicted insight deficits across three awareness categories. Overall, there was a loss of insight across all three investigated groups and the most deficits occurred in the dementia category.

Aalten et al. (2006) aimed to investigate whether awareness changed during the course of dementia and to determine whether awareness was associated with certain behavioral symptoms. What they found is that awareness is positively associated with
age, gender, education, and socioeconomic status, and negatively associated with psychosis, apathy, and overall behavioral disorders at baseline. In addition, they concluded that a higher level of awareness is associated with depression and anxiety, whereas lack of awareness is associated with psychosis and apathy and that the level of awareness decreases as dementia progresses.

Another study of how memory is affected by deficit awareness was conducted by Gallo, Chen, Wiseman, Schacter, and Budson (2007). They explored the relationship between episodic memory and anosognosia (lack of deficit awareness) among individuals with Alzheimer’s disease. Healthy older adults made fewer false recognition errors when trying to remember pictures compared with words. Participants with Alzheimer’s disease were able to discriminate between studied and non studied items, but they had much more difficulty discriminating between words and pictures. These results were associated with anosognosia in that unawareness was associated with impaired memory accuracy. Therefore, they concluded that memory is negatively affected by deficit awareness.

Ready, Ott, and Grace (2006) investigated if client insight and cognitive impairment are factors that can guide decisions regarding the reliability and validity of self-report data from cognitively impaired persons. Their results indicated that individuals’ insights may affect reliability of Quality of Life reports independent of cognitive impairment. They also found that individuals with higher insight and lower cognitive impairment had a lower rating of quality of life than their caregivers as well as individuals with lower insight and higher cognitive impairment had a higher rating of quality of life than their caregivers.
Clare (2002b) explored the nature of the contributions made by neurological, psychological, and social factors to the expression of awareness in early-stage dementia. She found that for people in early-stage dementia, apparent unawareness must be viewed as the product of psychosocial processes in interaction with cognitive impairment. Models that focus solely on neurological factors cannot provide a comprehensive explanation for unawareness in early stage dementia.

Clare conducted a similar study in 2003 trying to observe awareness or lack of awareness in individuals with early-stage dementia. She observed that participants were seen as engaging in the processes of acknowledging, reacting, explaining, experiencing the emotional impact, and adjusting. All participants acknowledged memory problems, indicating a basic awareness of changes in their memory functioning but made varying judgments about the meaning and impact of these.

Clare (2005) then conducted a follow-up study one year later to identify any emerging themes of change in perceptions. She reported that all the participants continued to demonstrate some awareness of difficulties with memory, but individuals varied in their evaluations of the extent and implications of these changes, with the majority tending towards more normalizing explanations. Many were nevertheless making practical adjustments to their activities, and the need to renegotiate relationships was a prominent issue. There also was some indication of increased polarization between self-maintaining and self-adjusting styles of coping. The findings suggested that expression of awareness interacts with coping style, illustrating the need to consider both factors in combination in order to better understand individual expressions of awareness of change.
Hannesdottir and Morris (2007) explored anosognosia for memory impairment in dementia from a neuropsychological profile approach. They found that there may be multiple components to the phenomenon, damage to which can cause different types of anosognosic disturbances. They concluded that anosognosia should not be seen as a single entity but as having multiple causes. They also stated that anosognosia problems are at the executive functioning level, indicating that memory may affect the immediate ability to judge cognitive performance in a domain-specific manner.

In summary, literature reviewed concerning awareness in dementia indicates a few themes. The most prolific theme identified is that clients that suffer from dementia have extreme difficulty with understanding and identifying their inability to be aware of their deficits. Most often, it was identified that it is the unawareness that causes most problems with clients with dementia, including emotional, social, and physical symptoms. The other major theme included the necessary opinions and conclusions from caregivers and proxies that care for the individuals with dementia. Often, it is their input and insight that assists in identifying types of services for the clients. Problems often occur when the individuals do not realize their needs and are unable to accept help offered to them. Dementia clients also suffer specific cognitive and neurological deficits that add to the inability to update their awareness but also lose capacity to care for themselves. Because of these themes, this study utilizes not only the client input, but also caregivers and professionals alike in order to better understand specific areas of unawareness, but also how different the opinions are between caregivers and clients as well as how the deficit affects clients’ reception of care.
Review of Empirical Literature Related to Client Satisfaction

Client satisfaction of services, from this author’s perspective, is an important factor to consider when dealing with care for any individual. Satisfaction with care can be markedly more difficult with persons having dementia due to the nature of the illness and complexity of issues.

A study by Hirschman et al. (2005) was designed to examine the factors associated with the preferences of Alzheimer’s disease patients to participate in a decision to use an Alzheimer’s-slowing medication and how involved their caregivers would let them be in the process. Their results showed that most mild to moderate Alzheimer’s patients wanted to participate and that most caregivers wanted them to as well. Most caregivers reported that their agreement to allowing involvement revolved around their belief in the amount of capacity that exists.

Gardner, Foreman, and Davis (2004) investigated the amount of satisfaction of clients and their caregivers had with a memory clinic. They found that there is a positive effect of memory clinics which incorporate multidisciplinary assessment and take the time to sensitively explain diagnostic and management options to both the client and caregiver. They also noted that for caregivers, a supportive and caring attitude from the clinic staff was a most influential factor. For clients, they found that the most influential factor for satisfaction was the appropriateness of the information given.

Engel, Kiely, and Mitchell (2006) looked into factors associated with the satisfaction of family members with the care provided to persons with advanced dementia in a nursing home setting. They found that the most important factor that determined satisfaction with care was time spent by a care provider discussing advanced directives
with the health care provider at the time of admission of the nursing home setting. This helped identify that there are modifiable factors that could be targeted to improve end-of-life care for people with advanced dementia in a nursing home setting.

Reid, Ryan, and Enderby (2001) explored the question of unmet needs in relation to people with dementia receiving respite services and to consider their status as people actively shaping their care. This was completed by interviewing 19 individuals using an interview-based research. They concluded that existing research suggests that semi-structured interviews and group discussion provides a productive way of allowing people with dementia to speak about their experience of care and life more generally. They also posited that there is a lack of methodological guidance available to those seeking to include people with dementia as “users” of service. Also, people with dementia do not have uniformity of experiences, but individual differences which makes the experience different for all. This argues the “one fits all” idea of service.

Although there is a dearth of information regarding satisfaction with care, the research here identified that clients appreciate information that helps explain what is happening to them; as long as they have the capacity to understand. Also, caregivers also have shown a satisfaction when information is given regarded dementia and care for clients with dementia. Most importantly, people must remember that these are individuals and that individually designed treatments are needed to assist individuals with dementia. With this in mind, this study aims to identify the areas in which the caregivers and clients agree as well as disagree in service provision and satisfaction from both. Finally, the addition to this particular research area will hopefully expand choices for clients with dementia.
Review of Empirical Research Related to Dementia Clients’ Personal Experiences

Much like client satisfaction, the experience of individuals with dementia is equally important to consider when discussing outcomes and plans of care. As you will read, subjective experience of individuals can have an impact not only on their perception of lifestyle, but also perception of care given to them.

Spector and Orrell (2006) conducted a study that compared the quality of life of people with dementia as assessed by the individuals and their care staff and possible factors associated with the discrepancy between ratings. Their results showed that people with dementia and care staff rated quality of life differently. They also found a positive correlation between increased hope in care staff and higher belief in quality of life by individuals with dementia.

Menne et al. (2002) interviewed six individuals with dementia to explore the experience of dementia from the perspective of the persons with dementia. In this study, they interviewed each person in their home setting. Their reported findings included that each individual wished to continue the lifestyle they were used to, but also that they were able to adapt to new situations.

Carpenter and Dave (2004) reviewed literature in an effort to document previous opinions and practice in the area of disclosing diagnoses. They found that there is an abundance of arguments both for and against disclosing a diagnosis of dementia for ethical and practical purposes. Mainly, they identified that the professional opinions were dramatically different from the experiences of caregivers, family members, and the individuals themselves.
Snow, Kunik, et al. (2005) investigated the reliability and validity of self-reported depression in clients with dementia. This was reportedly the first study to combine the use of multiple depression criteria with dementia and depression control groups. They identified that clients with poor deficit awareness reported fewer symptoms of depression; but that the presence of dementia alone does not necessarily predict inaccurate depression self-reports. This identifies that clients with dementia also suffer emotional issues like depression and anxiety just as “normal” people would; and maybe even more so in the early stages of dementia since awareness of the disease is still high.

Farias, Mungas, and Jagust (2005) examined whether degree of discrepancy between individuals with Mild Cognitive Impairment (MCI), a pre-cursor to dementia, and informant-reported everyday functioning was associated with cognitive status. The purpose was to study the discrepancies between self- and informant-reported everyday functioning across groups of healthy older adults, individuals diagnosed with MCI, and those diagnosed with dementia. Dementia group scores showed a significantly higher difference score than the cognitively normal and MCI groups. Therefore, individuals with dementia rated themselves as having much less decline in everyday cognitive and functioning abilities than their informants reported. This indicates a decreased awareness of deficit on the part of the dementia individual. These findings are consistent with previous findings that caregivers tend to provide more accurate observations of cognitive abilities than do individuals with dementia (e.g., Koss, Patterson, Ownby, Stuckey, & Whitehouse, 1993; Kuriansky, Gurland, Fleiss, & Cowan 1976; Tierney, Snow, Szalai, Fisher, & Zorzitto, 1996).
Pearman and Storandt (2005) studied which facets of conscientiousness and neuroticism are involved in the relation between personality and subjective measure. They wanted to provide clearer understanding of memory complaints. They found that memory complaints by non-demented older people are related to personality rather than actual memory deficits, replicating a study by Pearman and Storandt (2004).

Lingler et al. (2006) examined the experience of living with and making sense of the diagnosis of dementia from the individual’s perspective. Specifically, they targeted the process of making sense of a diagnosis of Mild Cognitive Impairment (MCI). Their analysis revealed a wide range of personal interpretations of a diagnosis. Although participants’ virtual non-usage of the clinical label MCI raises the possibility of a failure to own, reflect on, or identify with one’s diagnosis, most participants’ narrative accounts suggested otherwise. They also found that factors such as expectations of normal aging, prior personal experience with dementia, and concurrent health conditions are influential in shaping perceptions of the meaning of diagnosis of MCI. Therefore, they are at risk for both over and underestimating the significance of their diagnosis.

This research indicates that similar to satisfaction with care, personal experiences of clients with dementia are indeed specialized and individualized to each person’s experience. One common theme that appeared the most included that both caregiver/proxy and client had the best experiences when they felt that they were informed by either professionals or other caregivers. This gives rise to the importance of this particular study in that identifying differences in satisfaction with care between clients and caregivers will target specific areas that produce the most separation.
Critique of Research on Dementia

A literature review indicated that there has been more research conducted in the area of dementia in the last several years than the years prior to 1990 combined. Several of these studies have focused on clinical perspectives, while there has been an increase in the amount of research that utilized the personal experiences of individuals with dementia. Within this research, several significant limitations were noted by the authors. From these limitations, we can gain a better understanding of how to design future research in order to further the research that is critical in order to expand theory and practice in the area of dementia. Weaknesses in methodology and other limitations of previous research are described below in broad categories according to type of limitation.

One of the most significant methodological weaknesses of studies focused on dementia is the use of small sample sizes. According to Cohen (1992), small sample sizes reduce statistical power, reducing the probability of statistical significance being found. Small sample sizes also affect the generalizability of findings because results can less easily be broadened to the larger population. Of the studies mentioned above, 15 employed sample sizes that were less than 50 participants (i.e., Clare, 2003, Clare, Roth, & Pratt, 2005, Dunn & Clare, 2007; Cottrell et al., 2006; Dunham & Cannon, 2008; Gallo et al., 2007; Gant, Steffen, & Lauderdale, 2007; Graham et al., 2005; Hirschman et al., 2005; Lingler et al., 2006; Menne et al., 2002; O’Keefe et al., 2007; Piechniczek-Buczek, Riordan, & Volicer, 2007; Reid et al., 2001; Vogel et al., 2004). There were eight other studies used that utilized more than 50 participants but less than 100 (i.e., Derousne et al., 1999; Dourado et al., 2007; Hannesdottir & Morris, 2007; Pearman & Storandt, 2005; Ready et al., 2006; Snow et al, 2005; Spector & Orrell, 2006; Zanetti et al., 1999). There
were, however, eight studies that included more than 100 individuals in their research. Inclusion of a sample size of 100 or more would provide sufficient power to find significant results (i.e., Chappell & Reid, 2002; Engel et al., 2006; Farias et al., 2005; Foreman et al., 2004; Gaugler et al., 2003; Menne & Whitlatch, 2007; Snow et al., 2005; & Zhang, Mitchell, Bambauer, Jones, & Prigerson, 2008).

