Identifying Needs Of Older Adults With Alzheimer’s Disease And Related Dementias In A Rehabilitation Setting:
Perceptions Of Formal And Informal Caregivers

by

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ABSTRACT

The purpose of this study is to identify the needs of older adults with Alzheimer’s disease (AD) and related dementias (ADRD) admitted to a rehabilitation setting where they are expected to physically and mentally function to their optimal level of health. To date, no studies have identified the needs and concerns of ADRD patients in rehabilitation settings. The Needs-Driven Dementia-Compromised Behavior (NDB) Model, the researcher’s clinical experience, and the state of the current scientific literature will help guide the study. An exploratory qualitative research approach was employed to gather data and discover new information about the ADRD patient’s needs and related behavioral outcomes. The qualitative findings on the discrepancies and similarities in perceptions of ADRD patient needs were obtained by examining formal and informal caregivers’ perceptions. The researcher recruited registered nurses and certified nurse assistants (RNs and CNAs, formal) and family/friends (informal) who have provided care to patients in inpatient rehabilitation facilities to participate in focus groups and individualized focused interviews. The data were collated and analyzed using a thematic analysis approach. The overarching theme that developed as a result of this approach revealed discordant perceptions and expectations of ADRD patients’ needs between the formal and informal caregivers with six subthemes: communication and information, family involvement, rehabilitation nurse philosophy, nursing care, belonging, and patient outcomes. The researcher provided recommendations to help support these needs. These findings will help guide the development of nurse-lead interventions for ADRD patients in a rehabilitation setting.
I dedicate my PhD degree to my late grandmother, Alice Geneva Hamilton, who was my greatest inspiration throughout all of my academic pursuits. She encouraged me, protected me, guided me and loved me. My beloved grandmother suffered from Alzheimer’s disease in her later years. She could only be here in spirit when I completed this goal.

_Alice centered her life around the word of God and would always encourage me to “Use What I Had”_

I dedicate my research to older adults with Alzheimer’s disease and related dementias who are and have suffered from this disease.

I dedicate my dissertation to all caregivers (formal and informal), caring for older adults with Alzheimer’s disease and related dementias. For a special informal caregiver, my uncle, your love, patience and dedication towards your mother is something I cherish, respect and hope to live up to.
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CHAPTER 1:
INTRODUCTION

Dementia is an irreversible, progressive brain disease that slowly destroys memory and erodes cognitive function, eventually preventing patients from performing simple tasks related to activities of daily living (ADLs). Alzheimer’s disease (AD) is the most common form of dementia and accounts for 60%–80% of cases (Alzheimer’s Association, 2014). AD progresses from mild to severe over 8–10 years, with early clinical symptoms including memory lapses affecting ADLs, language difficulties, apathy, and depression. Patients in more advanced stages of AD experience impaired communication, disorientation, confusion, poor judgment, and behavior changes; they eventually have difficulty speaking, swallowing, and walking (Alzheimer’s Association, 2014). AD is currently the fifth leading cause of death among adults in the United States and is a leading cause of disability and poor health (Alzheimer’s Association, 2014). The risk of developing AD increases with age; approximately 11% of Americans who are 65 years and older have AD, and this number doubles for every 5-year interval beyond age 65 years (Alzheimer’s Association, 2013). In the U.S., the annual prevalence of older adults with AD is growing exponentially from 377,000 in 1995 to an expected 959,000 in 2050 (Herbert, Scherr, Bienias, Bennett, & Evans, 2003). Notably, an estimated 70% of older adults with AD and related dementias (ADRD) live in community settings (Alzheimer’s Association, 2012; Bynum, 2011; Zarit, Gaugler, & Jarrott, 1999). According to 2011 data from the American Health Care Association, 47% of all nursing home residents report have some form of dementia according to their nursing home records (American Health Care Association, 2011).
As the incidence rates of AD and ADRD increase, so too does the demand for formal and informal caregivers (Orrell et al., 2008). The burden on caregivers is especially high for those providing care to those older adults with ADRD who exhibit disruptive behaviors. This subset of individuals is more likely to require institutionalization compared to their nondisruptive counterparts (Gaugler, Kane, Kane, & Newcomer, 2005; Spira & Edelstein, 2006; Lowery & Warner, 2009). From the caregiver’s perspective, disruptive behavior is interpreted as wandering, inappropriate vocalizations, and aggression (Cohen-Mansfield & Billg, 1986). Such disruptive behaviors have been proposed to be manifestations of unmet needs of older adults with ADRD (Kar, 2009). The concept of “need” will be operationally defined throughout this study as “a need to be met” to focus on recognizing the physiological and psychosocial requirements to ensure the well-being of individuals with ADRD.

The incidence and prevalence of functional disabilities associated with ADRD are high (Zekry et al., 2008), as is the need for rehabilitative care. Older adults have fueled an increased demand in rehabilitative services because of the growth in the number of individuals in this age demographic with a higher incidence of disabling conditions (Brandstater, 2011). Information about older adults with ADRD admitted to acute rehabilitation units is limited; however, it is estimated that up to 45% of individuals admitted to an inpatient rehabilitation setting have some form of dementia or cognitive impairment (Wells, Seabrook, Stolee, Borrie, & Knoefel, 2003), and this number is expected to rise as the population continues to age. Despite the increasing number of older adults with ADRD, no studies have assessed how their needs in rehabilitation settings are likely to impact their ability to function.
Purpose of the Study

The purpose of this study is to identify the needs of older adults with ADRD in a rehabilitation setting from the perspectives of both formal caregivers (registered nurses and certified nurse assistants [RNs and CNAs]) and informal caregivers (family members). A series of focus groups and individualized focused interviews will be conducted to address the following specific aims: (a) identify the needs of older adults with ADRD in rehabilitation settings through the perceptions of the formal and informal caregivers, (b) explore formal and informal caregivers’ ideas on how to address these needs, and (c) determine similarities and differences in the formal and informal groups’ perceptions of needs. These findings will be used to guide the future development of a nurse-led intervention for ADRD patients in a rehabilitation setting.

Statement of the Problem

Behavioral disturbances associated with ADRD have been characterized as the person’s attempts to express or communicate unmet needs (Deschenes & McCurry, 2009; Kolanowski, 1999; Smith & Buckwalter, 2005). For example, an individual with ADRD crying out for help while being bathed prompts the caregiver to stop and ask what is upsetting her. This interpretation of behaviors as manifestations of unmet needs can be regarded as relatively positive. Prior to the movement toward this view, older adults with ADRD exhibiting behaviors such as wandering or vocalizations were regarded as “disruptive,” and the behaviors were labeled as “disturbing” (Algase et al., 1996). Several studies have shown that older adults with ADRD were provided with impersonal care for their “hopeless” and “foreseeable” decline (Dunkin, 1998; Cohen-Mansfield, Marx, & Rosenthal, 1989; Zimmer, Watson, & Treat, 1984). More recent studies have recognized
the validity of the Needs Driven-Dementia Compromised Behavior (NDB) Model, which posits that psychological and behavioral symptoms of dementia are a form of communication (Smith & Buckwalter, 2005; Cohen-Mansfield, 2001). However, researchers using this model have not considered the key needs of older adults with dementia from the perspectives of formal and informal caregivers’ perspective, especially within a rehabilitation setting. According to Algase et al. (1996), these behaviors are expressions of needs that are reflected by the interaction of the factors driving the need. An understanding of needs is required to develop appropriate interventions. From a quality of life (QoL) perspective, the physiological and psychosocial consequences of identifying the needs show that caregivers’ actions might moderate the events that lead to older adults needs actually being met (Kovach, Noonan, Schlidt, & Wells, 2005).

Identifying and subsequently addressing the needs of patients with dementia treated in the rehabilitation settings is critical because it may decrease the likelihood of readmission to acute care settings, decrease hospital stay lengths, increase QoL, and ultimately deter institutionalization (Hopper et al., 2003; Morris, Robin, & Becker, 2004; Rozzini et al., 2005; Rusted & Clare, 2004). Rozzini et al. (2005) observed 214 older adults with dementia who were admitted to a rehabilitation unit and found that placement improved their functional status and decreased the likelihood that they would be institutionalized. In addition, the authors reported that while physical, behavioral, and psychological disturbances were major reasons for admission into rehabilitation facilities, they were not risk factors for institutionalization (Rozzini et al., 2005). The overall goal of rehabilitation is to restore and maintain the ADRD patient’s physical, behavioral, and psychological functioning (Remington, Abdallah, Melillo, & Flanagan, 2006; Waters,
in a manner that does not endanger the safety or well-being of the patient or the informal caregiver (Buhr & White, 2006). Patients with dementia appear to have poorer functional and nutritional statuses than patients without dementia or those with mild cognitive impairment (Fu, Chute, Farag, Garakian, & Cummings, 2004). This may be due to the underestimation of co-morbid conditions by clinicians during and after their acute care stay. Problems in maintaining levels of function established in a rehabilitation setting have been attributed to a lack of support of informal caregiver support and poor communication between formal and informal caregivers during the transition back into the community setting (Rozzini et al., 2005; Shanks, 2005). Improving support and communication between formal and informal caregivers may help identify the needs, improve quality of care, and maintain the functional ability of the ADRD patient in rehabilitation settings and after discharge.

**The Concept of Need**

The concept of need is subject to a wide range of interpretations. According to McWalter, Toner, and Corser (1994), the concept of need is clarified by distinguishing between a need and what causes it. This requires clearly defining the need based on consideration of communicating the need, the current help a person receives, and determine what help is required by a person to meet the need (e.g., the ability of a person with ADRD to communicate the need to fulfill basic ADLs to a formal caregiver in an unfamiliar setting). The use of this concept allows researchers to investigate formal and informal caregivers’ perceptions of patient needs.

Numerous studies have attempted to identify the needs of older adults with ADRD in long-term care (LTC) and community settings, (Bruce & Paterson, 2000;
Isaksson, Aström, Sandman, & Karlsson, 2009; Royner, 1990). Likewise, there is literature that focuses on interventions that address the needs of ADRD patients (Benito-León, Bermejo-Pareja, Vega, & Louis, 2009; Spira & Edelstein, 2006; Tractenberg, Singer, & Kaye, 2003). For example, a review by Cohen-Mansfield (2001) examined 83 studies of nonpharmacological interventions for inappropriate behaviors of patients; 76% and 24% of the studies were conducted in nursing homes and community settings, respectively. The majority of interventions had positive but not always significant impacts on behavior; therefore, the author proposed that better matching of available interventions to the patient’s needs and capabilities could benefit both patients and their formal and informal caregivers. Morgan and Stewart (1999) examined environment-behavior relationships in dementia care settings and special care units (SCUs). Eighteen in-depth interviews revealed that staff and family caregivers described the ADRD patient’s needs in relation to both the physical and social environments. Examples include repetitious verbalizations or physical actions expressing a need for privacy or social interaction, resisting care as an expression of unfamiliar surroundings, and agitation in environments that demand complex interactions and high expectations. However, Swanson, Maas, and Buckwalter (1993) compared the effects of an SCU on 22 in-patient residents with AD and 9 who lived in traditional integrated nursing home units and found that by addressing the needs of the participants with AD and modifying their environments, the SCU participants were more cooperative and functioned better than participants on traditional units as measured by socially accessible behavior. Disruptive behavior to express a need was predicated on the ADRD person’s exceeded level of stress in the environment (Hall & Buckwalter, 1987). Few studies have examined the beneficial
effects of addressing the needs of ADRD patients, and the benefits of rehabilitation and rehabilitation-like settings remain unclear. In-depth research into outcomes of older adults with ADRD is needed in a rehabilitation setting, where care involves highly structured, task-oriented routines (Bowers, Esmond, & Jacobson, 2000; VanOrt & Phillips, 1995; Remington et al., 2006) and the basic needs of the ADRD person are usually catered to.

A search of the literature revealed a lack of information on the experiences of older adults with ADRD and their needs within rehabilitation settings. In fact, until the mid 1980s, it was relatively rare for older adults to receive rehabilitation services (Frank, 1990) because their QoL was viewed as functional dependence (Creditor, 1993; Hirsch, Sommers, Olsen, Mullen, & Winograd, 1990), and the principles of rehabilitation were not considered applicable to the aged population. However, both formal and informal caregivers assume that older adults with ADRD in a rehabilitation have needs that differ from those of older adults with ADRD in other settings or without ADRD in this particular setting (Huusko, 2000).

Assumptions

This study attempts to identify the differences in needs, possible interventions, strategies, and techniques to care for older adults with ADRD in a rehabilitation setting. As such, this study will take a first significant step in gathering data relevant to the development of intervention programs for older adults with ADRD receiving care in rehabilitation settings.

Research Method and Justification

This study was conducted using an exploratory qualitative method to obtain
complementary data and provide a picture of the phenomenon under investigation (Breitmayer, Ayres, & Knafl, 1993) from the perspectives of the formal and informal caregivers. The qualitative method is useful when there is a lack of research in a given area and a need for in-depth understanding (Knafl & Howard, 1984). A thematic analysis was implemented to discover shared and distinct perceptions among formal and informal caregivers regarding the needs of older adults with ADRD in a rehabilitation setting. Data was collected via focus groups and individual focused interviews. Although many studies have been performed in LTC and community settings, the key needs of older adults with ADRD in rehabilitation settings from the caregiver perspective have been ignored.

Potential connections and or disconnections between the formal and informal caregivers’ perceptions and the actual needs of older adults with ADRD are critical to advancing the field. Dröes et al., (2006) discussed some of the issues associated with the needs of older adults with ADRD in community and nursing home settings and highlighted the need to study the different perspectives of persons with ADRD and their caregivers to enhance patient QoL. They also underscore the need to investigate whether there are discrepancies between the need for care and the actual support provided for individuals with ADRD person. As Kroll and Naue (2011) stated, replication or multi-center rehabilitation studies that focus on people with ADRD and their needs are rare.

**Research Questions Addressed in this Study**

1. What are the key needs of older adults with ADRD in a rehabilitation setting as perceived by formal caregivers?

2. What are the key needs of the older adults with ADRD in a rehabilitation setting as perceived by informal caregivers?
3. What are the differences and similarities between formal and informal caregivers’ perceptions of these needs?

4. How can the needs best be met from the perspectives of formal and informal caregivers?

5. How are the needs of the older adults with ADRD similar or different from older adults without ADRD in a rehabilitation setting?

6. How well does the NDB model explain the needs of older adults with ADRD in a rehabilitation setting?
CHAPTER 2:
LITERATURE REVIEW

Introduction

The scientific literature addresses the needs of older adults with ADRD and their caregivers in LTC and community settings, but very few studies have explore their needs during the transition from acute care settings to the community. In addition, many of the investigations focused on identifying ADRD-related behaviors and provided limited information related to interventions. The present study explores the needs of older adults with ADRD in a rehabilitation setting based on the perceptions of formal and informal caregivers tasked with understanding and addressing patient needs.