In order to further research in any area, precise methodological approaches, including standardized measures, must be used by researchers. This not only helps with uniformity, but also eases ability to compare and contrast results. While reviewing the research above it was noted that there were a total of 34 different measures used. In addition, results were often reported with the use of measures that were not reliable or valid. For example, there were two different studies that utilized semi-structured interviews (Lingler et al., 2006; Reid, Ryan, & Enderby, 2001). One study utilized a non-standardized in-home interview for their research data (Menne et al., 2002). There were three other studies that employed only partial sections of measures to gather data with. These included the partial use of the Alzheimer’s disease Assessment Scale (Graham et al., 2005), the Anosognosia Questionnaire-Dementia Scale (Gallo et al., 2007), and the Dementia Deficit Scale-Deficit Awareness (Snow et al., 2005). The one consistent measure used by most of the researchers included using the Mini-Mental Status Exam (MMSE) scores as criteria for inclusion in studies. However, the MMSE has documented weaknesses that will be discussed in Chapter III.

Another limitation noted by the authors included the lack of generalizability with results. Generalizability is an important consideration in terms of developing a research design and progressing any field of study or topic of interest. It is generalizability that
enables clinicians and researchers to utilize best practices and continue to improve on helping people with problems. Generalizability also is important in order to compare results to as many different populations as possible. As stated previously, a small sample size was one culprit for poor generalizability in many studies. However, other limitations to generalizing results included race (Clare, 2002, 2003, 2005; Engel et al., 2006; Ready et al., 2006; Spector & Orrell, 2006); limited sample base (Derousne et al., 1999; Engel et al., 2006; Farias et al., 2005; Gauger et al., 2003; Hirshman et al., 2005; Piechniczek-Buczek et al., 2007); culturally insensitive (Cotrell et al., 2006); poor socio-economic differences (Menne et al., 2002); and variable diagnoses (Menne et al., 2002). For example, race is an important factor to consider as a weakness because of the cultural differences in different races which can lead to different belief symptoms not only in the type of care that could be given to dementia clients but also how much care may be given. This can skew results of previous studies that may not be able to be utilized by other races. In the same sense, a limited sample base does not necessarily allow for the results to be duplicated or usable in other sample types. Different types of diagnoses may have causal factors that influence types of care and perception of care. This is similar to cultural bias and socio-economic standing.

A further weakness acknowledged by the authors of studies reviewed above includes the inability to control or account for important factors that may have affected outcomes. Controlling variables from contaminating results is most important if one would like to achieve pure data with which to draw conclusions and utilize to create best-practice techniques. The ability to draw conclusions based on results that as many factors as possible are figured into the results provides one an opportunity to create useable
solutions across different sample types. Control issues included Mood (Chappell & Reid, 2002; Farias et al., 2005; Gaugler et al., 2003); Caregiver Burden (Dourado et al., 2007; Gaugler et al., 2003; Ready et al., 2006); Missing data (Gaugler et al., 2003; Zhang et al., 2008); Medications (Cotrell et al., 2006; Graham et al., 2005; Zhang et al., 2008); Memory (Derouesne et al., 1999); Poor control of responses (Chappell & Reid, 2002); Training of staff (Spector & Orrell, 2006) and Level of Unawareness (Graham et al., 2005). Admittedly by the above authors, the limitations that were listed confounded results to which results may not be duplicated or be utilized by all sample types. Mood, caregiver burden, and medication can affect results in the sense of emotional state of mind of the client or caregiver. Memory, level of unawareness, as well as control of responses are indicative of cognitive levels that are important to consider when trying to breakdown results for use. Missing data from studies limit its reliability and validity for use.

In summary, based on findings of the reviewed literature and limitations of these studies, it is difficult to draw firm conclusions without using caution. There are some interesting results reported, ones that bring hope to caring for older adults that suffer from dementia. However, most researchers agreed that further research needs to be conducted in the areas of awareness and dementia. A majority of research conducted included using the clinical perspective without input from clients and caregivers themselves. It is in this area that comparisons may not only be replicable, but also more powerful when drawing results. Therefore, while trying to grow the research base for dementia and care for clients with dementia, one must keep in mind the limitations listed above and attempt to
limit their impact on the research data so that data gathered can help to improve and grow the literature base and clinical practice.

Rationale for the Approach

Dementia is often socially defined as “an old person's disease”; and although the definition of dementia has changed over time, its correlation with the aging process has not. To achieve better-informed treatments and provision of care it becomes necessary to consider the person whose experiences might be exacerbated by how we approach their condition, and whose lived world might not be as limited as our professional nihilism. The opportunities open to individuals with dementia to describe their experience and thereby influence their treatment and care have hitherto been limited by a perception of assumed inability and incompetence of clientele, rendering such contributions as invalid or at best unreliable. Recently, more attention has been focused on the value of finding an appropriate means of harnessing such experiences and examining what can be learned from listening to subjective accounts. More attention needs to be paid to how those with dementia understand and manage their condition so that services can build on their efforts to retain abilities and maximize what remains of their self-esteem and dignity.

The majority of research reviewed lacked inclusion of personal perceptions of individuals with dementia. This is one area where the current body of research is lacking and where this research study will add to the research base. The purpose of this study was to investigate the difference between subjective (client-related) and objective (caregiver-related) awareness of disease-related symptomatology among persons with dementia. Comparing standardized measurements of mental status among dementia
clients was used to achieve this purpose. Specifically, the researcher evaluated whether there is a correlation between clients’ and caregivers’ evaluations of memory-related deficits (and related symptoms) and how perceptions of symptomatology relate to satisfaction with care.

The design of the research included data taken from the Chronic Care Networks for Alzheimer’s disease (CCN/AD) project conducted in 2004. The data also included a cross-sectional analysis of the first of three waves of data that was collected. The method of collection included instruments that have been tested for validity and reliability. The archival data was descriptive in nature from two different respondents (client and caregiver) via structured telephone interviews. The procedure included multi-variant analyses of variances using multiple regressions. The data was designed to control as much for limitations including medications, race, age, medical conditions, dementia diagnosis, and mood. This study utilized archival data from the CCN/AD project to retrospectively analyze whether clients’ degree of insight relates to caregivers’ and clients’ perceptions of illness and clients’ satisfaction with care received.
CHAPTER III

METHODOLOGY

The purpose of this study was to investigate the difference between subjective (client-related) and objective (caregiver-related) awareness of disease-related symptomatology among persons with dementia. Comparing standardized measurements of mental status among dementia clients was used to achieve this purpose. Specifically, the researcher investigated whether there is a correlation between clients’ and caregivers’ evaluations of clients’ memory-related deficits (and related symptoms) and how perceptions of symptomatology relate to satisfaction with care. This researcher gathered archival data using individuals involved in a study conducted by the Chronic Care Network for Alzheimer’s Disease, which employed standardized instruments to measure level of cognition and awareness in individuals with dementia. This goal was achieved by analyzing archival data collected from a study conducted by the Chronic Care Network for Alzheimer’s disease (CCN/AD) in 2004 via an ex post facto research design. This chapter provides an overview of the research questions, a description of the variables, and an overview of the research design for the study.

General Research Questions

1. Is there a relationship between dementia clients’ perceptions of self-reported deficits and their satisfaction with care?
2. Is there a difference between dementia clients’ and their caregivers’ perceptions of the clients’ dementia-related functional deficits?

Null and Directional Hypotheses

*Null hypothesis 1:* There is no statistically significant correlation between perception of memory deficits, functional deficits, and ratings of satisfaction with care (as measured by the CCN/AD Patient and Caregiver Outcomes Survey) among persons with dementia.

*Directional hypothesis 1:* There is a statistically significant positive correlation between perception of memory deficits, functional deficits, and ratings of satisfaction with care (as measured by the CCN/AD Patient and Caregiver Outcomes Survey) among persons with dementia.

*Null hypothesis 2:* There is no statistically significant group differences in perceptions of dementia-related functional deficits (as measured by the CCN/AD Patient and Caregiver Outcomes Survey) among clients with dementia from three different severity levels and their caregivers.

*Directional hypothesis 2:* There is a statistically significant group difference in perceptions of dementia-related functional deficits (as measured by the CCN/AD Patient and Caregiver Outcomes Survey) among clients with dementia and their caregivers, in that clients with dementia perceive fewer functional deficits than caregivers. Therefore, the more severe the deficits as measured by MMSE level, the larger the difference in perceptions between clients and caregivers.
Participants and Delimitations

In terms of minimum necessary sample size for adequate statistical power, Cohen (1992) asserts that using a one-way ANOVA with an alpha level of $p < .05$ and a medium anticipated effect size, at least 128 participants are required (64 in each separate group being investigated). The final sample size for the interviews used for this study yielded 972 participants; 746 participants were caregivers of clients with dementia, and 226 participants were clients with dementia themselves. Archival data from all participants were utilized in this study. All clients with dementia involved in the research interviews had diagnoses of dementia according to the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR; APA, 2000). These diagnoses were made after face-to-face interviews with their Primary Care Physicians (PCP) prior to admission to the study. All diagnostic interviews occurred face-to-face between the client and PCP in order to enhance the diagnosis. All data were originally collected via telephone interviews, and the setting for phone contacts included the client’s or caregiver’s place of residence.

For the purpose of this study, a total of 180 client and caregiver dyads were obtained through the use of archival data originally collected from the Chronic Care Network for Alzheimer’s Disease (CCN/AD). The original sample consisted of 226 clients with dementia and 746 caregivers. From that sample 180 caregivers and clients were matched together in order to generate usable data. Because the purpose of this study was to better understand dementia clients’ insight and satisfaction with care, only the demographic characteristics of the 180 dementia clients is reported here. Of the total sample, 174 participants reported their race: 151 (87%) identified as White, 12 (7%)
identified as African American, 7 (4%) identified as Hispanic, and 3 (2%) identified as Asian or Pacific Islander. Regarding the entire sample, participants ranged in age from 51 to 94 years (Mean = 79.5 years, SD = 7.46). A total of 113 participants were male (63%) and 67 (37%) were female. Table 1 shows demographic information for participants’ degree of education and income.

Table 1

Demographic Information About Participant Education and Income

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client education</td>
<td>8th or less</td>
<td>26</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>HS, no grad</td>
<td>23</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>HS, Grad</td>
<td>55</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>Voc train</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Some college</td>
<td>28</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>College grad</td>
<td>25</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Master’s</td>
<td>12</td>
<td>6.5</td>
</tr>
<tr>
<td></td>
<td>PhD, MD, JD</td>
<td>1</td>
<td>.25</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>1</td>
<td>.25</td>
</tr>
<tr>
<td>Client income</td>
<td>5K-10K</td>
<td>18</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>10K-15K</td>
<td>14</td>
<td>7.7</td>
</tr>
<tr>
<td></td>
<td>15K-20K</td>
<td>15</td>
<td>8.3</td>
</tr>
<tr>
<td></td>
<td>20K-30K</td>
<td>21</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>30K-40K</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>40K-50K</td>
<td>8</td>
<td>4.4</td>
</tr>
<tr>
<td></td>
<td>50K-75K</td>
<td>4</td>
<td>2.2</td>
</tr>
<tr>
<td></td>
<td>Over 75K</td>
<td>5</td>
<td>2.7</td>
</tr>
<tr>
<td></td>
<td>Missing</td>
<td>86</td>
<td>47.7</td>
</tr>
</tbody>
</table>

The sample population was delimited to clients assigned a DSM-IV-TR (APA, 2000) diagnosis of dementia. All clients with dementia will be 52 years of age or older.
These delimitations were imposed because dementia disorders are the target population for this study, and the age of onset for dementia is usually in late life (APA, 2000). Another delimitation involves the inclusion of only those clients that were able or willing to complete the surveys. During the original data collection period a number of potential participants were cognitively unable to complete the survey questions. Due to the nature of the archival data available, participants were delimited to geographic regions in the United States. In order to help enhance generalizability of results to the general population of clients with dementia, delimitations were not placed on participants’ sex, race, income, educational background, vocational history, prior treatment history, or living status.

Procedures

The Chronic Care Network for Alzheimer’s disease (CCN/AD, 2004) is a large, multi-site demonstration created by the National Chronic Care Consortium (NCCC) and the National Alzheimer’s Association. The demonstration’s overall goals were to improve the identification, diagnosis, and ongoing care for clients with dementia and their family members through partnerships between managed health care organizations and local voluntary Alzheimer’s Association Chapters. The Patient and Caregiver Outcome Survey components used in the original project (and used archivally for this research study) were supported in part by the Robert Wood Johnson Foundation. Additionally, part of the survey instrument was designed through the collaboration of CCN/AD clinical staff and evaluation team members. The initial procedures using the CCN/AD Outcome Surveys included three separate telephone interviews with clients
having dementia and their caregivers. The interviews were comprised of standardized, structured sets of questions based on previous research at the Margaret Blenkner Research Institute, as well as other published research. The survey interviews took approximately 45 to 70 minutes to complete. Archival data from only the first interview were utilized in this research study. Written consent was obtained by all participants before inclusion in the original data collection. Employees of the Margaret Blenkner Research Institute were utilized for the telephone interviews. The researchers utilized were trained in techniques specific to dealing with older persons and persons with sensory deficits. All interviewers had been trained in the use of the CCN/AD Outcome Survey and in interviewing clients with dementia. All interviewers were blind to the existence or protocol for this study at the time interviews were completed.

Instruments

The instruments used in this research study are from the CCN/AD research project. They include the CCN/AD Patient Outcome Survey and the CCN/AD Caregiver Interview, each of which has sub-scales which measure specific aspects of the constructs investigated. These instruments were created specifically for the CCN/AD research project described above. Only specific sub-scales of the Patient Outcome Survey and Caregiver Interview were used for this research study in order to ensure that data analyses focus on data relevant to the research questions posed. From the Patient Outcome Survey, these instrument sub-sections include the Blessed Memory Scale-Short Form, the Functional Activities Questionnaire, the Personal Self Maintenance Questionnaire, and the Quality of Care Scale. From the Caregiver Interview, sub-scales include the
Functional Activities Questionnaire, and the Personal Self Maintenance Questionnaire. All questions were answered by the client and caregiver via telephone interviews. Each of the sub-scales used in this study is described below:

**The Blessed Memory Scale**

The Blessed Memory Scale is a 22-item scale which measures the mental status of individuals. Included are areas such as short- and long-term memory, concentration, and other cognitive abilities typical of a Mental Status Examination conducted during clinical interviews. The instrument is scored by an interviewer on the basis of information provided by someone in close and continual contact with the client having dementia or the client themselves. For this particular research, questions were answered by the clients themselves. Each question that the client achieves correctly receives a certain quantity of points, ranging in value according to the correctness of the answer and the importance of the question for judging the client’s overall mental status. Questions that are incorrectly answered receive zero points. The total point score (i.e., all correctly answered questions added together) were used in this study. The Blessed Memory Scale used in this study is a shortened form of that questionnaire. See Appendix A for the questionnaire used.

**The Functional Activities Questionnaire**

The Functional Activities Questionnaire (FAQ) was included for use in the CCN/AD project. In this study the FAQ was completed separately by both the client and the caregiver. Nine of the FAQ items were used in this study, as they pertained directly to what was being investigated. This measure was designed to measure cognitive deficiencies in individuals with dementia. The person completing the instrument offers a
yes or no answer to each question based on their subjective belief about whether or not a particular cognitive functional deficiency is present. Each question that the individual answers with a ‘yes’ response receives one point, those that are answered with a ‘no’ response receive zero points. The total point score (i.e., all questions answered ‘yes’ added together) was used in this study. Questions on the FAQ were analyzed using a Cronbach’s Alpha in order to test the scale’s internal consistency reliability with this sample. See Table 2 for the reliability statistics. See Appendix B for the questionnaire used.

*The Personal Self-Maintenance Questionnaire*

The Personal Self-Maintenance Questionnaire (PSM) was included for use in the CCN/AD project. In this study the PSM was completed separately by both the client and the caregiver. Seven PSM items were used for this study, as they related directly to what was being investigated. This measure was designed to measure behavioral dysfunctions in persons with dementia. The person completing the instrument offers a yes or no answer to each question based on their subjective belief about whether or not a particular behavioral deficiency is present. Each question that the individual answers with a ‘yes’ response receives one point, those that are answered with a ‘no’ response receive zero points. The total point score (i.e., all questions answered ‘yes’ added together) was used in this study. Questions on the PSM were analyzed using a Cronbach’s Alpha in order to test the scale’s internal consistency reliability with this sample. See Table 2 for the reliability statistics. See Appendix C for details about the questionnaire used.
The Quality of Care Scale

The Quality of Care Scale is an 11-item scale which was modified for use in the CCN/AD project and is intended to measure clients’ perceptions of quality of care. That is, the Quality of Care Scale evaluates subjective satisfaction with healthcare. In this study care related to dementia treatment or support. The person completing the instrument offers an agree or disagree answer to each question based on their subjective belief about care received. Each question that the individual answers with a ‘disagree’ response receives one point; those that are answered with an ‘agree’ response receive zero points. The total point score (i.e., all questions answered ‘disagree’ added together) was used in this study. Questions on the Quality of Care Scale were analyzed using a Cronbach’s Alpha in order to test the scale’s internal consistency reliability with this sample. See Table 2 for the reliability statistics. See Appendix D for details about the questionnaire used.

Description of Independent and Dependent Variables

In order to test null hypothesis one, the independent variables included several measures of client-perceived memory and functional deficits using the CCN/AD Patient Outcome Survey. The perception of memory deficits was measured by portions of the Patient Outcome Survey, including the Functional Activities Questionnaire-Short Form, the Personal Self Maintenance-Short Form, and the Blessed Memory Scale-Short Form. The dependent variable included the CCN/AD Patient Outcome Survey Quality of Care Scale, designed to measure client-perceived satisfaction with care received.
In order to test null hypothesis two, the independent variable included membership in one of two mutually exclusive groups, which is membership in either the client with dementia group or the caregiver group. The dependent variables incorporated two tests related to perceptions of dementia-related deficits. The dependent variable included the Caregiver responses to portions of the CCN/AD Outcome Survey-Caregiver Interview. Both the independent and dependent variables were measured with portions of the CCN/AD Patient Outcome Survey, including the Functional Activities Questionnaire-Short Form, and the Personal Self-Maintenance Questionnaire-Short Form.

Research Design

In this study, archival data were collected and analyzed in order to test the statistical hypotheses posed above. Archival (or fixed) data are data that are collected and stored on a periodic basis, in this case by a participating health agency. Archival data included previously documented factual information about the client’s race, sex, age, and clinical diagnosis, in addition to quantitative data related to the CCN/AD Patient Outcome Survey and Caregiver Interview.

An ex post facto research design with tests of alternative hypotheses has been employed for this research. Ex post facto designs with tests of hypotheses attempt to provide or rule out other rationales for the effect other than the ones stated. This is to attempt to eliminate alternative hypotheses, thus providing greater internal validity of the research design (Newman, Benz, Weis, & McNeil, 1997). According to Kerlinger (1973), “ex post facto research is a systematic inquiry in which the scientist does not have direct control of the independent variables because their manifestations have already
occurred or because they are inherently not manipulable” (p. 379). Another distinction about ex post facto research is that “it contains an attribute or assigned variable that can only show relationships – not causation” (Newman et al., 1997, p. 38). Specifically, this study has examined the correlation between awareness of client’s level of dementia and level of care as well as the difference between client and caregiver perceptions of dementia in clients. Even though ex post facto research findings cannot be used to infer causation, the tests of relationships can be extremely useful to researchers. Newman and Newman (1994) explain that, “one of the most effective ways of using ex post facto research is to help identify a small set of variables from a large set of variables related to the dependent variable for future experimental manipulation” (p. 124). This means that when examining relationships of two or more variables, ex post facto research is appropriate.

In order to test statistical hypothesis one, the researcher investigated how much variance in the dependent variable (i.e., self-perception of satisfaction with services) is explained by the independent variables (i.e., measures of memory deficits and functional deficits). The researcher utilized archival data from clients with dementia to determine if memory deficits are correlated with satisfaction with care.

In order to test statistical hypothesis two, this researcher investigated group differences. This design utilized two dependent variables and one categorical independent variable (i.e., group membership). This research design assisted to identify whether group differences in the independent variable (clients with dementia versus caregivers) have a significant effect on the dependent variables (measures of dementia-related deficits).
Data Analyses

First, the researcher obtained descriptive statistics for all variables included on the CCN/AD Patient Outcome Survey and Caregiver Interview. The descriptive statistics included the means, standard deviations, and ranges of the independent and dependent variables. Descriptive statistics were also reported for demographic information about participants (i.e., age, sex, race, etc.). Once the descriptive statistics were gathered for all demographic variables, inferential statistics were used to test the statistical hypotheses. An alpha level of $p < .05$ was used to interpret results of all statistical analyses.

In order to statistically test hypothesis one, a multiple regression analysis was conducted. This analysis was appropriate to test hypothesis one because the goal of this research question was to test whether a combination of independent variables (i.e., one measure of client-perceived memory deficits and two measures of functional deficits using the CCN/AD Patient Outcome Survey) predict scores on the dependent variable (i.e., scores on the CCN/AD Patient Outcome Survey Quality of Care sub-scale). Standard multiple regression was chosen for the analysis because the research goal was to discover the unique influence of each independent variable on the dependent variable without being guided by a particular theory (i.e., hierarchical multiple regression) or solely by a statistical program for exploratory purposes (i.e., stepwise multiple regression) (Aron & Aron, 1999; Mertler & Vannatta, 2002).

In order to test statistical hypothesis two, three separate one-way multivariate analysis of variance (MANOVA) was utilized. A one-way MANOVA is an appropriate statistical test to investigate this hypothesis because this analysis identifies whether statistically significant differences exist between two independent groups of participants.
(i.e., clients with dementia and caregivers) on more than one dependent variable (i.e., the CCN/AD Patient Outcome Survey and Caregiver Interview subscales). A MANOVA is designed to test whether mean differences on a combination of dependent variables are likely to have occurred by chance, or if those differences are due to membership in one group or the other (Mertler & Vannatta, 2002). Mertler and Vannatta (2002) explain that the use of several dependent measures within one statistical analysis allows the researcher to obtain a more comprehensive picture of the phenomenon under investigation. By measuring several dependent variables instead of only one, the chance of discovering differences as a result of group membership improves greatly. If significant group differences are found in the main analysis (MANOVA), follow-up ANOVAs will reveal which dependent variables (i.e., which CCN/AD Patient Outcome Survey and Caregiver Interview subscales) were different among different groups of participants.