In this chapter, key terms and concepts used in the current study are defined, and the NDB model will be more thoroughly described. Support is provided from the relevant scientific literature on ADRD patients’ needs and the NDB model, which views behavioral symptoms of dementia from the perspective of the person with dementia, including the background (unmodifiable) and proximal (modifiable) factors. This chapter discusses what is currently known about the factors that impact the needs of older adults with ADRD and provides explicit information about studies into the needs of persons with dementia. It ends with a summary of the purpose and conduct of the present study.

Key Terms and Concepts

The purpose of this segment is to describe key terminology and concepts relevant to the proposed study.

ADRD.

The hallmark pathologies of AD are the progressive accumulation of extracellular
plaques comprised of amyloid-beta protein and tangles containing hyperphosphorylated tau protein inside neurons in the brain. Clinically, AD is characterized by difficulty remembering recent conversations, names, or events. Apathy and depression can also be early symptoms of the disease. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavior changes and, ultimately, difficulty speaking, swallowing, and walking (Alzheimer’s Association, 2014).

Dementia is an umbrella term for symptoms that encompass a variety of diseases including AD that produce progressive neuronal loss or related structural brain damage characterized by memory loss and one of the following cognitive deficits: aphasia (language impairment secondary to the disruption of brain function), apraxia (inability to perform complex motor activities despite intact motor abilities), agnosia (failure to recognize or identify objects despite intact sensory function), and disturbance in executive functions (e.g., planning, organizing, sequencing, and abstracting) (Blazer, Steffans, & Busse, 2004). In the current study, patients will be classified as having ADRD based on the information provided by their formal and informal caregivers.

**Dementia caregiver.**

Dementia caregiving is the most frequently studied type of caregiving described in the literature (Schulz et al., 2002, 2004). Barrett and Blackburn (2009) surveyed over 1,395 caregivers who were caring for someone over the age of 50 and found that the majority stated that ADRD was the main reason their care recipient required care. In addition, they found that caregivers described having a very difficult time dealing with care. Specifically, they reported a higher level of burden compared to caregivers helping aged individuals without AD. It becomes more difficult to meet the ADRD patient’s
needs as cognitive and physical decline progress. Treatment decisions and care are influenced by both symptomatic changes and the expectations of formal and informal caregivers (Schulz, 2008). Informal caregivers may respond to personal needs (Schulz, 2004), while the formal caregivers respond care recipients needs based on their training (Weinberg, Lusenhop, Gittell, & Kautz, 2007), such as maintaining scheduled times for eating or toileting.

**Informal caregiver.**

An informal caregiver has been defined as an individual (a) who may be a spouse/partner, an adult child, or a friend/neighbor (Rathge, Clemenson, & Danielson, 2002); (b) who is not paid (Alzheimer’s Association, 2012) and; (c) who is needed on a long-term basis. Most informal caregivers provide the same type of care as formal caregivers with limited or no training. In addition, caregivers provide other useful information about the clinical history of the patient who may have lived alone prior to admission. In this study, the term informal caregiver will be used to include the following: spouse/partner, an adult child, or a friend/neighbor. Typically, an informal caregiver plays many roles and still manages to take responsibility for attending to the daily needs of the ADRD patient (Harris, 2010; Wiles, 2003).

**Formal caregiver.**

A formal caregiver has been defined as a trained and/or paid provider who has some connection with an official organization or system of service (Family Caregiver Alliance, 2010). This type of caregiving can be found in hospitals, nursing homes, assisted living facilities, rehabilitation, and community centers. According to Smith, Buckwalter, Kang, Ellingrod, & Schultz (2008), the responsibilities of formal caregivers
vary from providing and dispensing medications to assisting with housekeeping. In this study, the term formal caregiver will be used to include rehabilitation RNs and CNAs within the rehabilitation setting. According to the Association of Rehabilitation Nurses (ARN), RNs in rehabilitation settings “help patients with disabilities adapt to their disabilities, achieve their greatest potential, and work toward productive, independent lives” (Mauk, 2007, p. 18). They take a holistic approach to meet patients’ medical, vocational, educational, environmental, and spiritual needs. CNAs help rehabilitation patients with health care needs and perform basic ADLs such as grooming, bathing, toileting, feeding, and transfers in a therapeutic manner based on the interdisciplinary plan of care. Yet, according to Yaffe (2008), there has been an increased need for family or friends to serve as informal caregivers of individuals with dementia. Solely relying on the assessment of needs by formal caregivers may prevent researchers and clinicians from recognizing and addressing the personal needs of patients and informal caregivers (Miranda-Castillo, Woods, & Orrell, 2010; Orrell et al., 2008).

**Needs.**

In health care, need has a variety of definitions that may change based on the caregiver who describes it (Jordan & Wright, 1997). Although each definition was meant to improve service delivery to the population, uncertainty increased to the extent that “it may be an illusion to suppose that there might ever be a consensus about the meaning of ‘needs,’ even if the context of its use were specific” (Culyer, 1998, p. 77). It is important to recognize the different views of the concept of needs, health care needs, and the settings in which they manifest. In the current study, the definition of needs may range from adequacy of care received to specified rehabilitation services related to the ADRD
patient’s physical diagnosis. It can be defined as insufficient amount of help from formal and informal sources for impairment in ADL and instrumental ADL (IADL) (Allen & Mor, 1997; Desai, Lentz, & Weeks, 2001). Unmet needs can negatively impact the QoL of disabled older adults (Branch, 2000), especially if they have difficulty performing ADLs (Kane & Boult, 1998; Scholzel-Dorenbos, Meeuwsen, & Olde Rikkert, 2010). According to Gaugler et al. (2005), needed care that is not provided to an older person with disabilities threatens their safety, and the unsuccessful management of acute or chronic health problems may set off a cascade of negative health-related events.

**Needs and the theoretical perspectives of need.**

The term “needs” in the present study refers to communicating the needs including the current help a person receives and the specification of the type of help required. The unmet needs model of assessment defines need as an individual attribute that is remediable through programmatic intervention (Phelan et al., 1995). An alternative formulation of this model suggests that organizational imperatives shape the definition of client’s needs while obscuring their role (Dunkin & Anderson-Hanley, 1998). To assist in defining the need from the perspectives of nurses and family members/friends, this study expresses theoretical perspectives by drawing from the fields of psychology, sociology, and nursing to define the physical and behavioral aspects of needs.

The concept of psychological needs has been arranged in two distinct ways. In the first, need is virtually equated with any motivating force including one’s desires, wants, goals, and values, whether these are implicit or self-attributed (McClelland, Koestner, & Weinberger, 1992). Similarly, the term “need” has also been used to express a strong desire. The second definition of needs involves the differentiation by one’s conscious or
unconscious wants or goals and is more technically useful when addressing psychological development and health. In this definition, needs refer to conditions that are essential to an individual’s growth and integrity. The use of the term psychological needs can be applied across the life sciences because all living things have empirically identifiable needs whose essentialness can be examined by systematically varying nutriments against the criteria of health and (Ryan, 1995).

Furthermore, the term “needs” addresses what is perhaps the most common superficial criticism of need-based constructs, namely, the number of potential needs one can have is endless. No doubt, one can posit infinite needs, using a looser term, but when the criterion for necessity for growth and integrity is imposed, the list of needs becomes shorter.

By need, sociologists refer to a person who was denied a specific kind of experience at the cost of an intra-personal experience (Etzioni, 1968). Sociologists’ attention focuses not on basic needs, such as nourishment and sleep, but on needs for affection and recognition. Etzioni (1968) stated that needs can be satisfied in a variety of ways; they are “universal,” which means they can be abstract; and they cannot be tested.

Broadly defined, the term “need” is a series of conditions that exist when the burden of care surpasses an individual’s resources (Branch, 2000). The focus of this study was to identify ADRD patients’ needs and their impact in a particular setting by analyzing the perceptions of formal and informal caregivers who are responsible for meeting the needs of a patient. Needs vary as the patients or their environments change. Needs are defined as implicitly and/or explicitly communicated states of deprivation, including basic, social, and individual needs (Kotler, 1980). They may be physical,
mental, and/or emotional and are often measured by the patient’s subjective perception (Eriksen, 1995; Mamon, 1992; Urden, 2002; van der Roest et al., 2007). However, Clare (2005) made a distinction between subjective and objective needs, where the former are expressed by the person and the latter are those that can be measured by instruments or perceived and expressed by others. In this study, these “others” are formal and informal caregivers. Because their needs have often gone unrecognized, ADRD patients are perceived as having more needs than non-ADRD patients.

**NDB Model**

While, the concept of need is an obscure phenomenon, the exploration of need through the concept analysis process provides researchers an opportunity for further knowledge development in this area. Algase et al. (1996) introduced the NDB theory to advance nursing research knowledge and practice when working with individuals with dementia. The NDB model views behavioral symptoms of dementia from the perspective of the person with dementia and postulates that the “disturbed” behavior comes from a need or goal of the person with dementia (Algase et al., 1996). Specifically, background and proximal factors are involved in the manifestation of behavioral symptoms. Background factors are described as more stable or slowly changing characteristics (e.g., neurological, cognitive, general health, and psychosocial) that are difficult to influence or change. Proximal factors are considered as more modifiable characteristics of the person and their environment (e.g., personal factors and physical and social environments). The immediate cause of the disturbed behaviors can be identified through the proximal factors, and modifications can be customized once the individual needs are identified. Kolanowski (1999) more simply described need-driven dementia-compromised behavior
as a result of constant individual characteristics combined with inconsistent environmental factors that trigger behavior. For example, as an older adult with ADRD transitions from an acute care setting to a rehabilitation setting with various caregivers, they may patient feel anxious and frustrated, which may lead to aggressive behavior.

**Strength of the NDB model.**

The NDB model directs a more thorough investigation within a holistic framework that is based on comprehensive assessments of both the person and their environment. No publications were found that explicitly studied the needs of individuals with dementia in a rehabilitation setting using the NDB model; however, much of the existing literature can be conceptualized as dimensions of background and proximal factors that are relevant to the rehabilitation facilities, indicating that the model may be a useful framework for guiding research in this area. Evidence from several studies identifies circumstances in which background factors (e.g., motor ability and cognitive impairment) are modifiable in rehabilitation settings. According to Goldstein et al., (1997) and Diamond and Baddeley (1996), improvement in motor ability scores was independent of age and cognition. They found that cognitively impaired patients who were discharged from a rehabilitation setting to the community were more likely to return home than be institutionalized because their needs were addressed. In another study, though the cognitively intact patients scored better on their functional independent measurement tool (FIM), those with mild-to-moderate cognitive impairment showed a significant improvement in their functional ability scores (Heruti, Lusky, Barell, Ohry, & Adunsky, 1999). While these studies did not investigate ADRD patients’ needs in rehabilitation settings, they largely agreed with other reports suggesting that older adults
with dementia, despite their cognitive loss, retain basic human needs to belong and have
some form of identity to feel capable and useful in their environment (Fitzsimmons &
Buettner, 2002). The current study explores ADRD patients’ needs with an opportunity
for the meaningful involvement of formal and informal caregivers. The results lay a
foundation for the potential use of the NDB model as a guide for identifying the needs of
individuals with dementia in a rehabilitation setting.

Critiques and limitations.

The NDB model received some criticism regarding behavioral symptoms that
were not clearly defined when explaining affect, mood, and agitation (Kolanowski,
Litaker, & Buettner, 2005). Among the background variables, no studies have
investigated the relationships between circadian rhythms, motor abilities, general health
state, and passive behavior (Colling, 2004). Among the physiological need states of the
NDB model, it is unknown what roles, if any, hunger, thirst, elimination, pain, or sleep
disturbance play in passive behavior. In addition, dimensions of the physical environment
have not been researched in relation to passive behaviors. The limitations of the model
rest on the fact that the dimensions of the proximal social environment are derived from
community (Fitzsimmons & Buettner, 2002; Kovach, Noonan, Schlidt, & Wells, 2005;
Rajasekaran et al., 2011) and nursing home settings (Collins, 2005; Fitzsimmons &
Buettner, 2003; Kolanowski et al., 2005; Kolanowski, Litaker, & Baimann, 2002;
Richeson, 2003; Sifford-Snellgrove, Beck, Green, & McSweeney, 2012). Further
expansion of the model to include comparable factors in rehabilitation settings would be
helpful. The findings from the current study are important from the caregivers’
perspectives as they relate to their understanding of the ADRD patient’s needs, as well as
the outcome of the ADRD patient’s behavior. However, rigorous outcome studies are also needed to test the model’s effectiveness in identifying needs and reducing undesirable behaviors in rehabilitation settings.

**Other Theoretical Approaches as They Relate to Needs**

Other theoretical approaches to address the behavioral symptoms of dementia have been proposed and used to guide research studies. These approaches were built on theories of acute confusion, patient-centered therapy, stress, anxiety, and coping to explain and predict the behaviors of dementia (Cohen-Mansfield et al., 1989; Lazaras, 1966; Rogers, 1951; Wolanin & Phillips, 1981). Six of the most commonly used theoretical approaches will be discussed: the Hierarchy Model of Needs in Dementia (HMND, Progressively Lowered Stress Threshold Model (PLST), Theory of Personhood, Antecedent-Behavior-Consequences (ABC) model, Habilitation approach, and Consequences of Need-Driven, Dementia-Compromised Behavior (C-NDB) theory.

Measuring QoL can be very challenging in ADRD patients (Rabins & Kasper, 1997; Novella et al., 2001; Santaguida et al., 2004). Being able to identify the needs of patients who are not able to accurately express them is imperative to help maximize health-related QoL (HRQoL). Scholzel-Dorendos et al. (2010) explored the interaction of the needs of dementia patients and Maslow’s Hierarchy of Needs, integrating both to develop the conceptual HMND. This theoretical framework has two pyramids: one portraying ADRD levels of needs in dementia, and the other showing the effects on HRQoL when needs are not addressed. Their study concluded that by identifying the needs in research related to dementia and focusing on dementia care, much can be done to improve the ADRD patients’ HRQoL.
The PLST is an environmental model of decreased threshold for stress in a modified environment that proposes that persons with dementia require modifications to environmental conditions as they experience cognitive decline so that cues can be more easily processed and are thus less stressful (Hall & Buckwalter, 1987; Smith, Gerdner, Hall, & Buckwalter, 2004). This model was designed to teach care providers to organize observations, make decisions, and plan care by modifying stressors that induce triggers and minimizing uncomfortable behaviors. Though used in several studies, not enough research information is available about the model to establish whether it consistently produces positive behavioral outcomes in individuals with ADRD.