Summary of Methodology

The purpose of this research study was to investigate differences between perceptions of caregivers and clients with dementia. Specifically, the researcher has studied the difference between a client with dementia’s satisfaction with their care and their memory and functional deficits, as well as the difference between clients with dementia and their caregiver’s perceptions of dementia-related dysfunctions. The individuals that have participated in this study and data pertaining to them (demographical, diagnosis, age, etc.) have been gathered archivally. Delimitations include specific DSM-IV-TR (APA, 2000) diagnoses of dementia and a minimum age of 60 years old. Scales from the CCN/AD (2004) Outcome Survey were used to gather data
for this research. The research utilized an ex-post facto design with tests of alternative hypotheses. Multiple Regression analyses were used to statistically test hypothesis one. Three one-way MANOVA were utilized to statistically test hypothesis number two.
CHAPTER IV

RESULTS

This purpose of this chapter was to statistically investigate the differences between individuals with dementia and care-givers. Specifically, the researcher studied whether there is a relationship between dementia clients’ perceptions of memory deficits and their satisfaction with care, and if there is a difference between dementia clients’ and their caregivers’ perceptions of the clients’ perceived memory deficits. This chapter presents the statistical results of the study. The chapter is organized into two sections: descriptive statistics and inferential statistics. The descriptive statistics section describes frequency distributions for participants’ demographic characteristics. Inferential statistics were utilized to test the research hypotheses. This chapter concludes with a summary of the results.

Descriptive Statistics

Instruments used in this study are from the CCN/AD research project. Two sections of the instrument included the Patient Outcome Survey and the Caregiver Interview. Specifically, surveys from the Patient Outcome Survey included The Blessed Memory Scale-Short Form, The Functional Activities Questionnaire (FAQ), The Personal Self-Maintenance Questionnaire (PSM), and The Quality of Care Sub-Scale.
From the Caregiver Interview, survey results from the Functional Activities Questionnaire (FAQ), The Personal Self-Maintenance Questionnaire (PSM), and the Quality of Care Sub-Scale were used. A Cronbach’s Alpha statistic was used to test the internal consistency reliability of each of these instruments in this study. Table 2 summarizes these statistics.

Table 2
Internal Consistency Reliability Statistics for Instruments Utilized

<table>
<thead>
<tr>
<th>Scale</th>
<th>Cronbach’s Alpha</th>
<th>Cronbach’s Alpha based on standardized items</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSM - client</td>
<td>.824</td>
<td>.834</td>
<td>6</td>
</tr>
<tr>
<td>FAQ - client</td>
<td>.830</td>
<td>.830</td>
<td>10</td>
</tr>
<tr>
<td>QOC/Docs-client</td>
<td>.815</td>
<td>.824</td>
<td>11</td>
</tr>
<tr>
<td>QOC/Other-client</td>
<td>.873</td>
<td>.875</td>
<td>11</td>
</tr>
<tr>
<td>PSM-CG</td>
<td>.865</td>
<td>.864</td>
<td>6</td>
</tr>
<tr>
<td>FAQ-CG</td>
<td>.816</td>
<td>.824</td>
<td>10</td>
</tr>
<tr>
<td>QOC/Docs-CG</td>
<td>.888</td>
<td>.889</td>
<td>11</td>
</tr>
<tr>
<td>QOC/Other-CG</td>
<td>.873</td>
<td>.874</td>
<td>11</td>
</tr>
</tbody>
</table>

For the PSM-Client the Cronbach’s Alpha of .824 indicates a high reliability for the measure. As noted, 169 of the 180 were valid scores and 11 scores were not included due to missing data from the responses. For the FAQ-Client a Cronbach’s Alpha of .830 was achieved, indicating a high reliability of the measure. Of the 180 participants, a total of 163 were considered valid scores. The Cronbach’s alpha score for the QOC-Docs-client indicates a high reliability for this measure. There were 121 valid scores and 59 scores that were not used due to invalid or missing data. This is due to 59 individuals not
having doctors currently providing them care. The Cronbach’s Alpha for the QOC/Other-Client indicates a high reliability measure. Of note, only 99 scores were valid due to the fact that of the 180 participants, only 99 care providers were other than doctors. Caregiver responses to the FAQ, PSM, and QC-Docs and QC-Other were also statistically analyzed with Cronbach’s alpha’s to determine reliability. The CG received an alpha of .816, the PSM received an alpha of .865, the QC-Docs received an alpha of .888, and the QC-Others received an alpha of .873. These all had high enough alphas to indicate reliability.

The following tables are the descriptive statistics for each measure used as well. They are described in the headings as to which one is by the client and which one is by the caregiver. The Quality Care Subscale, as with the client and caregiver, was split into two different scales, that is, the Quality Care-Doctors and the Quality Care-Other. The Quality Care-Doctors indicates clients’ responses based on their beliefs of care they have received from their doctors. The Quality-Care-Others is based on clients’ responses to their beliefs of care from other individuals, including case workers, therapists, and others caring for them besides doctors.

Table 3
Descriptive Statistics for Individual Items of PSM (Client) (N = 169)

<table>
<thead>
<tr>
<th>Item description</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty: Eat, cut food or butter bread</td>
<td>.05</td>
<td>.213</td>
</tr>
<tr>
<td>Difficulty: Toileting</td>
<td>.14</td>
<td>.350</td>
</tr>
<tr>
<td>Difficulty: Dressing</td>
<td>.11</td>
<td>.309</td>
</tr>
<tr>
<td>Difficulty: Grooming</td>
<td>.13</td>
<td>.337</td>
</tr>
<tr>
<td>Difficulty: In/Out Bed</td>
<td>.16</td>
<td>.367</td>
</tr>
<tr>
<td>Difficulty: Washing</td>
<td>.14</td>
<td>.344</td>
</tr>
</tbody>
</table>
Table 4
Descriptive Statistics for FAQ Items by Client (N = 163)

<table>
<thead>
<tr>
<th>Item description</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty: Write Checks</td>
<td>.45</td>
<td>.499</td>
</tr>
<tr>
<td>Difficulty: Record Keeping</td>
<td>.53</td>
<td>.501</td>
</tr>
<tr>
<td>Difficulty: Shopping</td>
<td>.37</td>
<td>.485</td>
</tr>
<tr>
<td>Difficulty: Play games</td>
<td>.23</td>
<td>.420</td>
</tr>
<tr>
<td>Difficulty: Heat water</td>
<td>.16</td>
<td>.367</td>
</tr>
<tr>
<td>Difficulty: Prepare meal</td>
<td>.23</td>
<td>.424</td>
</tr>
<tr>
<td>Difficulty: Current Events</td>
<td>.33</td>
<td>.472</td>
</tr>
<tr>
<td>Difficulty: Pay Attention</td>
<td>.31</td>
<td>.465</td>
</tr>
<tr>
<td>Difficulty: Remember Appt</td>
<td>.48</td>
<td>.501</td>
</tr>
<tr>
<td>Difficulty: Traveling</td>
<td>.39</td>
<td>.488</td>
</tr>
</tbody>
</table>

Table 5
Descriptive Statistics for Quality Care-Doctors Items by Client (N = 121)

<table>
<thead>
<tr>
<th>Item description</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors spends enough time</td>
<td>.18</td>
<td>.387</td>
</tr>
<tr>
<td>Doctor respects my ideas</td>
<td>.15</td>
<td>.357</td>
</tr>
<tr>
<td>Doctor concerned about health</td>
<td>.37</td>
<td>.485</td>
</tr>
<tr>
<td>Doctor comfortable to talk to</td>
<td>.05</td>
<td>.218</td>
</tr>
<tr>
<td>Doctor understands memory</td>
<td>.27</td>
<td>.447</td>
</tr>
<tr>
<td>Doctor availability</td>
<td>.21</td>
<td>.407</td>
</tr>
<tr>
<td>Types of need available</td>
<td>.12</td>
<td>.331</td>
</tr>
<tr>
<td>Doctor gives excellent care</td>
<td>.05</td>
<td>.218</td>
</tr>
<tr>
<td>Doctor gives care in rushed way</td>
<td>.22</td>
<td>.418</td>
</tr>
<tr>
<td>Doctor very knowledgeable</td>
<td>.16</td>
<td>.365</td>
</tr>
<tr>
<td>Doctor helpful suggestions</td>
<td>.16</td>
<td>.365</td>
</tr>
</tbody>
</table>
Table 6
Descriptive Statistics for Quality Care-Others Items by Client (N = 99)

<table>
<thead>
<tr>
<th>Item description</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Others spends enough time</td>
<td>.20</td>
<td>.404</td>
</tr>
<tr>
<td>Others respects my ideas</td>
<td>.17</td>
<td>.379</td>
</tr>
<tr>
<td>Other concerned about health</td>
<td>.32</td>
<td>.470</td>
</tr>
<tr>
<td>Others comfortable to talk to</td>
<td>.10</td>
<td>.303</td>
</tr>
<tr>
<td>Others understands memory</td>
<td>.24</td>
<td>.431</td>
</tr>
<tr>
<td>Others availability</td>
<td>.26</td>
<td>.442</td>
</tr>
<tr>
<td>Types of need available</td>
<td>.11</td>
<td>.316</td>
</tr>
<tr>
<td>Others gives excellent care</td>
<td>.08</td>
<td>.274</td>
</tr>
<tr>
<td>Others gives care in rushed way</td>
<td>.15</td>
<td>.360</td>
</tr>
<tr>
<td>Others very knowledgeable</td>
<td>.17</td>
<td>.379</td>
</tr>
<tr>
<td>Others helpful suggestions</td>
<td>.17</td>
<td>.379</td>
</tr>
</tbody>
</table>

Table 7
Descriptive Statistics for Caregiver Responses to PSM (N = 179)

<table>
<thead>
<tr>
<th>Item description</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty: Eat, cut food or butter bread</td>
<td>.20</td>
<td>.402</td>
</tr>
<tr>
<td>Difficulty: Toileting</td>
<td>.30</td>
<td>.458</td>
</tr>
<tr>
<td>Difficulty: Dressing</td>
<td>.28</td>
<td>.450</td>
</tr>
<tr>
<td>Difficulty: Grooming</td>
<td>.34</td>
<td>.473</td>
</tr>
<tr>
<td>Difficulty: In/Out Bed</td>
<td>.31</td>
<td>.463</td>
</tr>
<tr>
<td>Difficulty: Washing</td>
<td>.34</td>
<td>.475</td>
</tr>
</tbody>
</table>
Table 8

Descriptive Statistics for FAQ Items by Caregiver (N = 174)

<table>
<thead>
<tr>
<th>Item description</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty: Write Checks</td>
<td>.93</td>
<td>.264</td>
</tr>
<tr>
<td>Difficulty: Record Keeping</td>
<td>.92</td>
<td>.273</td>
</tr>
<tr>
<td>Difficulty: Shopping</td>
<td>.80</td>
<td>.402</td>
</tr>
<tr>
<td>Difficulty: Play games</td>
<td>.71</td>
<td>.454</td>
</tr>
<tr>
<td>Difficulty: Heat water</td>
<td>.40</td>
<td>.492</td>
</tr>
<tr>
<td>Difficulty: Prepare meal</td>
<td>.75</td>
<td>.436</td>
</tr>
<tr>
<td>Difficulty: Current Events</td>
<td>.74</td>
<td>.442</td>
</tr>
<tr>
<td>Difficulty: Pay Attention</td>
<td>.72</td>
<td>.448</td>
</tr>
<tr>
<td>Difficulty: Remember Appt</td>
<td>.89</td>
<td>.320</td>
</tr>
<tr>
<td>Difficulty: Traveling</td>
<td>.82</td>
<td>.389</td>
</tr>
</tbody>
</table>

Table 9

Descriptive Statistics for Quality Care-Doctors Items by Caregiver (N = 141)

<table>
<thead>
<tr>
<th>Item description</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors spends enough time</td>
<td>1.06</td>
<td>.773</td>
</tr>
<tr>
<td>Doctor respects my ideas</td>
<td>.95</td>
<td>.625</td>
</tr>
<tr>
<td>Doctor concerned about health</td>
<td>1.35</td>
<td>.708</td>
</tr>
<tr>
<td>Doctor comfortable to talk to</td>
<td>.86</td>
<td>.605</td>
</tr>
<tr>
<td>Doctor understands memory</td>
<td>1.05</td>
<td>.565</td>
</tr>
<tr>
<td>Doctor availability</td>
<td>1.18</td>
<td>.700</td>
</tr>
<tr>
<td>Types of need available</td>
<td>1.14</td>
<td>.593</td>
</tr>
<tr>
<td>Doctor gives excellent care</td>
<td>.95</td>
<td>.602</td>
</tr>
<tr>
<td>Doctor gives care in rushed way</td>
<td>1.07</td>
<td>.672</td>
</tr>
<tr>
<td>Doctor very knowledgeable</td>
<td>.99</td>
<td>.592</td>
</tr>
<tr>
<td>Doctor helpful suggestions</td>
<td>1.08</td>
<td>.610</td>
</tr>
</tbody>
</table>
Table 10