The Personhood Theory was designed to restore people with dementia based on their previous state of care, something that has been left out because the focus has been on the care of the informal caregiver (Kitwood, 1990). Though Kitwood spends quite a bit of time elaborating his views on dementia, very little of the study describes the methodology for collecting and analyzing data, which tends to weaken his assertion regarding dementia and dementia care (Goodwin & Mangen, 1990).

When describing the ABC model, Volicer and Hurley (2003) theorized that behavior is determined by a specific antecedent. If the behavior is described and consequences are identified, then the antecedents can be eliminated. In this model, global interventions are not as effective as individualized interventions that address the specific behavioral triggers for an individual person (Beck et al., 2002).

The habilitation approach (Raia, 2011) addresses six domains of proactive and caregiving controlled environmental therapy to maximize the functional independence and morale of individuals with dementia. This is more of a philosophical approach or
way of thinking rather than an actual model.

Finally, an extension to the NDB model, the (C-NDB) theory explains the consequences of unmet needs in people with dementia who have difficulty clearly and consistently communicating their needs (Kovach et al., 2005). Limited research information is available for this model.

Although these models are well-established, they do not comprehensively assess the variables identified in the NDB model (Algase et al., 1996). The theoretical approach for the current study is that ADRD patients have basic needs that must be identified and met to reduce behavioral problems. Because the NDB model provides a more complete conceptualization of aspects of perceived needs, it was used to guide the present study.

**Factors that Impact the Needs of Older Adults with ADRD**

Older adults with ADRD often have difficulty expressing their needs, and this situation can lead to misinterpretations (Potkins et al., 2003). Over the past three decades, numerous studies have examined the prevalent needs among older adults with ADRD. The research literature was systematically search English language studies using CINAHL, Psych Info, PubMed (Medline), Cochrane, Ageline databases, Google Scholar, and the library catalog for books (1986-2013) using the following terms: dementia, Alzheimer’s disease, need, caregiver, cognitive, functional, physical, psychosocial, LTC, community setting, and rehabilitation. Additional publications were identified by manually searching the reference lists of these articles. Articles were chosen and categorized based on the factors that impact the needs of older adults with ADRD and the focal settings in the article. The categories included: QoL, cognitive and health, environmental and physical, psychosocial, and behavioral factors of the older adults with
ADRD in LTC, community, and rehabilitation settings, as well as transitions between these settings.

**QoL.**

Although the need of older adults with ADRD has been associated with both their level of functioning (Galasko, 1998) and QoL (Hoe, Hancock, Livingston, & Orrell, 2006; Holmquist, Svensson, & Hoglund, 2003), the NDB model identifies several background and proximal factors that may impact QoL and increase the level of care. In studies that have compared patient and formal caregiver views regarding the care of people with dementia, QoL scales have been used to rate the perceptions of both. High levels of needs have been associated with high levels of resident distress and poorer QoL (Hoe et al., 2006; Farran, Keane-Hagerty, Tatarowicz, & Scorza, 1993). Hancock, Woods, Challis, and Orrell (2006) reported that from the clinical researcher’s perspective, physical disability and mental and social needs were often unmet in residents and were associated with psychological problems; however, the study did not provide information from the patient or informal caregiver’s perspective. In another study, Logsdon, Gibbons, McCurry, and Teri (2002) proposed that the differences between caregiver and patient reports were due to the varying perception of the patient’s QoL. For example, in different stages of the patient’s cognitive impairment, caregivers were more attuned to the needs in their patients’ instrumental activities of daily living (IADLs), whereas, the patient was not aware of their needs due to their memory and IADL impairments. This study described the theoretical, psychometric, and practical considerations of the QoL scale for older adults with a cognitive impairment. The authors’ identified 155 patients, who were able to complete the QoL-AD tool. The tool seemed to be reliable and valid for
individuals with MMSE scores greater than 10, yet further research is needed to clarify the relationship between patient and caregiver reports of patient QoL and to identify factors that influence QoL throughout the progression of dementia.

**Cognitive and health factors.**

Impaired memory and decreased cognitive function are the defining characteristics of ADRD. These changes often occur in response to the dysfunction or death of neurons in specific brain regions (Jellinger, 2007; Schneider, Arvanitakis, Bang & Bennett, 2007) as evidenced by abnormal deposits of amyloid-beta (plaques) and twisted strands of tau protein (tangles) (Price, Davis, Morris, & White, 1995; Katzman et al., 1988). Changes such as forgetfulness, short-term memory loss, visuo-spatial deficits, and language impairment may have an effect on the ability of ADRD patients to express their needs.

A vast majority of people in residential care have cognitive function problems (Gray et al., 2008). Several studies have identified a direct link between cognitive impairment and decreased physical function in terms of ADLs and IADLs (Bassett & Folstein, 1991; Njegovan, Man-Son-Hing, Mitchell, & Molnar, 2001; Suh, Ju, Yeon, & Ajit, 2004). To determine whether there was a predictable hierarchy of functional loss associated with cognitive decline, a cohort of 5,874 community-dwelling elderly subjects were surveyed by study nurses using the Modified Mini-Mental Examination (3MS) and functional status with 14 Older American Resources and Services (OARS) items. The results revealed that for each functional item, the 5-year declines in the 3MS scores of persons who lost independence were significantly greater than those who remained independent (Njegovan et al., 2001). Estimates of cognitive function in subjects when
they developed dependency in specific functional items demonstrated a natural hierarchy of functional loss associated with cognitive decline. The results suggest that higher levels of IADL functioning may enable cognitively impaired persons to partially satisfy their needs and goals, thus reducing needs-driven behavior. Reduced functional ability may hamper personal need satisfaction, resulting in an increase of needs-driven behavior.

A prospective cohort study of 3,954 patients aged 60 years and older compared the prevalence of cognitive impairment among elderly primary care patients using evaluations (Callahan, Muralidhar, Lundgren, Scully, & Thomas, 1995). The baseline findings were cognitive impairment in 15.7% of subjects, with 10.5% and 5.4% having mild and moderate-to-severe impairment, respectively. Those with moderate to severe impairment were significantly older than those with no impairment. Dementia was ultimately recorded in 25% of subjects. Those with moderate-to-severe cognitive impairment were more likely to be in and out of the hospital and use more health services. The authors noted that further research is needed to determine if better documentation of impairment would improve diagnostic evaluations, patient management, counseling, and outcomes.

To assess the physician’s (formal caregiver) recognition of dementia and cognitive impairment and compare it to documentation through medical records, Petitti, Buckwalter, Crooks, and Chiu (2001) surveyed physicians who cared for patients in the Women’s Memory Study (WMS) cohort. The results showed that the 364 physicians who responded identified 81% of the patients with dementia (compared to 83% recorded in the medical records). Similarly, physicians identified 44% of the patients with cognitive impairment without a dementia diagnosis (compared to 26% recorded in the medical
records). This suggests that physicians’ documentation about dementia was better than their documentation about cognitive impairment. Still, for the percentage of those patients with dementia for whom there was no chart documentation (17%), the physician was apparently unaware of their seriously impaired cognitive status. Also, physicians with geriatric credentials were more likely to identify cognitive impairment compared to those without (Chodosh et al., 2004), underscoring the importance of formal caregivers in accurately identifying and documenting cognitive impairment, as well as the need for geriatric education and training.

Another study conducted face-to-face and telephone interviews with LTC administrators and staff, residents under their care, and family members of residents (Gauge, 2005). The telephone interviews measured staff perceptions in two domains: perceived feelings of closeness between staff and residents and knowledge of residents’ personal lives and care needs. It was anticipated that variables from multiple domains including the residents’ levels of function would account for dimensions of staff-resident perceptions across facilities. For example, cognitive and functional impairments may have a negative influence on staff perceptions and act as barriers to communication, and complexity of care may increase as a result. These findings support the importance of facility size in assisting with positive staff perception of residents and the need to consider elements of staff-family relationships when examining staff perceptions of residents and their care needs, such as resident functional status, resident perspective, and facility environment. The facility may be a key to intervening and improving outcomes in various environments. These findings also support the use interventions attempting to promote strong family-staff partnerships (Maas et al., 2000, Pillemer et al., 2003).
In another study in a LTC facility, the authors adopted a cross-sectional design that surveyed 253 nursing home staff from 12 nursing homes and carried out behavioral assessments of 647 residents from 11 of the 12 nursing homes. The staff members’ attitude, strain, and satisfaction towards cognitively impaired residents were measured, and it was found that they commonly perceived residents with dementia as anxious, resistant, deliberately difficult, and unpredictable (Brodaty, Draper, & Low, 2003). In addition, residents had little control over their difficult behavior, which made it difficult for caregivers to meet their basic needs. Nursing home staff tended to perceive residents in more negative than positive ways because they were not able to recognize their needs.

A recent literature review describes the use of technology to meet the needs of the older adults with dementia (Topo, 2008). Among the 66 studies included, nearly half focused on support in residential or hospital settings, and only 10 described their aim as supporting the well-being and independent living of the person with dementia at home. Some needs identified included safety in the home, a lack of meaningful activities, and difficulties experienced in time orientation (Bank, Argüelles, Rubert, Eisdorfer, & Czaja, 2006; Nolan, Ingram, & Watson, 2002).

ADRD-related visuo-spatial deficits affect color vision, depth perception, contrast sensitivity, and higher order visual perception (Mendez, Mendez, Martin, Smyth, & Whitehouse, 1990). These deficits may lead to difficulties performing simple tasks such as bathing and grooming and can cause disorientation (Galasko, 1998).

Kálmán, Maglóczky, and Janka (1995) conducted a pilot study to assess previously unrecognized disturbances in 45 elderly AD patients living in the community. Informal caregivers provided information about patients’ performance prior to their.
disease. The results revealed a high frequency of visuo-spatial skill deficits in mild and moderately demented patients. However, the mild and moderate AD patients had lower scores in the mental rotation subtest, indicating that their right-left orientation to their own body was intact. These findings are in line with another study (Fischer, Marterer, & Danielczyk, 1990) and indicate that mild-to-moderate AD patients are better at performing daily tasks relevant to themselves (e.g., bathing and grooming) compared to the ability to perform tasks for others. The authors also noted that there were other deficits (for example, AD patients were not capable of performing recall, reading, or writing tasks) and recommended regular testing for this high-risk population.

An extensive literature review confirmed the hypothesis of the present study that dementia patients’ unmet needs were not being met in a rehabilitation setting. Furthermore, this results in patients acting out in ways deemed inappropriate, which and leads to care providers distancing themselves from patients and even projecting indifference.

The studies reviewed by the researcher and referenced in this study do examine needs from the patients’ or caregivers’ view; however, they do not provide information from both the formal (nurse) and informal (family) members’ perspectives. In addition, the literature review did not identify any studies of how needs were addressed in rehabilitation facilities (settings). Consequently, the importance of recognizing distinctions between those settings has not been appreciated.

Cognition and physical function are perceived differently in rehabilitation settings where the primary focus is on physical function rather than improvement or restoration of independence. This finding was established from interviews of formal caregivers who
collectively felt that their efforts were futile because there is no cure for AD; therefore, working toward improving a patient’s ability to care for themselves was not a productive use of their time.

This research is based on the belief/assertion that many patients are unable to communicate effectively and their discomfort (pain) and/or sleep deprivation become unmet needs that trigger behaviors some caregivers perceive as disruptive or inappropriate. Stated differently, unmet needs too often trigger a reaction that unnecessarily results in nursing home placement.

**Environmental factors.**

A patient’s environment includes physical and social factors. The physical environment is the patient’s daily routine and the setting’s physical layout, such as ambient lighting, noise, and temperature. The social environment comprises social contacts, the patient’s personal network, and caregivers.

In many health care settings, these factors play an important role when identifying the needs of ADRD patients. The qualitative component of a larger research project examined the environment-behavior relationships in dementia care settings (Morgan & Stewart, 1999). Thematic analysis using grounded theory techniques involved 18 in-depth interviews with nine staff and nine family members of SCU residents. Participants described residents’ needs in relation to both the physical and social environments. The authors focused on five areas of need identified by participants in relation to the physical environment: safety, homelike setting, optimal stimulation, cues, and options for privacy and social interaction.

de Rooij et al. (2012) asked nurses and nursing assistants to complete
questionnaires to examine the benefits of small-scale homes for residents with dementia versus traditional care facilities. The results suggest that both small-scale and traditional settings appear to have beneficial effects on different domains in residents with dementia, but future research should focus on the content and quality of care rather than the scale of the LTC environment.

In a cross-sectional study designed to examine the prevalence, correlates, and negative consequences of unmet need for personal assistance with ADLs among community-dwelling older adults, 20.7% of those requiring help to perform one or more ADLs reported inadequate assistance (Desai et al., 2001). This unmet need was associated with lower household income, multiple ADL difficulties, and living alone. The authors recommend greater targeted efforts to reduce the prevalence and consequences of unmet needs for ADL assistance in elderly persons. Research has also suggested the need for the development of more targeted strategies for use by particular individuals including older adults who live alone and family caregivers in community, independent living, and assisted living settings (Moran & Stewart, 1999).

An exploratory descriptive study of 329 residents diagnosed with dementia living in an LTC setting showed that residents had severe limitations with ADLs, social activities, and leisure activities. However, most of the residents understood what people were saying, ate independently, and interacted sociably (Rocha, Marques, Pinto, Sousa, & Figueiredo, 2013). This suggested that caregiver input, multidimensional activities, and participation can help address resident needs. By recognizing the unmet needs of caregivers, more attention is ultimately given to the person with dementia and their needs.
Physical factors.

Various physiological needs such as insomnia or pain may produce specific behaviors, but these can be difficult to recognize if the person is unable to express their needs appropriately. A pilot exploratory study was performed to determine whether pain was problematic during changes in care levels (e.g., from home to nursing home or hospital settings). The authors used a survey of a convenience sample of informal family caregivers of people with dementia. Of the 34 family members who responded, 50% reported that pain was not discussed at admission or after entry into a new care setting, whereas 67% were not confident that staff members could detect pain (Buffman & Haberfelde, 2007). Those who responded to the study recommended that patients’ needs could be better met with scheduled observation and assessment, timely pain medication administration, increased communication with family caregivers, and staff education.

Sleep disturbance and insomnia were found to be prevalent in AD (Dauvilliers, 2007). Insomnia in patients with ADRD can cause distress and depression and is frequently associated with cognitive and functional decline and behavioral symptoms such as aggression (Dauvilliers, 2007). According to McCurry et al., 1999, insomnia affects up to 44% of ADRD patients assessed in clinic and community-based samples. Unidentified physiological factors can have a significant impact on both patients and their caregivers and significantly influence whether a patient is institutionalized (Friedman, Steinwachs, Rathouz, Burton, & Mukamel, 2005; Gaugler, Kane, Kane, Clay, & Newcomer, 2003).

The current body of research supports the hypothesis that multiple factors impact the ability of dementia patients to retain some level of independence. Two key
components are environmental and physical factors, both of which impact an individual’s ability to feel “grounded.” Caregivers report that patients in familiar settings are less likely to exhibit disruptive behaviors.

As noted later in this dissertation, a close family member suffered from AD and passed away just a few months ago. This researcher witnessed firsthand the patient’s difficult transition when “deprived” of the familiar surroundings that had been home for decades. The move contributed to a sense of everything being “new” and “not as it was or should be.”

Collectively, anecdotal and study evidence indicate that it is imperative that both formal and informal caregivers understand the significance of intentional depravation from social, residential, and physical surroundings and their impact on the patient.

**Psychosocial factors.**

According to the NDB model, psychosocial factors such as age, gender, psychosocial stress, and behavioral response to stress may promote need in older adults with ADRD (Algase et al., 1996). Hancock et al. (2006) recruited a nationwide sample of 238 people with dementia from residential homes. Their goal was to identify unmet needs and the care associated with high levels of needs that were identified using the Camberwell Assessment of Needs for the Elderly (CANE), which assesses the needs of older adults with some form of mental illness. Needs are assessed in 24 areas, covering a broad range of health, social, and psychosocial domains (plus two items for informal caregiver needs) and records staff, informal caregiver, and patient views (Reynolds et al., 2000). Staff and informal caregivers were informed about the study and provided guidance as to whether they felt the resident would be able to participate. The
participating staff members were primary formal caregivers; they identified a mean of 16.5 needs for residents with dementia. Of these, 4.4 and 12.1 were unmet and met needs, respectively. While environmental and physical needs were usually met, one in five people had seven or more unmet needs, typically related to physical functioning, mental health, and social aspects of life. The findings of this study demonstrate that formal and informal caregivers who assist these individuals require appropriate training and support in order to be able to identify and meet complex needs (Hancock et al., 2006).

In a study that employed nursing assistants to test the efficacies of three interventions (an ADL intervention, a psychosocial activity intervention, and a combination of the two) to reduce disruptive behaviors and improve affect in nursing home residents with dementia, the authors found that nurses found ways to meet the needs, but may not have actually met the needs that have triggered disruptive behavior (Beck et al., 2002).

Boettcher (1983) emphasized that the goal of theoretically derived nursing interventions is to decrease violent behavior, which is a constant source of anxiety for both patients and staff. The theoretical basis of this study was that individuals had psychosocial needs (Algase et al., 1996) such as territoriality, communication, safety and security, personal identity, and cognitive understanding.

Friedemann, Montgomery, Maiberger, and Smith (1997) conducted semi-structured telephone interviews with 177 family members regarding their family-oriented practices. The study was guided by a conceptual framework of systematic organization in which each family develops a basic pattern of functioning relative to the way it emphasizes and balances four psychosocial areas: (a) stability, focused on the
maintenance of existing in a family structure; (b) control, defined as acceptance, rejection or channeling for major resources; (c) growth, achieved through adjustment of family processes to change from within the family or the environment; and (d) connectedness, achieved by attuning the family system to its environment (Friedemann, 1995). Ideally, the nursing home supports families by offerings various activities addressing the needs of the ADRD person that pertain to these four family targets. The findings of Freidemann et al. (1997) showed a wide range of involvement patterns that promoted family connectedness, maintenance of control, growth, and learning. Families desired various types of staff cooperation when it came to meeting the psychosocial needs of patients. Care of the person with dementia was the greatest need in nursing homes that were ranked the lowest.

Harmer and Orrell (2008) used focus groups with 17 residents, 17 staff members, and 8 family caregivers from 3 care homes to explore the concept of meaningful activity for older people with dementia in care homes from different perspectives. They identified four activity themes: reminiscence, family and social, musical, and individual. There were also two related themes: lack meaningful activity and what makes activity meaningful. Residents found meaning in activity that addressed their psychological and social needs. In contrast, staff and family caregivers viewed activities that maintained physical abilities as meaningful. The authors concluded that people with dementia, staff, and caregivers had different views about what made activities meaningful.

In a study that interviewed 152 persons about their cognitive status and QoL and 128 informal caregivers about the QoL of the person with dementia, social networks, behavioral and psychological symptoms, functional status, and services used, individuals
with dementia reported fewer needs. The most frequent unmet needs described by both groups were daytime activity, company, and psychological distress; however, people with dementia rated psychological distress as the most common unmet need (Miranda-Castillo et al., 2010). Because the priorities of people with dementia can be different from those of formal and informal caregivers, it is important to consider all perspectives when designing interventions and making treatment plans. Thus, the treatment adherence of people with dementia and their QoL could potentially be improved by a more collaborative partnership among formal and informal caregivers and patients.

Meaney, Croke, and Kirby (2005) assessed 82 community-dwelling patients with a diagnosis of dementia based on seven domains: health and mobility, self care and toileting, social interaction, thinking and memory, behavior and mental status, house care, and community living. The results showed that increased age, living alone, and a lower mini-mental status exam score were associated with greater total levels of unmet needs.

Cohen (1991) described the subjective experiences of AD from the viewpoints of patients and their families when psychiatric symptoms and behavioral disturbances begin to emerge in early and middle stages of AD. These symptoms manifest when patients, family members, and health care professionals are unable to perceive and cope with the patients’ deterioration or their own reactions to the deterioration. More research is needed regarding patient, family, and professional experiences to help develop meaningful interactions, behavioral and psychosocial interventions, and clinical prevention strategies.

One may ask why this area of research is significant. The existing findings indicate that each of these factors is relevant and therefore important. Nevertheless, psychosocial factors are of significant importance because the research appears to
conclusively indicate that when those needs are understood and met, disruptive behavior decreases (as indicated in various studies). This is a critical finding because unmet needs trigger behaviors that are deemed/perceived inappropriate, which can lead to institutionalization that generates feelings of guilt in informal caregivers and may create dissension in the household. Additionally, displacement of the dementia sufferer has been shown to increase patient discomfort and confusion. Furthermore, research indicates that allowing the patient to remain in familiar surroundings may be the best option to maximize self-sufficiency.

**Behavioral factors.**

In a longitudinal study, 210 community dwelling patients with AD were prospectively examined by psychiatrists, and 25 of these patients who were institutionalized during the next 3 years were compared to 25 patients who were not institutionalized. The results suggested that potentially treatable (non-cognitive) behavioral and psychiatric symptoms are risks factors for institutionalization, and that treating these symptoms might delay or prevent institutionalization of some patients (Steele, Rovner, Chase, & Folstein, 1990).

Yaffe et al. (2002) carried out the prospective Medicare Alzheimer’s Disease Demonstration Evaluation study (MADDE) of 5,788 community-living persons to develop and validate a prognostic model to determine the predictors of placement of an ethnically diverse population of subjects with advanced dementia. They found that 86% of the patients had one difficult behavior, and 37% had three difficult behaviors. The following characteristics of patients with dementia were identified as determinants of LTC placement because these needs were not identified by their caregivers: (a) psychotic
symptoms, (b) anger and aggressiveness, (c) danger to self and others, and (d) wakes
caregiver up at night. Interventions directed at delaying placement such as reduction of
the burden of care or difficult patient behaviors need to consider the patient and their
caregivers as a unit. In contrast, another study found that cognitive and behavioral factors
were not the primary predictors for placement for Latinas and non-Hispanic White
females caring for loved ones with dementia; rather, positive aspects of caregiving
experienced by these informal caregivers was the driving factor for delaying
institutionalization (Mausbach et al., 2004).

Narrowly focused research has repeatedly shown that institutionalization is not
the preferred method of caring for dementia sufferers as their deterioration accelerates. It
is this researcher’s assertion that a template/model for the treatment and care of dementia
patients assess and acknowledge each of these factors to tailor an individual treatment
approach. By doing so, formal and informal caregivers can be comfortable that their
approach will maximize opportunities for success rather than expedite failure.

**Summary and Conclusion**

The existing research focuses primarily on the needs of ADRD patients in LTC
and community-dwelling settings; little is known about their needs in rehabilitation
facilities. Information on decreased physical and mental functioning provides evidence to
plan individualized rehabilitative care programs for older adults with ADRD.
Rehabilitation through engagement in activities seems to be crucial for this population. In
addition, by incorporating unmet needs as a separate dimension in conceptual models,
future research may be better able to explain the manifestation of key outcomes by
including patient and formal and informal caregivers’ perspectives in different situations.
and settings (Gaugler et al., 2004).

The present study has taken a first step by interviewing formal and informal caregivers for future ADRD patients to address the proximal and background factors of unmet needs. The research described here was designed to (a) reflect on the literature; (b) build on the knowledge of the behavior impact of ADRD, including how identifying the needs of the patient contribute to reduce stress for both the caregiver and the patient; and (c) provide empirical support for the use of these approaches with ADRD patients.
CHAPTER 3:
RESEARCH METHODS

This chapter describes exploratory qualitative research and its use in the current study to collect data through focus groups and individualized focused interviews of formal and informal caregivers. Included in the data analysis process is a description of thematic analysis and the strategies used to verify the data. Finally, the chapter concludes with the treatment of the data.

Characteristics of the Research Design

Qualitative method.

According to Speziale & Carpenter (2002), “qualitative research is an accepted, meaningful, and important methodological approach to the development of a substantive body of nursing knowledge” (p. 1). The practice of qualitative research has expanded to clinical settings because empirical approaches have proven to be of limited use in answering some of the challenging and pressing clinical questions, especially when human subjectivity and interpretation are involved (Thorne, Kirkham, & MacDonald-Emes, 1997). Qualitative research generally uses an exploratory approach because it allows researchers to connect with people through in-depth interaction while exploring the rich, meaningful data comprised of their experiences and thoughts (Gilgun & Abrams, 2002).

Exploratory qualitative approach.

The exploratory qualitative research seeks to generate ideas, insights, and hypotheses; determine how people interact in the study setting; and provide meaning to actions and issues that concern the people (Schutt, 2006; Stevens & Wren, 2013).
Furthermore, exploratory research is open-minded and flexible; it uses using qualitative techniques to gather data and build a range of evidence for different topics, especially those for which little is known (Singleton, Straits, & Straits, 1993). Focus groups are one of the most standard techniques for conducting exploratory research. The purpose of employing an exploratory qualitative approach in the current study was to use focus groups and individualized focused interviews to explore formal and informal caregivers’ perception of the needs of ADRD patients in a rehabilitation setting.

Research Process

Focus group.

A focus group is essentially an interview based in a group discussion setting (Neuman, 2007). According to Patton (2001), benefits of focus groups include greater data quality, more diverse viewpoints, and cost effectiveness. Padgett (2008) described homogeneous focus groups as those that include individuals with similar backgrounds and experiences and discuss the issues that affect them. Each homogeneous focus group typically includes 7–10 participants who have provided informed consent. It is not always easy to identify the most appropriate participants for a focus group; if a group is too heterogeneous (e.g., both professional and nonprofessional perspectives), the differences between the participants can considerably impact the outcome. Alternately, if a group is too homogeneous, diverse opinions and experiences may not be revealed. Meeting with others whom participants think of as possessing similar characteristics or levels of understanding about a given topic, will be more appealing than meeting with those who are perceived to be different (Morgan, 1997). In addition, a focus group should be large enough to generate diverse opinions, but small enough to permit everyone to share in a
discussion. Focus groups that include persons from different status levels, such as nurses and nurse assistants, can be problematic when subordinates have understandable concerns about the consequences of being outspoken (Morgan, 1997), so this study maintained a homogenous group of caregivers. The goal was to identify the full range of relevant responses from professionals and lay persons; therefore, the participants were separated into formal (RNs and CNAs) and informal (family/friend) caregiver focus group. In this study, the researcher’s first focus group was the largest, consisting of eight participants. It was somewhat challenging to try to keep up with the observation notes and stay on tasks with the questions. She was initially nervous at first because she thought she had done something wrong or left something out, and she checked her recorder several times to make sure it was on. However, as the focus group proceeded, the researcher was able to employ a system that overcame these challenges. In subsequent studies, she would design focus group/interviews that would allow her to have a video recorder or second observer.

Individualized focused interviews.

Individual focused interviews were conducted for those who are unable to meet at the scheduled times. The flexibility within the individualized focused interviews provided the opportunity to elaborate on questions, ensuring clarity and an opportunity for each participant to fully explain their perceptions. Individual focused interviews were also conducted if a participant had been identified as a key informant (e.g., if they had participated in a focus group and appeared to have particular knowledge or was able to provide in-depth insight on their perceptions and/or give recommendations of the key needs of ADRD patients in the rehabilitation setting). This type of interview is an appropriate data collection technique for validating and eliciting understandings and
specific processes (Rubin & Rubin, 2005). The researcher’s first interview was an individualized focused interview, and she was very comfortable in this setting. The researcher and the participant spoke as if they knew each other and could relate to the other’s experience. Although the first focused interview was with an informal caregiver, she appeared very natural in her responses. This participant was one researcher’s key informants due to her knowledge of the subject and in-depth responses.

Setting.

The study was conducted in three rehabilitation facilities within the Phoenix metropolitan area. According to the health care organization’s advertisement, each facility is designed to help patients retrain their minds and muscles through a comprehensive and personalized rehabilitation program. Although the facilities do not have memory care units, over 30% of admitted patients have some form of dementia or other cognitive impairment, and many demonstrate inappropriate behavior (Health System data source, November 12, 2013). The facilities use a team approach to patient rehabilitation and work with individuals and their families to develop personalized patient treatment plans that focus on short- and long-term goals. In addition, the facilities pride themselves in patient care excellence and employee satisfaction. Each facility has a low turnover rate compared to the national average of acute and subacute settings, which allowed for appropriate recruitment for the current study.

Sampling process.

The study employed a purposive sampling technique, which has been defined as “a type of non-probability sampling to which the units to be observed are selected on the basis of the researcher’s judgment of which ones will be most useful or representative”
(Creswell, 2006, p. 184). This type of sampling was guided by *a priori* expectations about the needs of persons with dementia. A purposive sampling procedure involves a deliberate process of selecting respondents based on their ability to provide the information required to address the research questions (Miles & Huberman, 1994). The researcher identified 54 formal and informal caregivers who provided care to patients with ADRD in a rehabilitation setting and were willing to participate in a focus group or individualized focused interview.