Descriptive Statistics for Quality Care-Others Items by Caregiver (N = 131)

<table>
<thead>
<tr>
<th>Item description</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Others spends enough time</td>
<td>1.02</td>
<td>.626</td>
</tr>
<tr>
<td>Others respects my ideas</td>
<td>.92</td>
<td>.563</td>
</tr>
<tr>
<td>Other concerned about health</td>
<td>1.15</td>
<td>.622</td>
</tr>
<tr>
<td>Others comfortable to talk to</td>
<td>.85</td>
<td>.488</td>
</tr>
<tr>
<td>Others understands memory</td>
<td>1.03</td>
<td>.525</td>
</tr>
<tr>
<td>Others availability</td>
<td>1.20</td>
<td>.600</td>
</tr>
<tr>
<td>Types of need available</td>
<td>1.08</td>
<td>.512</td>
</tr>
<tr>
<td>Others gives excellent care</td>
<td>.99</td>
<td>.519</td>
</tr>
<tr>
<td>Others gives care in rushed way</td>
<td>1.03</td>
<td>.525</td>
</tr>
<tr>
<td>Others very knowledgeable</td>
<td>1.02</td>
<td>.472</td>
</tr>
<tr>
<td>Others helpful suggestions</td>
<td>.98</td>
<td>.554</td>
</tr>
</tbody>
</table>

Inferential Statistics

Hypothesis one stated that there is a statistically significant positive correlation between perception of memory deficits, functional deficits, and ratings of satisfaction with care (as measured by the CCN/AD Patient and Caregiver Outcomes Survey) among persons with Dementia. In order to statistically test hypothesis one, multiple regression was used to test whether a combination of independent variables predicted scores on the dependent variable. The independent variables included several measures of client-perceived memory and functional deficits using the CCN/AD Patient Outcome Survey. The perception of memory deficits was measured by portions of the Patient Outcome Survey, including the Functional Activities Questionnaire-Short Form, the Personal Self Maintenance-Short Form, and the Blessed Memory Scale-Short Form. The dependent variable included the CCN/AD Patient Outcome Survey Quality of Care Scale, designed
to measure client-perceived satisfaction with care received. Because data were available for two different types of service providers, doctors and other providers (e.g., case workers, therapists, and others caring for them besides doctors), two different multiple regression analyses were conducted.

Results of the multiple regression analysis for satisfaction with other service providers indicated that the overall model including all three predictor variables was not statistically significant, $F (3, 119) = .10, p = .96$. $R^2 = .003$, indicating that less than 1% of the variance in ratings of satisfaction with care were accounted for by clients’ perceptions of their own cognitive and functional deficits. Relatedly, no independent variables significantly predicted satisfaction with care for other service providers. Table 11 shows the results of this follow-up multiple regression analysis.

Table 11

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>$\beta$</th>
<th>$t$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blessed Scale</td>
<td>-.017</td>
<td>-.042</td>
<td>-.454</td>
<td>.651</td>
</tr>
<tr>
<td>PSM Scale</td>
<td>.061</td>
<td>.031</td>
<td>.310</td>
<td>.757</td>
</tr>
<tr>
<td>FAQ Scale</td>
<td>-.005</td>
<td>-.006</td>
<td>-.059</td>
<td>.953</td>
</tr>
</tbody>
</table>

Therefore, results of the multiple regression indicate that the clients’ satisfaction with other service providers’ care was not dependent upon their perceived level of impairment.

Results of the multiple regression analysis for satisfaction with doctors indicated that the overall model including all three predictor variables was statistically significant,
\[ F(3, 153) = 3.19, \ p = .025. \ R^2 = .06, \] indicating that 6% of the variance in ratings of satisfaction with care were accounted for by clients’ perceptions of their own cognitive and functional deficits. Follow-up tests revealed that one independent variable, PSM scores, significantly predicted satisfaction with care for doctors. Table 12 shows the results of this follow-up multiple regression analysis.

**Table 12**

Results for Multiple Regression Analysis for Satisfaction With Care – Doctors

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>( \beta )</th>
<th>( t )</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blessed Scale</td>
<td>-.015</td>
<td>-.04</td>
<td>-.505</td>
<td>.614</td>
</tr>
<tr>
<td>PSM Scale</td>
<td>.410</td>
<td>.221</td>
<td>2.511</td>
<td>.013*</td>
</tr>
<tr>
<td>FAQ Scale</td>
<td>.037</td>
<td>.043</td>
<td>.483</td>
<td>.629</td>
</tr>
</tbody>
</table>

Note. * \( p < .05. \)

Therefore, results of the multiple regression indicate that the clients’ satisfaction with doctors’ care increases as PSM scores increase.

In order to make sure specific demographic factors, such as client level of education or income, did not impact the results reported above, these were correlated with the measures of cognitive and functional deficits and satisfaction used in this study. Results of Pearson correlations showed that client level of education was not significantly correlated with FAQ scores (\( r = -.14, \ p = .084 \)), PSM scores (\( r = -.12, \ p = .81 \)), Blessed Memory Scale scores (\( r = -.09, \ p = .19 \)), satisfaction with other service providers (\( r = .01, \)
Results of Pearson correlations also showed that client income was not significantly correlated with FAQ scores ($r = -0.07$, $p = .53$), PSM scores ($r = -0.07$, $p = .51$), Blessed Memory Scale scores ($r = -0.19$, $p = .07$), satisfaction with other service providers ($r = 0.02$, $p = .88$), or satisfaction with doctors ($r = -0.08$, $p = .53$).

Hypothesis two stated that there is a statistically significant group difference in perceptions of dementia-related functional deficits (as measured by the CCN/AD Patient and Caregiver Outcomes Survey) among clients with dementia and their caregivers, in that individuals with dementia perceive fewer functional deficits than caregivers. Therefore, the more severe the cognitive deficits experienced by clients, the larger the difference in perceptions of functional deficits between clients and caregivers. In order to test statistical hypothesis two, multiple analysis of variance (MANOVA) was used. This design utilized two dependent variables (i.e., the CCN/AD Patient Outcome Survey and Caregiver Interview subscales) and one categorical independent variable (i.e., group membership). This research design was used to help identify whether group differences in the independent variable (clients with dementia versus caregivers) have a significant effect on the dependent variables (measures of dementia-related deficits). Furthermore, in order to better understand this phenomenon among clients at different stages of cognitive decline, three separate MANOVAs were conducted, each including a separate sub-sample of clients with little (level 1), moderate (level 2), and high (level 3) degrees of cognitive deficits. The Mini-Mental Status Exam (MMSE), which was performed on all individuals, was used to determine the levels. Score cut-offs include: level 1 (27-30), level 2 (20-26), and level 3 (10-19). A total of 32 individuals rated in level 1, 108
individuals rated in level 2, and 22 rated in level 3. A total of 162 individuals’ scores were used, with 18 not completed enough to be utilized. A total maximum score of 30 is possible.

Before MANOVA was conducted, a Box’s Test was performed for each client sub-sample (level 1, 2, and 3 deficits) in order to test possible violations of statistical assumptions needed for MANOVA. Typically a Box’s Test is significant at $p \geq .001$. If this is the case, then robustness of the analysis cannot be assumed due to unequal variances among groups (Mertler & Vannatta, 2002). Results of the Box’s Test for the first sub-sample (level 1 clients) was not statistically significant using common cut-off scores ($F = 1.59, p = .19$). However, Box’s Test results for level 2 and level 3 were statistically significant ($F = 5.88, p < .01$ and $F = 5.84, p < .01$, respectively). Therefore, in order to be cautious about interpretation of MANOVA results, the researcher chose to use a more conservative Pillai’s Trace statistic to interpret the results (as opposed to the more common but less stringent Wilks’ Lambda statistic) (Mertler & Vanatta, 2002).

As shown in Table 11, results of the MANOVA for level 1 clients were statistically significant, $F (2, 58) = 80.14, p < .001$. This result indicated that there was a

<table>
<thead>
<tr>
<th>Table 13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Results for MANOVA Differentiating Perceptions of Deficits Among Level 1 Clients ($N$: CT = 32, Caregiver = 29)</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td><strong>Hypothesis</strong></td>
</tr>
<tr>
<td><strong>Effect</strong></td>
</tr>
<tr>
<td>Pillai's Trace</td>
</tr>
</tbody>
</table>
significant difference in client versus caregiver perceptions on one or both scales used. Therefore, a follow-up univariate ANOVA was used to determine which dependent variable resulted in the significant MANOVA results. Results of the ANOVA revealed that only FAQ scores differentiated clients from caregivers, in that clients’ FAQ scores (Mean = 3.06, SD = 3.14) were significantly lower than caregivers’ FAQ scores (Mean = 6.05, SD = 2.73). Table 14 shows results of the follow-up ANOVA for hypothesis two for level 1 clients.

Table 14

MANOVA Results for Differences in Between-Subjects Effects, Level I Clients (N: CT=32, Caregiver = 29)

<table>
<thead>
<tr>
<th>Source</th>
<th>Dependent variable</th>
<th>Type III Sum Source of Squares</th>
<th>df</th>
<th>Mean square</th>
<th>F</th>
<th>Sig</th>
<th>Partial Eta squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>FAQ Scale</td>
<td>173.395</td>
<td>1</td>
<td>174.395</td>
<td>19.977</td>
<td>.000*</td>
<td>.253</td>
</tr>
<tr>
<td></td>
<td>PSM Scale</td>
<td>2.715</td>
<td>1</td>
<td>2.715</td>
<td>.879</td>
<td>.352</td>
<td>.015</td>
</tr>
</tbody>
</table>

Note. * p < .05

As shown in Table 14, results of the MANOVA for level 2 clients were statistically significant, $F(2, 200) = 74.43, p < .001$. This result indicated that there was a significant difference in client versus caregiver perceptions on one or both scales used.
Table 15

Results for MANOVA Differentiating Perceptions of Deficits Among Level 2 Clients (N: CT=97, Caregiver = 106)

<table>
<thead>
<tr>
<th>Effect</th>
<th>Value</th>
<th>F</th>
<th>Hypothesis df</th>
<th>Error df</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pillai's Trace</td>
<td>.427</td>
<td>74.43</td>
<td>2</td>
<td>200</td>
<td>.0001</td>
<td>.427</td>
</tr>
</tbody>
</table>

Therefore, a follow-up univariate ANOVA was used to determine which dependent variable resulted in the significant MANOVA results. Results of the ANOVA revealed that both FAQ and PSM scores differentiated clients from caregivers, in that clients’ FAQ (Mean = 3.52, SD = 2.84) and PSM scores (Mean = .74, SD = 1.52) were significantly lower than caregivers’ FAQ (Mean = 7.90, SD = 2.30) and PSM scores (Mean = 1.85, SD = 2.07). Table 14 shows results of the follow-up ANOVA for hypothesis two for level 2 clients.

Table 16

MANOVA Results for Differences in Between-Subjects Effects, Level 2 Clients (N: CT=97, Caregiver = 106)

<table>
<thead>
<tr>
<th>Source</th>
<th>Dependent variable</th>
<th>Type III Sum Source of Squares</th>
<th>df</th>
<th>Mean square</th>
<th>F</th>
<th>Sig</th>
<th>Partial Eta squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group</td>
<td>FAQ Scale</td>
<td>972.033</td>
<td>1</td>
<td>972.033</td>
<td>146.67</td>
<td>.000*</td>
<td>.422</td>
</tr>
<tr>
<td></td>
<td>PSM Scale</td>
<td>62.04</td>
<td>1</td>
<td>62.046</td>
<td>18.499</td>
<td>.000*</td>
<td>.084</td>
</tr>
</tbody>
</table>

Note. * p < .05
As shown in Table 16, results of the MANOVA for level 3 clients were statistically significant, \( F(2, 37) = 10.32, p < .001 \). This result indicated that there was a significant difference in client versus caregiver perceptions on one or both scales used.