**Inclusion criteria.**

The first criterion to participate in this study was an age of at least 18 years. Formal caregivers (RNs and CNAs) were working as paid providers in the health care facilities for longer than 90 days and spoke and understood English. Informal caregivers (e.g., spouse, family member, or friend) were unpaid providers for individuals with dementia placed in a rehabilitation setting who provided at least 4 hours of direct care or supervision to the person with dementia before their stay at the rehabilitation facility and spoke and understood English. For the purpose of the study, no formal written diagnosis or assessment of ADRD was required by the researcher; rather, this diagnosis was based on the formal and informal caregivers being informed by a health care provider that the patients have AD or some form of dementia.

**Recruitment**

In accordance with Arizona State University’s Office of Research Integrity and Assurance (ORIA), any research activity involving human subjects conducted by Arizona State University personnel including doctoral students requires approval. Institutional Review Board (IRB) approval must be obtained from ORIA and any other involved
facilities. After receiving approval for this study, a meeting was scheduled with the nurse administrator and social workers and/or appropriate staff of the facilities to discuss the study, review the inclusion criteria, and recruit potential participants (Appendix A).

For the 6 months of data collection, the researcher identified days during the week when she would be on site in one of the three facilities. Later, the researcher’s schedule became extremely flexible as she was on call at any given day and time for each facility. The purpose of the researcher’s presence was to become familiar with the unit, establish trust, and provide structure for recruitment and enrollment. According to Ryen (2004), “trust is established within the relationship between the researcher and the participants, and to the researcher’s responsibility not to ‘corrupt’ the field for the potential research subjects that may become reluctant to research” (p. 234). Trust is the traditional key to building good field relationship, which is a constant challenge during the research process. Trust applies to the report or the discursive practices defining the standards for presenting both the researcher and the work as trustworthy (Fine, 1993). During the initial meeting, information regarding “trust” was shared with the nurse managers and social workers. Specifically, the researcher informed them that she would establish a rapport with all potential participants without interfering in their goals of providing and receiving care.

**Formal caregivers.**

The nurse administrator and/or other appropriate staff helped to identify formal caregivers to recruit for the study. The researcher approached potential formal caregiver’s individually or in a group setting (e.g., a staff meeting) and provided a brief overview of the study (Appendix B). In addition, flyers (Appendix C) that explained the purpose of
the study, answered basic questions, and provided contact information were posted at the nurses’ station and in break rooms to inform formal caregivers about the project. In the event that a potential formal caregiver was interested and wished to be contacted, a contact sheet (Appendix D) was made available in a designated confidential area and was later collected by the researcher. Each facility allowed the researcher to have a locked drawer in the social workers’ offices.

**Informal caregivers.**

The social workers and/or other appropriate staff helped identify informal caregivers who were initially approached by the social worker and/or other appropriate staff and given a brief overview of the study (Appendix E). Flyers (Appendix F) that explained the purpose of the study, answered basic questions, and had the researcher’s contact information were posted at the nurses’ station and community information board. In the event that a potential informal caregiver was interested and wished to be contacted, a contact sheet (Appendix D) was available in a designated confidential area and was later collected by the researcher. In addition, the social worker informed the researcher of any potential informal participant in person when she was on site.

**Enrollment**

**Formal caregivers.**

If the formal caregivers showed interest in the study, the researcher would contact them to gather basic demographic information (Appendix G) for screening. If the inclusion criteria were met, the potential participant was given an informational letter (Appendix H) that explained their participation in the study in greater detail. They were informed that participation in the study would be kept confidential and were asked not to
disclose the research methodologies with others after the project’s conclusion. According to Padgett (2008), “like in any group research, the researcher has no control over the group members’ breaching confidentiality, however providing written warning to prospective group members is appropriate” (p. 102). The participants were also informed that completion of the focus group and/or focused interview and participation in the study were entirely voluntary, that no evaluation of them as employees would occur, and that the results of the study would not be connected to them in any way, including their employment records. If the participant completed the focus group and/or focused interview, they were confirming that they voluntarily consented to participate in the study and understood that participation in the study was not a condition of employment at their organization. All focus groups and/or focused interviews took place during their off hours, and they were not paid their salary for time spent participating in the study. Each participant received a $10 gift card for enrolling.

**Informal caregivers.**

Once informal caregivers demonstrated interest regarding study participation during initial contact with the researcher, they received a request for further discussion in person or by telephone for screening purposes (Appendix I), and demographic information collection (Appendix J) was established. The informal caregivers were assured by the social worker that agreeing to hear more about the study did not commit them to participate. If an individual was contacted and determined to meet the inclusion criteria, they were provided with an informational letter (Appendix K) that explained their participation in the study in greater detail. They were informed that participation in the study would be kept confidential and were asked not to disclose the research
methodologies with others after the project ended. “Like in any group research, the researcher has no control over the group members’ breaching confidentiality, however providing written warning to prospective group members is appropriate” (Padgett, 2008, p. 102). The participants were also informed that completion of the focus group and/or focused interview and participation in the study was entirely voluntary and that none of the information provided would be held against them or their loved ones. They were also explicitly informed that whether they participated or not would not affect the care that their loved ones/friends would receive during their rehabilitation stay.

**Formal and informal caregivers.**

Upon contact with the prospective formal and informal participants who were eligible, the researcher informed them and they were told that within of 2–4 weeks they would be contacted with a specific date, time, and location (within the health care facilities) for the focus group to meet. The researcher suggested that potential participants take part in an individual focused interview if a potential participant showed interested in the study but was not able to attend the focus group, shared little interest in participating in a group setting, or the researcher observed that the participant may have more information to provide outside the focus group. Specific dates, times, and locations were also arranged for individual focused interviews.

**Data Collection**

**Instrument.**

Though the use of the interviewer is considered the main instrument in this study, data was collected by the interviewer through semi-structured interviews, field notes, and demographic forms. Fontana & Frey (1994) asserted that the interviewer needs to be
sensitive, flexible and empathetic, and avoid domination or lack of participation by some people in the group. “In using the semi-structured interview technique, the interviewer has more freedom to be creative with the questions” (Dearnley, 2005, p. 19). Having this flexibility allowed the participants in this study to fully explain their perceptions. A semi-structured interview with brief and open-ended interview questions allows participants to provide rich, detailed answers, and it permits follow-ups and clarification to the meaning of participant answers (Kvale & Brinkman, 2009). Recorded field notes describing each encounter with the participants assisted in the data analysis and interpretation. The demographic form was developed to help characterize the participants involved in the study.

**Interview guide.**

The interview guide (Appendix L, M) was designed to address the study’s specific aims. The current state of the science recommends that an interview guide include questions that explore the formal and informal caregiver’s perceptions in a particular setting in which caregivers are expected to work together to address the needs of the patient (Clay & Wade, 2003). For example, the lead question identifies the key need of the ADRD patient in the rehabilitation setting from each group’s perspective. The conceptualized framework also influenced the guide’s development. These questions prepared the participants to identify background and proximal factors. The purpose of the guide was to provide a foundation and context for discussion (Spradley, 1979).

**Demographic form.**

The demographic forms included questions related to (a) formal caregiver’s age, race/ethnicity, gender, education, months of employment in a rehabilitation setting, and previous experience with person’s with ADRD or (b) informal caregiver’s age,
race/ethnicity, gender, education, relationship to patient; length of time caring for the person with ADRD, average amount of hours spent with the person per day, and any formal training or resources identified. The caregivers who agreed to take part were required to complete the form prior to participating in focus groups and individual focused interviews.

**Field notes.**

Field notes are commonly used in qualitative research and include detailed information from observations and interviews. They provide a connection to larger and more self-reflective issues. The recording of field notes are influenced by the researcher’s experience, interest, and worldview and shape the questions that are asked (Muhall, 2003); they also reflect the researcher’s thoughts and reactions during the interview. Field notes can also be a source of validation of significant points made by the participants and help emphasize specific themes (Speziale & Carpenter, 2006). In the present study, field notes served as the second method of data collection and were transcribed immediately after each focus group or focused interview. They were then analyzed to conceptualize and clarify the themes in the data. In addition to identifying any differences among demographic information (e.g., age, education, and experience), a comparison was also made between the responses of formal and informal caregivers.

**Focus groups.**

Focus group sessions were conducted in a confidential meeting area and began with an introduction of the researcher, reviews of the information letters and demographic forms, and an overview of the study. Once the overview of the study was read, the participants were asked if they had any questions, and no questions were asked.
The processes of semi-structured interviews including the time (60–90 minutes), pseudonym use, tape recordings, and transcript verification to ensure accuracy were reviewed. The audio recorder was started, and the participants proceeded to answer the questions. The interview guide based on clinical experience, the current state of the science, and the conceptualized NDB model was used to address the research questions. Participants were encouraged to express their opinions and discuss issues through the use of open-ended questions. For example, the main topic was the key needs of ADRD patients in the rehabilitation setting, with an emphasis on information about background and proximal factors. The interview guide was designed to identify each participant’s individual view on dementia. Each focus group lasted between 60 and 90 minutes. The information shared at the focus group meeting was audio recorded and transcribed by the researcher. At the end of the session, gift cards valued at $10 were given to each participant.

**Individualized focused interviews.**

Focused interviews were conducted in a confidential area and began with an introduction of the researcher, reviews of the information letters and demographic forms, and an overview of the study. Once the overview of the study was read, the participants were asked if they had any questions, and no questions were asked. The procedures including the time (~60 minutes), pseudonym use, audio recordings, and transcript verification to ensure accuracy were explained. Individual interviewees were asked the same semi-structured interview questions as focus group participants. The audio recorder was started and the individual focused interview was carried out using the interview guides (Appendixes L, M) to address the research questions. The guide was based on
clinical experience, current state of the science and the conceptualized NDB model.
Audio from each interview was recorded and transcribed. Gift cards valued at $10 were
provided for each participant.

**Risks and benefits.**

The potential risk for all participants was minimal. During the focus group and
individual focused interviews, audio recording equipment and the topics discussed may
have caused some participants to feel uncomfortable. Participants were informed that
they could discontinue their participation in the focus group at any point without
explanation and without consequences to their relationship with the facility (informal) or
employment (formal). While not guaranteed, it was clearly explained that the potential
benefit of this study was to identify the needs of older adults with ADRD in a
rehabilitation setting to potentially address those needs and in turn promote a better QoL
for those patients and their family caregivers.

**Data Analysis**

**Demographic data analysis.**

The researcher summarized demographic data using descriptive statistics. Data
were manually entered into SPSS 21.0 software and checked for accuracy. Descriptive
statistics, including means and standard deviations, were computed. The researcher used
this information to describe the participants, thereby providing contextual information.

**Thematic analysis.**

This study employed a thematic analysis to explore how formal and informal
caregivers perceive the needs of ADRD patients in the rehabilitation setting. Thematic
analysis is considered a conservative practice in qualitative research: “This type of
analysis involves looking through data to find any recurrent themes or patterns by working back and forth between data and the themes that are developed to establish a comprehensive set of themes” (Braun & Clark, 2006, p. 81). There are inductive and deductive approaches to thematic analysis. The former involves discovering patterns, themes, and categories in a data set (Patton, 2001). A theme (or themes) is derived from a cluster of linked categories with similar meanings that emerge from the inductive analytical process describing the qualitative paradigm. When using an inductive approach, the themes that emerged are linked to the data, and the researcher does not attempt to “adapt” the data into a pre-existing framework. This is known as data-driven analysis (Braun & Clark, 2006). In an deductive approach, themes are driven within an existing framework and tend to be driven by the researcher’s theoretical interest in the area (Braun & Clark, 2006; Patton, 2001). For the purpose of this study, an inductive thematic analysis was used. While the NDB model was used to help guide the questions, it was not used to analyze the data.

**Process of analysis.**

The researcher listened to and transcribed audio recordings of focus groups and focused interviews. Transcription accuracy was assured by comparing the transcripts with the interview tapes and the field notes. Nonverbal responses were recorded in field notes and thoroughly reviewed. The researcher began with open coding; that is, data in each set was examined line by line to focus on each focus group content. It is critical to code each sentence using as many codes as possible to ensure thorough data examination (Speziale & Carpenter, 2002, p. 116–118). According to Stern (1980), “this level of coding, known as substantive codes, codifies the substance of the data and often use the words
participants have used” (p. 21). The researcher’s substantive codes were words used from the language of the participants who were observed and interviewed. The researcher identified and listed (coded) patterns of experience on the left side of the transcripts. These patterns often came from quotes or paraphrasing common ideas. Related patterns were then combined and categorized into key phrases. This level of coding, called categorizing, allowed the use of constant comparative methods in the treatment of the data. Categories were viewed as simply coded data that seemed to cluster as a result of the condensing of substantive codes with all other substantive codes (Hutchinson, 2001). This process allowed the researcher to determine what particular category would be appropriate for grouping other substantive codes. The researcher then made a decision to compare each substantive code with the others to ensure that the categories were mutually exclusive. Categories were recorded on the right side of the transcripts and then transferred onto a separate sheet of paper to highlight overarching themes as they emerged. Unique terms were identified to describe recurring themes and subthemes. Once the themes were established, each term was defined to clarify the subthemes. The second analyses of the themes were categorized by the interview questions and coded within the themes. After reviewing the field notes and rereading the transcripts, an overarching theme of process of analysis took place. The researcher reflected on the formal and informal caregivers’ data to identify the overarching theme. These additional findings strengthened the researcher’s ability to discuss the recommendations and propose environmental modifications.

The reflection process was also important to develop the researcher’s ability to critically analyze the psychosocial backgrounds of the participants and themes based on
the rich dataset. Throughout the analysis, the researcher found that the clinical experience as it relates to formal and informal caregivers emerged from the data. Constant journaling, by way of memoing, provided an outlet for processing her own experiences and emotions. Memos were written on paper during reflection and weekly meetings with her research committee member, and they clarified how the concepts fully integrated with one another. The researcher eventually wrote a one-page “Memo” for each of the field notes. Memoing is used to maintain ideas pertinent to the emerging theme (Speziale & Carpenter, 2003). Several experts (e.g., Glesne & Peshkin, 1992; Maxwell, 1996, 2005) recommend writing memos during a research project and proposed that writing ideas down as they occur is the beginning of analysis. Maintaining notes and subsequent journaling and reflective writing allowed the researcher to understand reflexivity.

**Methodological reflections.**

The role of reflexivity played an important part in this study. The term “reflexivity” is used to describe a researcher’s sensitivity to the often subtle ways that their particular location, experience, worldview, and assumptions contribute to shaping the data that is collected and analyzed (Hunt, 2010). According to Patton (2001), “a reflexive researcher will consider the perspectives and voices of research participants” (p. 544). Reflexivity has been linked to quality in research rigor and ethics (Guillemin & Gillam, 2004; Koch & Harrington, 1998; Mays & Pope, 2000). The researcher’s experiences as a formal and informal caregiver and a qualitative researcher during the data collection and analytic processes made it challenging to keep her personal experiences separate. Taking notes throughout the different stages of the research provided an opportunity to reflect, identify, and distinguish her professional and personal
experiences from her research. During the researcher’s first interview, she found herself
feeling empathy toward the participant as she asked questions that she wished someone
would have asked her in her role as an informal caregiver. Upon writing her journal
entry, the researcher realized she was reflecting back on her own experience with her
grandmother and how her needs were or were not being met. She asked herself what her
grandmother’s key needs were and how they were being addressed. The researcher
became even more motivated to recruit more participants, especially formal caregivers, to
hear what their answers would be. As time went on, she had to approach each group and
participant in an open way, working to be aware of how her experience might impact the
research and working to maximize the participants’ voices and experiences. The role of
reflexivity in the researcher’s study allowed her to be aware of how her personal,
professional, and academic experience might potentially influence her research (Hunt,
2010). This allowed her to appreciate the critical role of reflexivity in her ongoing
development as a researcher.

Validity.

Kidd & Parshall, (2000, as cited in Speziale & Carpenter, 2003) described a
common form of content validity used in focus groups: “The history of focus groups
suggests that they were not originally developed as a stand-alone method.” Therefore, to
enrich the findings of a study that uses focus groups or individual focused interviews, the
researcher should be prepared to use data triangulation. The use of triangulation through
two sample sources (formal and informal caregivers) and two data sources (focus groups
and individualized focused interviews) were identified as a means to ensure validity. In
addition, three expert researchers were able to examine the data and related findings.
Bringing forth their research experience related to ADRD, family caregiving, and qualitative and quantitative methods. “The goal of triangulation is to enhance the validity of the research by using two or more sources” (Denzin, 1978, p. 291) and increase the probability that the findings will be found credible and dependable.

**Credibility.**

In addition to triangulation, credibility demonstrated accuracy and validity that were assured through prolonged engagement, persistent observation, and a search for clarification and confirmation from the key informants. According to Lincoln & Guba (2000), credibility refers to the idea of internal consistency, where the core issue is to ensure rigor and communicate to others (Gasson, 2004). In this study, the researcher spent sufficient time in the rehabilitation facilities to gain a full understanding of the phenomenon under investigation. It was noted during the focused interviews and in the final observations that there were no new concepts emerging, which confirmed that saturation had been achieved in the analysis.

The researcher used clinical experience and research studies to build a foundation to understand the needs that drive the behavior of persons with ADRD.

**Treatment of Data**

**Confidentiality.**

For all potential participants identified in this study, the decision to participate or not was voluntary and kept confidential. Each participant was asked to choose a pseudonym for the focus group, individual focused interview, and demographic survey. Observed interactions or quotes also were recorded by pseudonym. Raw data were protected and could only be accessed by the researcher. All digital audio recordings,
transcribed data, and field notes are kept on a computer secured by a password. All data are kept in a locked file cabinet at the researcher’s assigned office at Arizona State University’s College of Nursing and Health Innovation. No information that disclose participant personal identification will be released or printed.

Summary

This chapter outlines the strategies that were employed to ensure the qualitative research process. While the flexibility of the nature thematic analysis should be embraced, strategies to ensure data verification need to be in place.
CHAPTER 4:
RESEARCH FINDINGS

This chapter begins with a brief introduction of the research environment, rehabilitation facilities, and formal and informal caregivers’ interactions within the facilities. Next, the background characteristics of the formal and informal caregivers are described. The chapter proceeds with qualitative findings on the discrepancies and similarities in the perceptions of ADRD patients’ needs that were generated by querying and examining formal and informal caregivers’ perceptions. The findings include the overarching theme and associated subthemes. Examples drawn from the formal and informal caregivers’ statements and experiences are used to enhance the findings. Chapter 5 summarizes and discusses the findings in the context of the extant literature, as well as conclusions and recommendations for further research.

Description of the Rehabilitation Facilities

The three rehabilitation facilities included in this study provide intense therapy to patients who experienced life-changing events that affect their ability to care for themselves. In this study, the facilities will be identified as inpatient rehabilitation facilities 1, 2, and 3 (IRF-1, IRF-2, and IRF-3). Two of them are considered to have the largest elderly populations within their respective health care systems. The other facility has been recognized for its diverse population. The facilities are designed to help patients regain their functional ability through a comprehensive and personalized rehabilitation program provided by a multidisciplinary team of specialists. According to Admissions Coordinators, a multidisciplinary team of specialists (i.e., physiatrists, nurses, occupational therapists, speech therapists, and social workers) work with individuals and
their families to develop a personal treatment plan that focuses on short- and long-term goals. Once treatment plans are established, families are encouraged to participate in the patient’s rehabilitation program. The program includes 3 hours of customized one-on-one therapy, state-of-the-art technology, and community reintegration activities. The success of this program is measured by the fact that approximately 80% of the patients are able to return to their previous living situation.

**Environmental characteristics of the units.**

Each facility provides a unique setting for rehabilitation. According to nurse managers’ descriptions, each facility was designed to meet the health care system’s mission and vision and the population it serves.

*IRF-1.*

IRF-1 is a free-standing 24-bed rehabilitation facility. It is situated on one level with two parallel halls (one with 16 beds and one with 8 beds). Each hall has two small desk areas. In the front of each hall is one large nurses’ station that contains eight desks with computers. The dining/activity area is in front of the nurses’ station and separated by a wall. Therapy areas (i.e., a gym, occupational therapy suite, and speech therapy room) are located at the end of one of the halls. During therapy, patients are observed walking from their room to the nurses’ station and therapy areas. The ability of IRF-1 to accommodate older adults with ADRD is facilitated by its simple one-level design. Data analysis revealed that this set-up facilitated caring for older adults with ADRD.

*IRF-2.*

IRF-2 is a free-standing 63-bed rehabilitation facility that is Commission on Accreditation of Rehabilitation Facilities (CARF) accredited. The CARF is considered to
be the premier accrediting body for rehabilitation programs. IRF-2 is a multilevel facility that serves all types of patients. Two of the floors house patients with acquired brain injuries, strokes, and/or other neurological disorders. Outpatient services and therapy care are located on the other floor. Each floor has parallel halls that are situated on either side of the nurses’ station, which sits in the center, forming an “H” shape. Due to the shape of the units, nursing staff are unable to observe the patients in their rooms or any rooms. Because most therapy takes place on different floors, patients are often taken off the floor by elevator to receive therapy. Families, when present, are often seen in the room. Some families have opportunities to stay overnight with the patients. Data analysis revealed that the facility design and construction was not conducive to caring for older adults with ADRD.

**IRF-3.**

IRF-3 is a 32-bed facility located on the upper level of a hospital. Rooms and the nurses’ station are accessed in a circular walking area. According to one of the nurses, this layout ensures that persons with ADRD encounter no “stops.” The nurses’ station is located in the middle of the walking area, making it easy for the nurses to observe and communicate with patients and therapists. Therapy takes place in two large rooms located near the unit’s entrance. When families were present, they can be seen in the rooms or walking the patients around the nurses’ station. Analysis of the data from this study revealed that IRF-3 accommodated older patients with ADRD because of its construction and design, with nurses and nursing stations situated near the patients.

**Staffing levels.**

An average of three RNs and two CNAs worked on the units during the day shift.
(7:00 am–7:00 pm). Two RNs and one CNA were on duty during the night shift (7:00 pm–7:00 am). Staff was not modified relative to the acuity levels of the patients including those with cognitive impairments.

During the end of the data collection period, the researcher met with the IRF-1 nurse manager who mentioned that all three facilities had a low patient census, averaging about 60%–75% capacity, which translated to low numbers of older patients with ADRD admitted to all three IRFs. Each of the three IRFs had an average census of seven older adults with ADRD on the units at any given time, compared to 14 to 21 other non-ADRD patients on each unit during that same timeframe. While the reason for the low census was not immediately clear, the researcher reflected on theoretical memos and discovered that there were several possible explanations. One contributing factor could have been related to open enrollment. During this time, October 15 through December 7, 2013, enrollees had the opportunity to modify Medicare coverage in response to the newly adopted Affordable Care Act. Disruption and changes in health care coverage might have discouraged patients from seeking acute rehabilitation services. Another factor might have been related to the number of “snowbirds,” retired people who spend winters in warmer climates during winter months. Some may have been hospitalized after accidents or cerebrovascular events.

**Operational day of an IRF.**

Formal caregivers’ schedules were typically organized in two shifts. The day shift began at 7:00 am and ended at 7:00 pm. The night shift began at 7:00 pm and ended the following morning at 7:00 am. Most of the patients were awakened by the CNAs between 5:00 am and 6:00 am to be assisted with bathing, toileting, grooming, and
dressing. Others were awakened by RNs as early as 4:00 am for blood draws. Still others were made to get out of bed by therapists as late as 7:00 am. Therapy hours were from 7:00 am to 5:00 pm, with each patient receiving 3 hours of therapy daily. During therapy, the researcher observed patients grooming, bathing, eating, toileting, walking, and using exercise equipment. Some of the ADRD patients appeared to have a difficult time understanding what was expected of them and tended to spend more time on tasks compared to non-ADRD patients. Meals were served three times a day: breakfast at 8:00 am, lunch at 12:00 pm, and dinner at 5:00 pm.

Activity on the units was greatest between 7:00 am and 11:30 am. During that time, RNs, CNAs, therapists, the social worker assigned to each facility, and physicians were walking in and out of most of the patient’s rooms assessing and talking to patients. Often times, they were not able to locate the patients and would ask where they were and how long were they going to be in therapy. Because the researcher positioned herself at the nurses’ stations, she was also asked this question by various staff members. Activity on the unit slowed down after lunch. Family members were often present during lunchtime. In IRF-1 and -3, most of the family members would arrive after 1:00 pm and stay until dinner. In IRF-2, some of the family members were present after dinner, while others stayed overnight.

During nontherapy time, most of the patients were in IRF-1 and -3 remained in their rooms watching television or sleeping in their beds or wheelchairs. In IRF-2, patients spent nontherapy time sitting in their wheelchairs, visiting with their families or, according to the nursing staff, on another floor being observed by other staff. Although each facility had an activity room designed for patient use, they were rarely occupied.
There was a scheduled “quiet time” IRF-1 at 2 pm. At that time, hallway lights were turned off, and patients were encouraged to take a nap. Many of the patients complied, but there were some who chose to wheel their chairs up and down the halls, perhaps not understanding that naps were encouraged. Quiet times were not scheduled at the other two facilities. None of the facilities scheduled times for any additional activities during any part of the day or evening hours.

**Cognitive and psychosocial functional levels on each IRF.**

During the first few visits to each of the facilities, the researcher’s focus was on getting to know the staff and building trust. The researcher heard frustration being expressed by staff whenever patients with cognitive impairments required attention that would take them away from their routine scheduled tasks. Additionally, as a participant observer on the units, the researcher was able to explore dynamics between formal and informal caregivers and observe interactions between caregivers and older patients. The researcher began to realize that she could identify potential older adults with ADRD based on their behavior and the various interactions they had with formal and informal caregivers. For example, although several of them were being rehabbed following strokes, she could see and hear the family members of ADRD patients orienting or redirecting their loved ones. In each facility, the researcher observed different ways in which staff would care for patients with ADRD. In IRF-1, staff would position patients so they would have clear unobstructed views of them outside the rooms near the small nurses’ stations while they continued working on the computers. Some of the staff did not interact with the patients. In IRF-2, several of the patients who appeared to be cognitively impaired were removed from their primary formal caregivers. The patients were either
seen with their family members or were being observed by other formal caregivers on another floor. In IRF-3, according to one of the nurses, each cognitively impaired patient was positioned in a room where the staff had a clear view of them.

**Formal and informal caregiver interactions.**

Based on the researcher’s observations, formal caregivers in each of the facilities were often perceived by informal caregivers as secondary caregivers compared to the therapists. As a matter of fact, the therapists were the only staff members involved in the transferring the patients from their rooms to therapy rooms. Nursing staff used this time to take their break or interact with other staff members. When patients were present, CNAs would often assist the patient with toileting, dressing or undressing, or getting in or out of bed. Staff decreased their time in the rooms when family was present. Family would spend time talking with patients or interacting with them during a recreational activity.

Although each facility was described as a rehabilitation facility, each had a unique setting. The facilities strengths and challenges were described within each setting when working with older adults with ADRD. Some of the strengths were the environmental settings, the design of the unit, and structure of the building (as in IRF-1 and -3), and the opportunity for informal caregivers to stay overnight with their loved ones (as in IRF-2). The researcher also identified several challenges related to the needs of older adults with ADRD.

**Demographics**

A demographic questionnaire was administered to participants to help characterize the study sample.
Formal caregivers.

All 27 formal caregiver participants completed the demographic questionnaire (Table 1). The formal caregiver age range was 21–69 years old ($M = 44.7$ years). Seventeen (63%) identified themselves as non-Hispanic White, four (14.8%) identified as African American, one (3.7%) as Asian, and five (18.5%) as no primary group. In terms of ethnicity, seven (25.9%) self-identified as Hispanic or Latino. Twenty-one (77.8%) of the formal participants were female, and six (22.2%) were male. Twenty-three (85.2%) of the formal participants were 30 years or older. The majority ($n = 16$) (59.3%) were RNs, and ($n =11$) (40.7%) were CNAs. Six (22.2%) had completed an Associate’s degree, eight (29.6%) completed a Bachelor’s degree, and one (3.7%) completed a nursing diploma program. Nine (33.3%) CNA participants completed some form of postsecondary education. Twenty-one (77.8%) formal participants had worked in a rehabilitation setting for 2 years or more. Twenty-two (81.5%) formal participants had worked with ADRD patients for 2 or more years, and 19 (70.4%) spent 7 or more hours a day with ADRD patients.

Informal caregivers.