Table 17

Results for MANOVA Differentiating Perceptions of Deficits Among Level 3 Clients (\( N: \) CT=18, Caregiver = 22)

<table>
<thead>
<tr>
<th>Effect</th>
<th>Value</th>
<th>( F )</th>
<th>Hypothesis df</th>
<th>Error df</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pillai's Trace</td>
<td>.358</td>
<td>10.32</td>
<td>2</td>
<td>37</td>
<td>.0001</td>
<td>.358</td>
</tr>
</tbody>
</table>

Therefore, a follow-up univariate ANOVA was used to determine which dependent variable resulted in the significant MANOVA results. Results of the ANOVA revealed that both FAQ and PSM scores differentiated clients from caregivers, in that clients’ FAQ (Mean = 4.78, SD = 2.69) and PSM scores (Mean = .56, SD = .78) were significantly lower than caregivers’ FAQ (Mean = 8.18, SD = 1.99) and PSM scores (Mean = 1.64, SD = 1.99). Table 18 shows results of the follow-up ANOVA for hypothesis two for level 3 clients.
Table 18

MANOVA Results for Differences in Between-Subjects Effects, Level III Clients (N: CT=18, Caregiver = 22)

<table>
<thead>
<tr>
<th>Source</th>
<th>Dependent variable</th>
<th>Type III Sum Source of Squares</th>
<th>df</th>
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Note. * p < .05

Summary of Results

For results of the multiple regression analysis involving doctors reports, the main regression results were statistically significant, specifically the PSM significantly predicted satisfaction with care. Regarding results of the multiple regression analysis involving other caregivers, there was no significant correlation between individuals’ satisfaction with care and cognitive deficits. Therefore, one regression model (quality care-others) was not significant and one regression model (quality care-doctors) significantly predicted participants’ satisfaction with care. These results indicated that the null hypothesis one, that there is no statistically significant correlation between perception of memory deficits, functional deficits, and ratings of satisfaction with care among persons with dementia, was rejected. Results from the MANOVA’s, analyzing whether or not there is a significant difference between awareness of deficits between other caregiver’s and clients follows. Except for one measure (PSM scores for level 1 clients), all clients indicated fewer deficits than their caregivers. These results were statistically significant. These results indicated that clients do indeed identify fewer
deficits than their caregivers. Therefore, null hypothesis two, that there is no statistically significant group differences in perceptions of dementia-related functional deficits among clients with dementia and their caregivers, was rejected.
CHAPTER V
DISCUSSION

This chapter discusses the results of the study. This chapter is organized into five sections: descriptive summary and interpretations of statistical results, discussion of the results of this study to related/previous research, implications for clinical practice, implications of the results applied to Counselor Education and Supervision, and limitations of the study and recommendations for future research.

Descriptive Summary and Interpretation of Statistical Results

The purpose of this research study was to investigate differences between perceptions of caregivers and clients with dementia. Specifically, the researcher has studied the difference between a client with dementia’s satisfaction with their care and their memory and functional deficits, as well as the difference between clients with dementia and their caregivers’ perceptions of dementia-related dysfunctions. Participants in this study consisted of individuals with dementia and their caregivers; including doctors and other persons providing care to the individuals with dementia. Total sample size was 180 dyads of adult clients of multiple races (i.e., Caucasian, African-American, Hispanic, Pacific Islander, etc.); ages ranged from 51 to 94 years, and males totaled 113 and females totaled 67.
Hypothesis one stated that there is a statistically significant positive correlation between perception of memory deficits, functional deficits, and ratings of satisfaction with care (as measured by the CCN/AD Patient and Caregiver Outcomes Survey) among persons with dementia. Results showed that the analysis involving doctor reports, the main regression results were statistically significant, specifically the Personal Self Maintenance Questionnaire (PSM) predicted satisfaction with care. Regarding the results involving other caregiver responses when compared to individuals with dementia, there was no significant correlation between individuals’ satisfaction with care and cognitive deficits. For this particular hypothesis, individuals’ satisfaction with the care from doctors increases as the PSM score increases (indicating more cognitive dysfunction by the individual). To ensure that specific demographic factors of education and income did not impact the results, they were correlated with each individual measure used. Pearson correlations identified that there were no significant correlations of those two factors with the results.

This researcher believes that one possibility for these results occurred because the generation that was investigated grew during a time that trust was instilled in professionals such as medical doctors, but not necessarily other professionals such as social workers, home care providers, etc. Also, there could be a negative bias towards family caregivers given the loss of independence that occurs during the progression of dementia. These reasons are simply the opinion of this researcher and future research is needed to support these hypotheses.

Hypothesis two stated that there is a statistically significant group difference in perceptions of dementia-related functional deficits (as measured by the Chronic Care
Network for Alzheimer’s Disease (CCN/AD) Patient and Caregiver Outcomes Survey) among clients with dementia and their caregivers, in that clients with dementia perceive fewer functional deficits than caregivers. Therefore, the more severe the deficits as measured by Mini Mental State Exam (MMSE) level, the larger the difference in perceptions between clients and caregivers. This hypothesis was tested by using multiple analysis of variance (MANOVA). This design helps to better understand if group differences have a significant impact on awareness of deficit. To further understand differences, three separate MANOVA’s were conducted, determined by deficit-level using the MMSE scores. Results indicated that, overall, individuals with dementia do indeed identify fewer deficits than their caregivers at all levels. Closer inspection indicates that level I clients, when using the PSM, was not significantly different than their caregivers. However, when further analysis with the Pillai’s Trace indicated significance, as well as follow-up univariate ANOVA results.

As mentioned in Chapter II, there was no reported prior empirical research investigating the specific relationship between dementia clients and their satisfaction with care as well as no prior investigations of the relationship between dementia clients and their caregivers’ perceptions of functional deficits. Presented research involved caregivers’ beliefs of care satisfaction for the client as well as their beliefs about the care. Also, much previous literature was focused presented on the beliefs of the caregivers as it related to level of dysfunction in individuals with dementia, but there were no studies comparing clients and caregivers. This is the first empirical study to investigate both hypotheses. Both studies results do indicate that relationships exist and are significant enough to be useful in care for individuals with dementia.
Comparison of Results of This Study to Previous Research

In Chapter II, results of literature on satisfaction with care by individuals with dementia were reviewed and empirical findings were reported. The literature review was broken down by empirical research that examined individuals with dementia and their satisfaction with care. There are no direct comparisons that can be made to this study with previous research, but some similarities are noted.

Hypothesis one stated that there is a statistically significant positive correlation between perception of memory deficits, functional deficits, and ratings of satisfaction with care (as measured by the CCN/AD Patient and Caregiver Outcomes Survey) among persons with dementia. In other words, the more similar the results of the questionnaire between the individual and their caregiver, the higher the level of satisfaction. Closer scrutiny of these results indicate that the strongest correlation is with the Personal Self Maintenance (PSM) results from Doctors and the individual with dementia. This indicates that as an individual’s dysfunction increases (according to the PSM), their satisfaction with care from doctors increases. There was also no correlations found between individual’s satisfaction with care when compared to their caregiver’s reported belief of level of dysfunction of the individual with dementia.

As reported by Dourado et al. (2007), any awareness of impaired cognition or functioning is more prevalent in mild dementia than others. Whereas however, Cotrell et al. (2006) reported that people with deficits in awareness of ability often resist treatment intervention because of their unawareness of it. Therefore, it is relevant to state that the belief of this investigator believes that individuals who do not believe that they need treatment or interventions often will be dissatisfied when they receive it. Robertsson et
al. (2007) reported that individuals that lacked awareness of their deficits were embarrassed and found it difficult to accept the deficits. They reported that individuals losing their ability to perform daily tasks become devastating. Derousne et al. (1999), Migliorelli et al. (1995) and Ott et al. (1996) all reported that dysfunction in abilities to perform daily activities is associated with lower awareness of dysfunction. Weinstein et al. (1994) reported that the onset of dementia includes unawareness of problems that contain denial and avoidant coping. Finally, Tappen et al. (1999) stated that low expectations for therapeutic interventions are often causal from failure to recognize dysfunction or lack of awareness of problems. Clinically speaking, the inability to be aware of deficits or dysfunctions often leads to poor treatment for individuals because of their disbelief of need (Flashman, 2002).

David’s (1990) empirical research suggested that the extent an individual complies with the appropriate medical treatment or intervention relies on the individual’s level of awareness of dysfunction. Sevush and Leve’s (1993) empirical results indicated that levels of insight or awareness of dysfunction are related to levels of cognitive impairment, with the individuals with the most severe level having the least awareness. Again clinically, if an individual is unaware of their deficits, then treatment will most likely not be successful and satisfaction with care will be limited or low. There were only four empirical studies somewhat related specifically to satisfaction with care. Of those, one by Foreman et al. (2004) reported that clients found the most satisfying care had to do with appropriateness of information received. This would obviously reduce satisfaction as level of awareness of dysfunction reduces. The other three involved
mostly caregiver reports as to what they feel is appropriate (Engel et al., 2006; Hirschman et al., 2005; Reid et al., 2001).

Results from this study do not necessarily correlate with previous research described above. Although there is not a direct link from previous research, it mostly indicated that deficit awareness had a relationship with satisfaction with care. This included compliance with treatment, satisfaction with treatment, and belief in need of treatment. These results indicated that satisfaction with care was not directly related to awareness of deficits as it is compared to their caregiver’s beliefs. These results provide insight that satisfaction with care may be due to other indicators, such as familiarity with care providers.

Hypothesis two stated that there was a statistically significant difference between what caregivers reported and what individuals with dementia reported as it related to perceptions of deficits. The findings of this investigation provided empirical evidence that caregivers report significantly more deficits than do caregivers. Even further, the design was separated into three different levels of impairment to identify if there were any differences in level of deficit awareness. What was identified was, for the exception of the PSM at level I, there were significant differences present. This parallels the description of dementia as progressing through series of stages: the early stage of dementia can show intact levels of awareness, which degrades as it progresses (David, 1990; Flashman, 2002; McGlynn & Kaszniak, 1991; Sevush & Leve, 1993). As in hypothesis I, there is no direct relationship of this current study and past studies. No empirical information regarding direct relationships of caregivers and individuals with dementia has been presented.
The differences in identification or awareness of deficits can be related to literature presenting empirical evidence that individuals with dementia do have limited or reduction in ability to recognize limitations and declining abilities. Prigatano et al. (1986) reported that individuals’ awareness could be assessed according to the severity of their impairment, whereby the higher the impairment the lower the awareness will be. Schacter (1991) reported that performance on specific tests assessing level of impairment and comparison to other scores can predict level of awareness. Berrios and Markova (1998) also provided evidence that individuals that have mental disorders and dysfunctional cognitive abilities often show little awareness or insight into having symptoms of loss of functioning. Another empirical study by Derousne et al. (1999) indicated that awareness of cognitive deficits varied greatly in individuals; however, individuals were intellectually aware of their cognitive deficits but could not ascribe the severity of the consequences of their deficits on daily living skills. These results are somewhat opposite of one empirical study completed and presented by Michon et al. (1994). Their results indicated that individuals that had dementia actually rated themselves as much worse than their relatives. However, the relatives were not necessarily their caretakers and therefore do not necessarily match the findings in this investigation.

Other empirical results included those by Snow et al. (2005) which investigated what contributed to increased discrepancies between self-report and proxy report of deficits. Their results indicated that individuals with dementia had increased levels of higher cognitive impairment and lower functional scores than non-demented individuals. Their results also indicated that fewer deficits were acknowledged by the individuals with
dementia than their informants or proxies. In addition as well, the presence of cognitive
deficits was correlated with dementia and absence of depression. Dourado et al. (2207)
presented empirical evidence that awareness of impaired cognition is more prevalent in
milder cases of dementia and that the impairment worsens as the disease progresses,
matching the results of this investigation in the sense that MANOVA results indicated
more significant results as comparisons included higher level of dysfunction. Overall, the
literature suggests that individuals with dementia have tremendous difficulty with their
inability to be aware of their deficits and that individuals with dementia are unable to
update their level of awareness, often leading to dissatisfaction with care and
disagreement with caregivers as to their needs as the disease progresses.

The results of this research study are congruent with previous research described
above. This study provides evidence that deficit awareness of individuals with dementia
is significantly different from their caregivers. In fact, evidence was presented that as the
dementia worsens, individual’s ability to be aware of deficits decreases as rapidly.
Previous research reported that individuals with dementia have limited or reduced
awareness of functioning, the higher the deficit the worse the awareness, and the higher
the deficit, the lower the functioning. These results are in agreement of prior statements.

Implications for Clinical Practice

Dementia is a devastating and progressive disease that increasingly will affect
numbers of individuals expanding spanning the globe. Alzheimer’s disease is among the
most rampant of dementia, and there is an estimated 4 million Americans affected by it
today. Klein and Kowall (1998) have estimated that by 2050, 1 in 45 Americans will
have developed this devastating disease. The development of cognitive decline, which rate is dependent on the stage of the disease, is one of the characteristic markers of dementia. How we respond to these individuals with dementia, both as service providers and as individuals, will reflect how we are able to conceptualize the personal loss by the individual. It is the understanding of how individuals with dementia are aware of their loss of cognitive functioning as well as understanding their satisfaction with care as it relates to their care that we as caregivers and providers can enhance the care that is given.

Dementia presents any number of challenges, with one of the most important being how to treat it with as much input as possible from the individual with dementia can give. The way in which dementia demoralizes personhood is through the deteriorating of the individual’s identity. This can lead to loss of self, ability to communicate, and an experience of distress as they begin to feel their sense of identity slipping away. Losing the ability to perform daily tasks leads to identifying the loss of independence, which can be demoralizing to the individual as well as their family members. As Derousne et al. (1999), Migliorelli et al. (1995), and Ott et al. (1996) presented, deterioration of the ability to perform daily living often leads to lower awareness of dysfunctions.

One of the critical components of client care studied in this investigation consisted of unawareness of deficits and its effect on an individual’s satisfaction with care. Previous studies have shown that awareness of deficits, both cognitively and socially, is higher during the early stages of dementia development; as well as often leads to embarrassment, humiliation, and makes the loss of ability hard to accept (Dourado et al., 2007; Robertsson et al., 2007). Further studies indicated that failure to recognize
continuing degradation of abilities and loss of functioning often leads to low expectation of interventions, both therapeutically and medically, resulting in low satisfaction with care (Tappen et al., 1999).

People with dementia search for meaning in much the same way as most people do, as well their struggles to understand and ascribe meaning to loss of functioning is common to others. The experience of frustration, fear, loss of control, and anger are common to all people. Although loss of cognitive functioning may occur, experiential and emotional feelings remain quite the same. It is important to remember that individuals with dementia are still people, and that their experience of any decline in their functioning and quality of life often will lead to emotional reactions much like anyone else.

To achieve better treatment outcomes, as well as satisfaction with care received, it is necessary that clinicians and care providers take into consideration the individual with dementia’s experiences, and include this in their planning for care. Tom Kitwood’s (1997) suggestion that fuller attention to emotional and relational well-being is paramount when considering just how the individual will fair with treatment. To achieve better informed treatment of care it is necessary to consider the individual’s experiences, which can lead to a better idea of how to approach their condition. Understanding that there are two major forms of care for individuals with dementia, the formal and informal, can also lead to better care. Identifying which level the individual is most satisfied with and why strengthens the approach one can take with the stricken.

While the medical professional was identified as the most positive correlation with satisfaction of care, it is important to include other necessary realms of the person.
Research that was reviewed indicated that individuals that have dementia receive physical and emotional benefits from family members and friends because of inclusion of decision-making and treatment options (McCallion et al., 1999). Satisfaction with care is connected with the emotional well-being of the individual as well. It has been noted that emotional disorder such as anxiety and depression often co-exist with dementia (Harris & Sterin, 1999; Lee & Lyketsos, 2003; MacCallion et al., 1999; Terri & Wagner, 1992). If these co-existing conditions are not treated as well, it can lead to less satisfaction and adherence, which can lead to more frequent hospitalization, have more medical complications, and have more psychiatric medication needs (Bartels et al., 2003).

Therefore, much more needed attention should be paid to the individual with dementia’s emotional well-being as well as the pharmaceutical strategies of care. Extra care and attention should be placed on social services available, such as case management, counseling services, and home care services to provide the individual with consistent social needs as well as respite for care providers that might be feeling burden or burnout. Clinicians need to take into consideration other available services to the individual as well as their caregivers. Clinicians need to be prepared to offer education and possible referrals to outside sources that are not available in a hospital or clinic setting. These would include peer support groups for caregivers, treatment planning that involves the caregiver, as well as close assessment and continual observation of emotional or psychological conditions that may be co-occurring with the infliction of dementia.

Finally, treatment considerations should not occur without discussing the course with the individual themselves.
Another major component of this study considered the difference in awareness of deficits between caregivers and individuals with dementia. For many of the same reasons listed above, the understanding that a difference exist can mean the difference in treatment provided. It is important to remember that awareness and judgment is influenced by social and cultural expectations. As the awareness of deficits decreases, an individual loses ability to understand the need for care and therefore will be more likely to identify less with their care providers. It is also presumable that our ability to ascertain how another can perceive dictates how we respond to that person. Therefore, if we as care providers identify that a need exists, it is also presumable that the individual with dementia does not. This has been verified by this current study. In almost all categories, caregivers identified more areas of need and concern, or problems, than did the individual with dementia. As discussed prior, unawareness of need often leads to unwillingness to participate in treatment or be compliant with treatment. Cotrell et al. (2006) also pointed out that apathy and psychosis are frequently present in people with less awareness and often resist treatment interventions because of their unawareness; which can place them at risk of harming themselves or others because they cannot judge situations adequately.

As treatment providers, it is clinically important to remember that dementia cuts across clinical disciplines including counseling, psychology, neurology, and psychiatry. How each discipline decides to evaluate and treat dementia is extremely important. One discipline alone does not appear to be able to provide adequate care solely. Instead a unified approach using multiple resources appears to be most suitable. For example, instead of merely identifying through neurological means the use of psychiatric interventions, as well as counseling and home care or case management services would
be more appropriate and helpful. Therefore, a more unified, cross-discipline approach should be involved when treatment planning for an individual with dementia.

Clinicians need to ensure that they are willing to work with a multi-discipline and/or cross-discipline approach. Constructing treatment planning and treatment expectations utilizing information and insight from all care providers, including psychiatrist, medical doctors, social workers, caregivers, and paraprofessionals will only solidify a united approach by all to provide the best care possible for the individual with dementia. Holding multi-disciplinary conferences with as many different care providers as possible will only help with providing quality care and making necessary updates as needed.

Implications for Counselor Education and Supervision

When considering the implications for the professional field of Counseling Education and Supervision, and the training of future counselor educators and counselors, counselor educators need to be well-informed and educated on the difficulties in treating individuals with dementia. The most notably from this research is the difference found in deficit awareness between individuals and their caregivers and satisfaction with care and the impact they have on treatment. Students and counselor-trainees receiving appropriate training and preparedness of the symptoms of dementia, the differences of awareness, how the loss of awareness affects an individual emotionally as well as socially, and its effects on adherence to treatment. Additionally, students and counselor-trainees should be trained on how to access or utilize the different areas that care can be received when developing treatment plans.
Counselor educators should provide education surrounding specific effects of deficit awareness on treatment of the individual as well as incorporating how to treat the caregiver when treating a person with dementia. Lectures should include specifics about dementia, as well as assessing for co-occurring illnesses and its affect on treatment outcomes. Specifics should identify how deficit awareness affects treatment expectations as well as its affect on caregivers and other care providers. Lectures can be boosted with guests that can speak to their experiences towards treating individuals with dementia and the difficulties with working with individuals who are not satisfied with care, do not believe they need it, as well as caregivers experiences with caring for dementia-inflicted individuals.

With dementia and Alzheimer’s disease to be estimated to inflict 1 in 45 people by 2050 (Klein & Kowall, 1998), there will be an increased need for knowledgeable individuals to have treatment skills. One of the initial skills necessary for proper treatment of dementia is the ability to effectively and consistently diagnose dementia accurately. This will also lead to appropriate treatment planning. Including educating training clinicians about specific dementia criteria, as well as the different types of cognitive deficits such as Alzheimer’s disease will enhance the future counselor’s ability to incorporate as many services in an earlier fashion.

Understanding the intricacies of dementia will certainly enable counseling educators to prepare their students to become superior in identifying this issue. A necessary step in this is to be able to use appropriate diagnostic tools. Not only has it been presented that diagnostic tools such as the Mini Mental Status Exam have been crucial in assisting in identifying dementia, but it is also became evident that cross-
interviews with caregivers, family members, and physicians be utilized when creating treatment options. The early introduction to cross-discipline interaction and cooperation can only create better treatment options. Class lectures should include guest-appearances by caregivers to provide insight into their experiences, professionals who have worked with individuals with dementia as well as their caregivers, and possible attendance at treatment planning conferences with multiple professionals in attendance. Education should be specific to working with multiple professions when deciding treatment planning for individuals with dementia. Counselor-trainees and students should have experience with participating or observing multi-disciplinary meetings when discussing treatment options for individuals with dementia. Specific classwork and experience should be designed around assessment tools specific to dementia including its usefulness and limitations.

In designing treatment courses around dementia, specific attention should be paid to how the cognitive decline in individuals with dementia tend to lead to poor treatment follow-through by the individual. Treatment planning courses can also design training not only on cross-discipline interaction, but also on specific goals aimed at dealing with the individual’s difficulty emotionally and socially with loss of ability and loss of self-identity. Although there has not been any specific treatment modality to improve outcomes for people with dementia, supervisors of counselor-trainees that are working with individuals with dementia can ensure that the trainee spotlights identifying how the client identifies their world and where they see difficulties and loss as well processing with the individual the differences between themselves and others in their lives.
Counselor Educators will be most beneficial for their students if they help students with the understanding that lack of awareness of dysfunction is as much a part of treatment as satisfaction with care. The understanding of the interplay of the two as well as the significance of each should be emphasized when treating an individual with dementia. Students and counselor trainees should be educated on appropriate treatment approaches for the individual’s deference to treatment when awareness is obscured as well as train how to appropriately discuss these specific topic areas with their caregivers, who may also come to counselors for support due to frustration, lack of understanding, and burn-out. There is an abundance of literature that present data to indicate that those that care for individuals with dementia often suffer from anxiety, depression, and low level of frustration that can leak into other parts of their lives (Koltai et al., 2001; Rymer et al., 2002; Smyth, Neundorfer, Koss, Geldmacher, Ogrocki, & Whitehouse, 2002; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999). Counselor trainees and Counselor Educators must understand the interplay between the individual with dementia and the relationships with their caregivers and family members. It is not only significant to treat the individual but also the support system around them.

It is paramount that Counselor Educators, and by extension, the students and counselor trainees, understand and implement in their training and practice proper determination of stage of dementia, identify the support system in place, recognize the needs of the care provider as well, and utilize all the information to create an effective treatment plan. Through proper supervision, appropriate practice skills can be assessed and corrected as needed. Opportunities should be utilized to not only assist the student
and counselor trainees to implement appropriate treatment goals and plans, but also allow
the supervisor to gain invaluable experience working with this specific population.

The ultimate goal here is that supervisors will be able to provide counselor
trainees and students with proper training, interventions, education, and skill-building to
allow for future counselors to provide appropriate care and treatment and clinical
judgment so to provide the individual with dementia a satisfactory life and meaning.
Results from this study identified that there is a significant difference between what
individuals with dementia understand and report as problems and what caregivers
identify as problems. Also, satisfaction with care is not totally dependent upon level of
severity. This is important for counselors to incorporate when creating treatment options
for the individual and the inclusion of significant others when considering treatment
options.