All 27 informal caregivers completed the demographic questionnaire (Table 2). The informal caregivers age range was 41–90 years old ($M = 69.4$ years). Twenty-four (88.9%) identified themselves as non-Hispanic White, two (7.4%) as African Americans, and one (3.7%) as Native Hawaiian or other Pacific Islander. In terms of ethnicity, one (3.7%) self-identified as Hispanic or Latino. Seventeen (63%) of the informal participants were female, and 10 (37%) were male. Eighteen (66.4%) were age 65 years or older. In terms of relationship to the patient, eight (29.6%) identified as daughters, seven (25.9%)
as husbands, five (18.5%) as wives, two (7.4%) identified as sons, two (7.4%) identified as sisters, and three (11.1%) as other relatives. Nine (33.3%) of the informal participants had some college education, four (14.8%) had a Bachelor’s degree, three (11.1%) completed a Master’s degree, and two (7.4%) completed a Doctoral degree. Twelve (44.4%) informal participants had cared for their loved ones with ADRD for two years or more, twenty-three (85.2%) visited them in the rehabilitation facility, at least once a day, and eight (29.6%) spent 7 hours or more a day helping provide care for their loved ones with ADRD in the rehabilitation facility.

Overall, formal caregivers were younger, more racially and ethically diverse, and had a higher educational level than informal caregivers. This may be due to the higher number of RNs based on their educational requirement. The majority of both types of caregivers were female. Formal caregivers spent more time and had more experience caring for ADRD patients in rehabilitation facilities than informal caregivers.

**Formal and Informal Caregivers’ Perceptions of Needs**

Both formal and informal caregivers identified several key needs of the ADRD patient in the rehabilitation facility, and the majority of these needs were perceived differently by the two groups. This finding is consistent with a 2007 study by Weinberg et al. that found that formal caregivers may respond to needs based on their training, while informal caregivers respond to the care recipient’s personal needs.

**Discrepant Findings**

During the process of data collection and analysis, the researcher found that her prior assumptions about the formal and informal caregivers’ perceptions of the needs of older adults with ADRD in a rehabilitation setting were incorrect. Initially, the researcher
assumed that both types of caregivers would be able to perceive the needs of older adults with ADRD largely in terms of the ADRD person’s disruptive behavior. Because of this, the NDB model was used to guide the development of the study’s questions. According to the NDB model, dementia-related behavior occurs because of an inability of the caregiver to comprehend needs and the inability of distressed persons with ADRD to make their needs known; however, analysis of the data did not support this assumption. Instead, the analysis indicated that there were fewer problems with actually identifying the key needs and more concerns regarding discrepancies of how needs were currently being met and how they should be addressed in the future. Although some similarities emerged, differences appeared throughout the data across both focus groups and individualized focused interviews.

The impact of discordant perceptions and expectations.

The discordant perceptions and expectations concretely refer to misunderstandings about the care provided, roles played, and responsibilities attributed to and/or assumed by formal and informal caregivers when meeting the needs of older adult with ADRD in the rehabilitation facility. These concepts are identified in the following examples. During an individualized focused interview, an informal caregiver perceived the formal caregivers as spending less time with their loved one who had ADRD as compared to non-ADRD patients.

And it seems like nurses spend so much time working on the computer and talking to patients [non-ADRD patients] that they are not giving care …to other patients [ADRD patients].
I see the aides and the nurses spending a lot of time on those computers instead of up on their feet... And just checking on them [ADRD patients] in their rooms. I feel the staff should be walking around more checking in on people.

I have not seen the staff interacting... I do recall seeing a lady who had her leg amputated and ummm, she and the staff were talking up and down the hallway. So, I do not know if the staff is talking to my dad while they are on their way to therapy, but in my opinion I would say most of the time they are not. Because when people have dementia, I think most people just automatically don’t spend time with them or speak to them. Hi I am here, let’s go to therapy and that’s it. Not, just small talk of ummm, (looking down).

In contrast, formal caregivers shared that they perceived that they actually spent an inordinate amount of time caring for ADRD patients:

Because caring for a patient with Alzheimer’s disease tends to be very time consuming... a large time component... because that person required a lot of attention.

We spend more time, sometimes one-on-one time.

They require a lot of time... we spend so much time on physical functions with them.
One formal caregiver in a focus group shared this with his Team Leader co-worker:

…your time with the patients is much more structured than our time, ok structure, when you are talking about the recovery, structure is really important.

Decreased time spent can be perceived as discordant for formal versus informal caregiver expectations regarding the amount of time needed and meeting the patient’s needs, generalize misunderstanding, and having different beliefs of meeting patient needs. For example, an informal caregiver agreed that her loved one’s needs go unmet because the patient does not understand them [nursing staff] and they [nursing staff] do not understand him or have time to communicate what they need to him.

In this study, a striking amount of discordant perceptions and expectations were discovered between formal and informal caregivers regarding the needs of older adults with ADRD in a rehabilitation facility. This overarching theme of discordant perceptions and expectations was also linked to the following subthemes: communication and information, family involvement, rehabilitation nurse philosophy, nursing care, belonging, and patient outcomes.

Communication

Discordant perceptions and expectations may also be related to broader issues concerning communication. Communication emerged as a subtheme, with both caregivers describing a lack of communication and information exchange between each other and with the older adult with ADRD. Communication is defined as an act or process
of using words, sounds, signs, or behavior to express or exchange information or express ideas, thoughts, or feelings to someone else (Communication, Merriam-Webster’s online, n.d.). Information is knowledge that you obtain about someone or something (i.e., facts or details about a subject) (Information, Merriam-Webster’s online, n.d.); however, the exchange of information with the aim of understanding has been the most widely used definition (Norby, 2007; Usher & Monkley, 2001; Vivian & Wilcox, 2000). In the literature, the term communication is generally not distinguished from information. The terms are used interchangeably in this study and other cases. In many publications, only an implicit definition can be found suggesting a relationship between communication and information.

As communication and information are quite often used synonymously, it is not surprising that certain characteristics of both concepts are quite similar. A daughter shared her experience while spending time with her mother in rehab: “Though I was available, they never communicated any of her medications or blood sugar levels to me.” In this situation, the term communication is being used, based on her statement, the researcher was aware that the caregiver was referring to “information.” Throughout this study, both nursing staff and the family members would share their perceptions of communication as they refer to information.

In a study performed by Watt, Wertzler, and Brannan (2005), health care staff in a hospital and residents in the community who recently used the facility were interviewed in focus groups regarding their expectations of each other. Residents shared how they expected staff to communicate with them. For example, residents wanted staff to treat them as individuals, listen to their concerns, and provide reassurance and frequent
updates. In this study, families believe communication is necessary for understanding the professional care provided to their loved one in health care settings; however, they reported experiencing a lack of communication between nursing staff and patients, as well as between the nursing staff and family members.

Informal participants stated the following:

There is something about her medication. You know I come in every day, well I didn’t ask today, but I will before I leave here. I think it is important that they share the numbers. What is her blood pressure? What’s the rate? What is her blood sugar? So for me, my role is to be the patient advocate and ask the questions, because I know my mom….

I look out for the things that she needs. And, you know… no one has come in and asked if she needs to go to the bathroom. So I'm there to say, ok she needs to do this. She needs to do that.

And sometimes she doesn't even know with dementia, and when she's sitting. She won't know until she's standing up that I should have voided a half hour ago or I already did. She's more incontinent here now than she was before.

The other thing I noticed was the nursing staff reports at 7 o'clock and gives information [to the oncoming nursing staff], and that's a vital time where people have been [falling or needing help the most]...they eat at 5:30 pm so that's a big toilet time. And they [nurses] gave the information, but when I asked about my mother, the aide [CNA] did not know anything about her.
Yet, formal participants shared this information:

As the nurse, I am the advocate for the patient, because the patient is unable to share their needs and some family members do not come and tell me anything. They are here to be supportive to the patient.

This nurse believed the family should approach the nursing staff to ask questions as opposed to nursing staff providing them with information. In one formal focus group, most of the nursing staff responses were often followed by the words “need to” (this term was actually stated 46 times within the transcript). They would say these words when they referred to communication, care, and education as though they were not taking place but it was important that they did.

Some of the health care staff clearly perceived their means of communication differently. They believed they understood patients’ expectations regarding communication and that they did a good job of communicating and providing information to the patients and their families (Watt et al., 2005). As it pertains to nursing, communication is often aimed at or intended to improve the patient’s health status (Flaskerud, 1986; Shattell, 2004). This form of communication is known as instrumental or task-related communication, a term often used during nursing assessment and education of patients and/or families (Williams & Gossett, 2001). The goal of communication is determined by the extent to which communication needs occurs (e.g., a nurse communicating a patient’s new medication may take more time than a CNA communicating a patient’s bathroom schedule) (Caris-Verhallen, Kerkstra, van der
Heijden, & Bensing, 1998). In a formal caregiver focus group, a nurse stated the following regarding her perception of communicating with informal caregivers:

It’s like ok, if the family is there and they need anything, they will let us know. We are here to communicate to them needs of their loved ones. When they are here, they are helpful….

Interestingly, the perception is that family members may have been expected to initiate the conversation.

However, some CNAs took an active engagement approach:

I always ask them [the family and the patient] if I can help them. I know they may have questions about the care, because they are not like me, they have not been trained. If they don’t answer me, I don’t know what they need.

Clearly, there were discordant formal-informal and formal-formal caregivers’ perceptions and expectations about communicating and informing each other about patient needs.

**Communication between caregivers in a rehabilitation setting.**

When identifying the needs of ADRD patients, formal and informal caregivers often expressed their need for communication with either each other or the ADRD patient. ADRD patients gradually lose their ability to make their own decisions as their cognitive impairment increases (Ekman & Norberg, 1988). This leads to decreased communication with the ADRD patient and increased communication between the formal
Logically, communication between formal and informal caregivers of ADRD patients in a rehabilitation setting is necessary for meeting the patient’s needs and achieving the shared goal of optimal QoL. Rehabilitation offers a unique setting that is different from acute care with regard to the types of clinical issues faced, the make-up of the team and their interactions, and the higher involvement of the rehabilitation professionals. Communication in the rehabilitation setting takes on an interdisciplinary approach among team members.

Lack of communication emerged as a subtheme with both formal and informal participants. Formal participants expressed concerns about their perceived inability to communicate with informal caregivers because they were often unavailable, showed no interest, or were not ready to learn. Dick, an informal caregiver, had this to say about his role as a family member: “Your job is to get him better so that he can come home and my job is to take him home.” He referred to me as one of the formal caregivers because I shared with him that I was a nurse. Mary, another informal caregiver had this to say about the nursing staff and their role: “If I wanted to be a nurse, I would have gone to school to become a nurse; I can barely take care of myself.”

Nursing caregivers from formal groups shared thoughts about family members:

Many of the family members work. They are not here. They consider this facility a place of respite.

…when her daughters come to visit her, they will tell us she has to do as much as possible, they do not have time to learn anything…”
…some of our dementia patient’s family members do not live around here….like Mr.______, he live in _____ and he does not have time to come here.

On the other hand, informal caregivers expressed concern regarding communication with formal caregivers due to the lack of attention to both the patient and the family or a lack of recognition of the disease. In addition, many participants conveyed so much concern about the depth or absence of communication that it clearly rose to the top as a significant theme.

Two sisters, who participated in a focus group shared:

They just stuck her in this room and left her….my thing was that she was sitting by herself almost every time I came in. And I know the rest of them are busy, but someone could have talked to her.

…sometimes I wonder if the nursing staff knows that we are here...

Another informal caregiver stated she was here every day but none of the nurses tell her anything.

Also, a long-term informal caregiver stated:

…they need to recognize that a person with Alzheimer’s disease has difficulty following instructions…I think they don’t give recognition to the fact that maybe they don’t really know what the dementia persons’ capabilities are.
Every caregiver discussed communication and gave examples of how communicating with each other was nonexistent or challenging. Discordant communication was evident with formal and informal caregivers, as was the informal caregivers’ understanding of information presented by the formal caregivers. Ralph, an informal caregiver shared his experience: “the nurse told me my wife was on Protonix, but she never told why she was taking it.” All of the informal caregivers described challenges communicating with the formal caregivers because they were either unavailable, did not have enough information on the patient, or could not provide resources for the informal caregivers.

And she was asking my mother, how do I transfer you? Do we use the board or do we use the swings? And one, my mother couldn't answer that question because she doesn’t understand. And two, I think the aide should have known that. Like there needs to be a whiteboard or something that you can communicate with others, such as, this person uses the board, this is the three point turn, whatever. I don't know what you call it. But the communication needs to be given to them so they know who they're dealing with.

They do not have a whole lot of time to spend in somebody’s [ADRD patient] room to make sure they are ok. The aides have a little bit more time, but not as much as an RN

…we are leaving tomorrow…I asked the nurses, they do not know [about Alzheimer’s disease resources], that would be the social worker...
During the analysis, the researcher discovered that many of the informal caregivers had expectations that the formal caregivers would approach them to share information about the patient’s current status and future goals. As stated before, the informal caregivers also noticed that many of the formal caregivers would spend more time communicating with patients who did not have dementia than those who did. As for the formal caregivers, they discussed the lack of attendance and participation from the informal caregivers’ perspective. Some expressed the word “visitors” as opposed to “learners.” Formal caregivers routinely assumed that informal caregivers had already been informed by other staff members.

You know so now the family has time to go shopping, to go, you know have their own meals. To go out with their girlfriends or whatever it is you know….and then come to visit them [ADRD patient] when they are done.

…because you know they [family members] have been away from them… and they have just come for visits you know and it has been a lot of change.

…if the person had some kind of dementia when they came here and then they [the family] have been used to dealing with that.

According to the formal and informal caregivers, communication and information exchange are often facilitated by other members of the interdisciplinary team, primarily the social worker, occupational therapist, and physical therapist. Formal caregivers did not perceive themselves as the ones charged with this responsibility. As a result,
communication and information sharing between the formal and informal caregivers and the older adult with ADRD were limited. Formal caregivers felt the information given to informal caregivers and their loved ones by other team members was sufficient. The informal caregivers discussed therapy time and information and how it was integral to rehabilitation care. When asked who addressed her loved ones needs, one informal caregiver stated: “I think it was physical therapy because I was really surprised in what the therapist told me.” One other informal caregiver shared:

I asked her occupational therapist can I walk her and she said yes, with assistance. I also talked to her speech therapist to give me papers that she could work on and she provided with several worksheets. Yet the formal caregivers commented, “…because the therapist just has the patient so much during the day… you'd have to communicate with therapists to get to know the patient.”

Besides challenges initiating conversations with the informal caregivers and the older adults with ADRD, other barriers of communication and information throughout this study were formal caregivers not having enough time for ADRD patients and their family, staffing concerns, and informal caregivers not being available because they believed having their loved one in rehab gave them an opportunity for respite. Most of the informal caregivers shared the same experience, saying formal caregivers did not have enough help, time, or availability. One informal caregiver shared what she observed while sitting in her mother’s room: “You guys are understaffed, I'm sorry but you all are really understaffed ….I feel the staff should be walking around more talking and checking in on people.” She referred to the staff making themselves available to the
ADRD patient.