Limitations and Implications for Future Research

Statistical significance was found in this study for both hypotheses posed; however, there are some limitations that need to be taken into consideration. Most prominent is that the sample was a sample of convenience and may not truly represent the national or international population. Although samples were taken from pockets within the United States, they do not necessarily represent the country as a whole or even the state from which participants were residing at the time. Heppner, Kivlighan, and Wampold (1992) reported that although it is difficult to achieve a true random sample, efforts need to be made to broaden external validity as much as possible. When
replication of this study is attempted, it should be considered that a more diverse 
selection from different geographical areas compromise the sample. 

While there were distinct variables that were utilized while conducting this 
research (satisfaction and dysfunction awareness), there are several other factors that may 
have prejudiced the final results. Although demographical information such as income 
level and level of education were ruled out as possible confounding variables, there are 
others that were not. These may include race, gender, onset of illness, as well as any co-
occurring illnesses, whether medical or emotional. The use of the archival data limited 
the ability to screen for any effects these may have had on the results. A study by 
Seignourel, Kinik, Snow, Wilson and Stanley (2008) identified that anxiety often co-
exists with the diagnosis of dementia and that there are some affects as to its treatment. 
Also identified in this study includes the limited scales available for the identification of 
anxiety and dementia concurrently. There is little information regarding any differences 
in the affect of awareness on dementia deficit awareness from those with anxiety and 
dementia. This article did bring to light a relationship of anxiety in individuals with 
dementia and poor quality of life standards, but not necessarily on satisfaction with care. 
A study conducted by Unverzagt et al. (2007) investigated differences in African-
Americans that are afflicted with dementia. This study placed particular emphasis on the 
perspective from African-Americans. They posed that there are cultural differences that 
should be taken into consideration when diagnosing and treating dementia in African-
Americans. Archer et al. (2007) identified that there are personality and psychological 
factors that also need to be taken into account and screened when deciding severity of 
dementia as well as treatment planning; particularly with caregivers. To this date, no
recent or past studies have been identified specifically for determining gender-specific factors surrounding diagnosis and treatment of dementia.

Another limitation of this study relates to the race and gender of the sample. This sample included 87% White participants and 67% were male participants. Generalizability becomes difficult with these samples for multicultural considerations as well as gender-specificity. Because of the reasons stated above, future research and attempt of replicability should take into account more differentiation of sample wherever possible for a more robust and generalizable results. Multicultural considerations and competencies need to be considered by all who are conducting research. No evidence was presented concerning this research that the clinicians involved were culturally incompetent. It should also be noted that all clinicians that have degrees and have graduated from a CACREP (2001) accredited program were trained in awareness of cultural differences when diagnosis mental health disorders. It is imperative that clinicians utilize culturally sensitive tools whenever possible when performing diagnostic interviews and assessments. Loss of awareness and memory may be seen differently as to its relevance and severity from culture to culture. Therefore, cultural differences and the multicultural skills of clinicians must be considered as well as the cultural viewpoints of the assessed. This was not a factor that was particular to this study.

An additional limitation to this study was that most of the information gathered for this study was collected using phone interviews. This limits the ability to accurately collect the data. Part of the inaccuracy of these data could be due to the individual that was interviewed having difficulty with hearing problems or understanding the questions. Obviously, this is difficult to check by telephone. Along with this is the possibility that
there may have been socially desirable responses given by the caregivers and/or individuals. The scales and questionnaires used did not include a scale of social desirability as a covariant to rule out.

A final limitation is the use of the Mini Mental State Exam (MMSE). Although it has been reported that the MMSE is the most utilized and cited tool for the diagnosis of dementia (Nilsson, 2007), it has its limitations. A study by Grober, Hall, Lipton, and Teresi (2008) conducted an analysis of diagnostic ability versus the Alzheimer’s Disease Screen for Primary Care (ADS-PC) for sensitivity of early dementia. In this process they identified that the MMSE has the advantage of being neutral when taking into account race and educational factors. However; they also identified that the MMSE fails for the most part to be race and gender specific, which can lead to misdiagnosis for individuals that are African-American or have limited education. This study is backed up by others, including Ferris et al. (2006) and Brodaty et al. (2006). It would be more favorable if the MMSE or another tool would be updated to correspond with the need for culturally sensitive and demographic specific identifiers when used as a diagnostic tool for individuals with dementia. Although internal consistency reliability was established for the measures used, validity measures were unable to be obtained. There was no concrete evidence for construct validity of the measures, although there appears to be face validity. It is recommended that the psychometric properties be more thoroughly tested in the future.
Summary of Discussion and Implications

This study examined cognitive and functional deficit awareness and satisfaction with care among individuals with dementia. Specifically, this study examined if there was a relationship between dementia clients’ perceptions of subjective memory deficits and their satisfaction with care, as well as if there was a difference between dementia clients’ and their caregivers’ perceptions of the clients’ dementia-related functional deficits. The results of the study showed that in the analysis involving doctor reports, the main regression results were statistically significant. Specifically, the Personal Self Maintenance (PSM) predicted satisfaction with care. Regarding the results involving other caregiver responses when compared to individuals with dementia, there was no significant correlation between individuals’ satisfaction with care and cognitive deficits. Regarding identifying deficit awareness, results indicated that individuals with dementia do indeed identify fewer deficits than their caregivers at all levels. Although there was no previous research specifically investigating this, results supported prior literature underscoring the importance of understanding awareness differences in dementia and other mental illnesses. These results were compared to previous research in the area, as well as implications for future research were discussed. This included specifics towards identifying multicultural and ethnic considerations as well as demographic-specific factors that may influence results.
REFERENCES


Clare, L. (2002b). We'll fight it as long as we can: Coping with the onset of Alzheimer’s disease. *Ageing & Mental Health, 6*, 139-148.


APPENDICES
### APPENDIX A

**BLESS Memory Scale-Short Form**

<table>
<thead>
<tr>
<th>Question</th>
<th>Score</th>
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| a.) To begin, please tell me what year it is now? | 0 = No Error  
4 = 1 Error |
| b.) What month is it now? | 0 = No Error  
3 = 1 Error |
| Now, I’d like you to repeat this phrase after me: John Brown, 42 Market Street, Chicago (AFTER PHRASE IS REPEATED: SAY) I’m going to ask you to repeat the phrase again in a few minutes | 0 = No Error  
3 = 1 Error |
| c.) Can you tell me about what time it is without looking at your watch or a clock? (CORRECT IF WITHIN ONE HOUR. BEWARE OF TIME ZONE DIFFERENCES) | 0 = No Error  
3 = 1 ERROR |
| d.) Now, I’d like you to count backwards from 20 to 1. | 0 = No Error  
2 = Self Corrected Errors  
4 = Uncorrected Errors |
| e.) Beginning with the last month of the year, please say the months in reverse order. | 0 = No Error  
2 = Self Corrected Errors  
4 = Uncorrected Errors |
| f.) Now, I’d like you to repeat the phrase that I said a few minutes ago. | 00 = No Errors  
02 = 1 Error  
04 = 2 Errors  
06 = 3 Errors  
08 = 4 Errors  
10 = 5 Errors |

*Interviewer: YOU MAY CUE RESPONDENT WITH THE NAME “John Brown.” IF CUE IS NECESSARY, THAT AUTOMATICALLY COUNTS FOR 2 ERRORS THAT WOULD BE ADDED TO THE SCORE FOR ANY OTHER ERRORS*  

**INTERVIEWER: IF ANY OF THESE PARTS ARE MISSING, COUNT EACH MISSING PART AS ONE ERROR**

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<td></td>
</tr>
<tr>
<td>Chicago</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX B

THE FUNCTIONAL ACTIVITIES QUESTIONNAIRE

Completed by both client and caregiver with CLIENT IN MIND
Please tell me whether you (or client) had difficulty with the following activities in the past **four weeks**
INTERVIEWER: IF HE/SHE SAYS HE/SHE NEVER DID AN ACTIVITY OR HAS NOT DONE THE ACTIVITY IN THE PAST FOUR WEEKS ASK: “If you did (activity), do you think you would have difficulty?”

In the past **four weeks**, did you have difficulty:

<table>
<thead>
<tr>
<th>Activity</th>
<th>NO</th>
<th>YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Writing checks, paying bills, or balancing a checkbook?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>b) Assembling tax records, business affairs, or papers?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>c) Shopping alone for clothes, household necessities, or groceries?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>d) Playing a game of skill, or working on a hobby?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>e) Heating water, making a cup of coffee, or turning of the stove?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>f) Preparing a balanced meal?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>g) Keeping track of current events)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>h) Paying attention to, understanding, discussing a TV show, book, or magazine?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>i) Remembering appointments, family occasions, holidays, or medications?</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
APPENDIX C

THE PERSONAL SELF-MAINTENANCE QUESTIONNAIRE

Completed by both client and caregiver with CLIENT IN MIND
Please tell me whether you (or client) had difficulty with the following activities in the past **four weeks**
INTERVIEWER: IF HE/SHE SAYS HE/SHE NEVER DID AN ACTIVITY OR HAS NOT DONE THE ACTIVITY IN THE PAST FOUR WEEKS ASK: “If you did (activity), do you think you would have difficulty?”

In the past **four weeks**, did you have difficulty:

<table>
<thead>
<tr>
<th>Activity</th>
<th>NO</th>
<th>YES</th>
</tr>
</thead>
<tbody>
<tr>
<td>j) Traveling out of the neighborhood, driving, arranging to take a bus?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>k) Eating including cutting food or buttering bread?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>l) Toileting, including getting to the bathroom on time, remembering to</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>go to the bathroom, or cleaning yourself?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>m) Washing or bathing including getting in and out of the tub or shower?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>n) Dressing or undressing?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>o) Grooming, including combing and shampooing hair, or trimming nails?</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>p) Getting in and out of a bed or chair?</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
The next statements ask for your opinion about doctors and other service providers who assisted you since you enrolled in the Initiative on (DATE). When I ask you "other service providers", please think about nurses, social workers, hired helpers, or staff from other agencies such as the Alzheimer’s Association. For each statement, please tell me if you “agree” or “disagree.”

<table>
<thead>
<tr>
<th>(INTERVIEWER: FIRST SUBSTITUTE “DOCTORS” IN STATEMENT THEN SUBSTITUTE “OTHER SERVICE PROVIDERS”)</th>
<th>Doctors</th>
<th>Other Service Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) My (PROVIDERS) spend enough time talking with me.</td>
<td>0 1 0 1</td>
<td></td>
</tr>
<tr>
<td>b) My (PROVIDERS) respect my ideas and opinions about my illness and care.</td>
<td>0 1 0 1</td>
<td></td>
</tr>
<tr>
<td>**c) My (PROVIDERS) are concerned about how my health problems affect (CAREGIVER)</td>
<td>0 1 0 1</td>
<td></td>
</tr>
<tr>
<td>d) I am comfortable talking with my (PROVIDES) about all issues related to my care.</td>
<td>0 1 0 1</td>
<td></td>
</tr>
<tr>
<td>e) My (PROVIDERS) understand how my memory problems complicate other health conditions that I have.</td>
<td>0 1 0 1</td>
<td></td>
</tr>
<tr>
<td>f) If I need them, I can call my (PROVIDERS) any time day or night.</td>
<td>0 1 0 1</td>
<td></td>
</tr>
<tr>
<td>g) The time of help I need are <strong>not</strong> available from my (PROVIDERS)</td>
<td>1 0 1 0</td>
<td></td>
</tr>
<tr>
<td>h) I get excellent care from my (PROVIDERS)</td>
<td>0 1 0 1</td>
<td></td>
</tr>
<tr>
<td>i) My (PROVIDERS) give care in a rushed way</td>
<td>1 0 1 0</td>
<td></td>
</tr>
<tr>
<td>j) My (PROVIDERS) are very knowledgeable about my memory problems.</td>
<td>0 1 0 1</td>
<td></td>
</tr>
<tr>
<td>k) When decisions about my care need to be made, my (PROVIDERS) give helpful suggestions.</td>
<td>0 1 0 1</td>
<td></td>
</tr>
</tbody>
</table>

**INTERVIEWER NOTE: SKIP ITEM IF RESPONDENT DOES NOT HAVE A CAREGIVER**