**Barriers to communication.**

The barriers to communication and information included: (a) decreased time on the part of the formal caregivers (Pillemer & Suitor, 1996), which can make interaction with the ADRD patient and informal caregivers brief and ineffective; (b) the formal caregiver not understanding the needs of the ADRD patient and their family; (c) the tendency of informal caregivers to not be present; and (d) formal and informal caregivers not initiating conversation.

**Family Involvement**

The differences found in the perceptions between the formal and informal caregivers were not completely unexpected as they reflect the underlying role differences in meeting the needs of older adults with ADRD. While informal caregivers agreed that individualized involvement was an important component of rehabilitative care, formal caregivers were less likely to agree that this was part of their role. Similarly, compared with informal caregivers, formal caregivers were less convinced that informal caregivers were spending adequate time with their loved ones in the rehabilitation facility to be informed and educated about their care. They were, however, more convinced that the rehabilitation facility was an opportunity for respite care for the informal caregivers. These discordant perceptions resulted in divergent expectations about meeting the needs of older adults with ADRD and carrying out relevant health care interventions.

In this study, increased and decreased family involvement were shared in both participant focused groups with regard to caring for ADRD patients in the rehabilitation setting. During a focus group meeting with formal caregivers, some shared how informal
caregivers were either not doing enough or were too involved with the care of their loved ones.

I think that in rehab the family should be getting more involved. They need to know the toileting, ADLs and have to care for them when they go home with the family. We care for them all during their stay at rehab.

…but if I had to change something it would be family. I would encourage family to come more to increase functional recovery. Their involvement means so much to the patient. Yes. I remember working with a patient who had dementia and his roommate did not, he had a stroke. His stroke affected his swallowing and the left side of his left body was weak. His roommate’s wife would come to visit her husband all day. She would not only advocate for her husband but also for the patient with dementia. When it was time for feeding, the wife would set up the room for both of them to eat and she would put the call light on when he had to go to the bathroom. At first we thought she was being bothersome, but we later realize that she was being helpful. His scores were going up because of her help. This is when we told the social worker to try to reach the family, they need to be involved.

….so it’s a lot of safety issues, and we also try to get the family involved, especially, if it comes to needing them to be here more at certain times.

In addition, a formal key informant described the role as rehab nursing staff compared to the informal caregivers’ role:
I think that as a rehab nurse I want them to do things for themselves while they are in the rehabilitation environment. Whereas, the family members will do everything for them and not encourage a certain level of independence that most Alzheimer’s patient's still have.

I've never seen a nurse or a nursing assistant make the patient too dependent on the care that they are providing to them.

Although, an informal caregiver agreed with the formal caregivers regarding them (informal) not being available:

…that’s my own fault, but it is only me. I have to take more time off. I just feel like such a novice, I got to be here to learn and it is starting to wear on me because there is so much to learn. But I am tired.

But most informal caregivers described the lack of formal caregivers’ availability:

And last night the nurses and the aides were running around putting out the fires, you know. Where it was so much better if they had had a schedule and said ok, now they've eaten, so now we've got to get everybody to the bathroom and rotate around. But they waited for people to say I need to go. And my mom can't push a call button you know. She can't even remember there is a call button.

Yet, the informal caregivers perceived “doing too much” as providing personal care. Being too involved (creating dependence) can be viewed as the informal caregiver
doing too much. However, the picture is complicated by formal caregivers’
misperceptions that informal caregivers either did not do enough or did more than they
should. They felt that patients in rehabilitation should be doing more for themselves.

When asked, “How does the older adult with ADRD needs get met?” informal
caregivers shared personal care examples, like:

I address his needs, I cut his nails, I brought him candy, I fed him cookies…I am
the only one who takes care of him at home.

I am here to help her in the bathroom and help her go to bed….

We address the needs. I cut up his meat. [Another informal caregiver says:] It
sounds like you spoil him. He is used to being enabled by you.

I come in and watch him. They call it being a “companion” because he is
impulsive.

**Barriers.**

Barriers to family involvement in their loved ones’ care were a result of both
formal and informal caregivers’ perception of involvement. The formal caregivers
perceived family involvement as being either too involved or not being present/involved
unless requested by the staff when their loved ones were agitated. A formal caregiver
stated the following: “When somebody goes crazy and needs one-on-one supervision it's
difficult to pull a staff member that can handle that…that's when we call the family in to
get involved lots of time.” Three of the informal participants identified themselves as
caregivers who were called in to “watch” their loved ones due to their inappropriate
behavior. An informal caregiver stated she had to postpone the interview because rehab
called her in to watch her dad. Conversely, the informal caregivers’ perceptions of
involvement were only related to providing personal care and emotional support. Just as
the formal caregivers try to acknowledge the fact that the person with ADRD needs more
help and time, all informal caregiver participants may also practice increased
involvement due to the ADRD person’s challenging behaviors.

Rehabilitation Nursing Philosophy

The philosophical basis of rehabilitation nursing can be described in terms of
values and beliefs, the goals formulated with patients to achieve successful rehabilitation
outcomes, and the processes used by rehabilitation nursing professionals to achieve those
goals. According to the American Nurses Association & the Association of Rehabilitation
Nurses (1988), rehabilitation nurses believe that a person with a disability has intrinsic
worth that transcends the disability and that each person is a unique holistic being who
has both the right and responsibility to make informed personal choices regarding health
and lifestyle. “Using an interdisciplinary approach, gerontological rehabilitation nurses
focus on prevention, safety strategies, client-family education, discharge planning, and
knowledge of community resources that enhances the care of elderly clients” (Mauk,
2007, p. 19).

Formal caregivers, who were identified as rehabilitation nurses, had a difficult
time demonstrating aspects of this philosophy when working with older adults with
ADRD and their families. They were remarkably candid when offering their remarks, and
each setting had formal participant(s) who expressed their concerns when sharing their
thoughts about their role as a formal caregiver.

….we just, we are not going to get them to a point where they will go home in an
environment and be independent. So we have to get them to a point where they are
medically stable.

Well as a rehabilitation nurse our goal is to rehabilitate the patient so that they return to the previous level of function or close to it. However with ALZHEIMER’S patients they may not benefit from this component because realistically they may never return to normal because of their cognitive deficit…. as a rehab nurse I want them to do things for themselves while they are in the rehabilitation environment.

Rehab is the restoration of one’s physical and mental ability, [to return to] their previous state. …And because the dementia, the retention, the memory is lost. I don’t know if it depends on what stage of dementia they are in. But in general, you know [referring to the researcher knowing their potential thought].

Formal caregivers described seeing disappointment on the faces of the staff when a patient with ADRD was admitted to the facility. They voiced their concern of safety for the patient and more importantly wondered how much the ADRD patient would actually retain from rehab. Claire stated, “I recall this patient that was admitted here previously who was being monitored because he would start “wandering” without assistance after dinner.” The group laughed at her story as they recalled his behavior and stated he never remembered anything they would tell him.

Conversely, an informal caregiver shared his perception of the rehabilitation nursing philosophy (formal caregivers’ role), using a holistic approach in an interview:
I believe these nurses [rehabilitation nurses] look at the whole person when caring for them [cognitively impaired patients] or do they? Some seem like they know and others, oh well…they should have a class to help them understand what they don’t know.

**Barriers.**

It stands to reason that if one does not know the people that they care for, they will less likely apply their philosophy of (rehabilitation) nursing. That is why it is important to understand patients and their family members. Family might also ask the meaning behind rehabilitation nursing care, if the caregivers understand the philosophy and does it apply to my loved one with ADRD. A further barrier to the application of the philosophy of rehabilitation nursing care stems from a need of formal and informal caregivers to differentiate between traditional and rehabilitation nursing care.

**Nursing Care**

Nursing care emerged as a theme in statements from both formal and informal caregivers when they described care in these rehabilitation settings. However, there was discordance on whether or not nursing care was appropriately provided. While the term care has been attributed to nursing over the years, it has been systematically researched for its meanings and expressions by various nursing theorists. According to Leininger (1984, 1988), care is the essence of nursing and essential to life, health, and well-being; it is necessary to face critical life events such as disability. The interpretation of rehabilitation nursing care was first researched when Rintala, Willems, and Halstead (1986) reported a study on team care in rehabilitation. This study determined that team conference interactions were a reflection of team care and found a need to monitor the perception and action of congruence in team conferences to assure effective team care. In
further research, Thompson (1990) explored rehabilitation care in an inpatient rehabilitation unit using a nursing theorist (Leininger, 1985, 1987) and discovered that rehabilitation nurses should have care values and beliefs that center around an interdisciplinary approach to care, openness to involvement and relationships with the clients, skills in teaching and coordinating, and a belief in the rehabilitation process.

Rehabilitation nurses serve in a variety of roles with clients of different ages (Mauk, 2007, p. 18). Their major role is to act as the primary educator for clients and their families. Nursing care includes but is not limited to helping clients and their families learn to maintain skin integrity, become independent in self-care and mobility, keep an effective bowel and bladder management program, manage safety, and use problem solving and creativity to adapt and cope with new situations. According to informal caregivers, this type of rehabilitation nursing care was observed. For example:

I'm looking for the well-being and the personal aspects of caring for my mother. Where she [mother] will be cared for by the nurse, who has the administrative and the medical [knowledge].

…I see the nurses’ job is like a therapist, [in a rehabilitation setting] they have an hour when they would work with the patient.

However, formal caregivers’ concept of rehabilitation nursing care was perceived differently, as demonstrated by the following formal caregivers’ statements:

…we have to work, we have to reorient them, constantly. And on top of that have to teach them even though they have dementia. We have to continuously teach them in
the hope that they will retain, as well as family members. Teach the family.

I think it's very important for us caregivers also to specifically to deal with the family that this is what we are doing. For example, we’re setting limits for the patients and teach the family members to be patient and the family members are not.

…as caregivers we are teaching them how to get up every 2 hours and retrain their bladder. We try to make sure they are rechecking their bowels regularly. Or that they are eating enough food and the nutrition, teaching them on why they are taking the nutrition, while they are taking their meds and why are they are getting their fingers poked for blood sugars?... and why they are getting a constant education list on everything that is happening to them.

They are not expecting us to be the teacher, they are expecting us to go address the statement, “I have to go to the bathroom,” oh by the way, I need some pain pills, can you look at this for me, I need water. A lot of time, if a patient was educated to only to what our different functionalities were then we can say, I am only here to give medications, if you need this I would have to have somebody else come and do this for you or I am only here right now to do education, but because we are holistic, we have to do all of it. A lot of times the patient care overturns the education part of it.

Barriers.

Both formal and informal caregivers discussed what they look for in each other as it relates to nursing care. Their perceptions of nursing care were different in respect to the type of rehabilitation nursing role. The informal caregiver identified the nursing care role as an administrator or one who administers medication. The formal caregiver identified
their role as an educator. Another barrier with nursing care was staffing. Several formal caregivers stated that they did not have enough staff to provide appropriate care. One formal caregiver noted the high acuity of the ADRD patients required more staff: “I want to say Alzheimer’s but I mean there is a higher level of acuity for the dementia patients.” Another formal caregiver stated: “…now I’m going to put their (ADRD patients) clothes on and it takes more time…the acuity is higher.” The informal caregivers shared: “And the staff is so overworked that they have left my mom in a bathroom for 20 minutes.”

**Belonging**

The subtheme of belonging revealed a link between the formal caregivers’ and informal caregivers’ understanding of what is meant by the rehabilitation of older adults with ADRD. Older adults with both dementia and mobility problems can be perceived as poor rehabilitation prospects (Reifler, Larson, Teri, & Poulsen, 1986). This situation is compounded by the fact that many health care professionals, including rehabilitation interdisciplinary team members share this view. In a survey of speech therapists, 44% of respondents did not agree that individuals with some form of dementia could benefit from speech therapy (Clearly et al., 2003). In fact, many formal caregivers included in this study stated that patients with some form of cognitive impairment “did not belong here” and that they were not benefiting from the interventions put in place for them.

Because we get cognitive impaired patients that come here and they really can’t do the therapy and they are really that sick and that is not our call.

However with Alzheimer’s patients, they lack that beneficial component because realistically they never return to normal because of that cognitive deficit.
...it's just that, they require more attention than the average patient and that can be difficult in a rehabilitation setting.

Alzheimer’s unit, there's a need for it. I don't know here what they feel, but you know if things were like that maybe a family could get more of a break instead of being with them all the time. You know if we were specialized or maybe have the right staffing that their needs could be met.

Well we have a mixture of patients. Maybe we need to address or assign our patients in one setting... I think prioritize and set up the environment for the Alzheimer’s people... but not in rehab.

Oh, even though we are supposed to be professional we are human also and if we've had a family member or bad experience with Alzheimer maybe we're not super great with working with Alzheimer’s patients. You know, so a unit where you choose to work with those people or not. I mean that might be farfetched but, you know, we do need to be professional and put our feelings aside but sometimes we're just human.

Well and like you said, his needs aren't getting met because he's in the wrong environment to have his needs met proficiently.

Informal caregivers’ views on rehabilitation are an extension of the care and are
guided by the medical staff:

We are here because our doctor is here, the doctor who did the surgery only works on the other side...this is where we are supposed to be.

...this due to trauma. We don’t want to be anywhere, we want to have the best.

...the care is equal. The staff here, they treat all of them the same. So it doesn’t matter if somebody doesn’t really know what is going on, they are still treating them as a sane person.

In addition, informal caregivers perceive rehabilitation, also known as, therapy as the most effective part of their hospital stay.

I don’t know, because he doesn’t comprehend. This is totally why he is here [rehabilitation]...this is where he belongs.

Here, the focus is belonging and whether older adults with ADRD are viable candidates for rehabilitation. There was an emphasis on the perceived need for a certain type of person to be in a rehabilitation setting, not a person who needs to be redirected and becomes agitated. A nurse shares her thoughts on transferring persons with ADRD to a segregated area in the rehabilitation setting or a different setting:

We can move them [ADRD patients]...If she [the nurse] is good with working with them, maybe say, well “Nurse Betty” is good with working with Alzheimer patients, therefore we would have her working in that hall with them [ADRD patients]. Let's get
During a follow-up call, the researcher asked formal key informants about their receptiveness to receiving ADRD patients in rehabilitation; all of them shared their willingness but acknowledged that they lacked knowledge and understanding of persons with ADRD but were open to training.

On the other hand, some informal caregivers assumed that formal caregivers had already been trained in dementia care, where others observed the need for this training: “Some nurses seem like they do not know what to do with my dad.”

**Barriers.**

Without a clear understanding of the benefits that physical functioning and other rehabilitative care can bring to ADRD patients and their families, it is easy to view ADRD behaviors as disruptive. The perception of this disease is that it is incurable and the patients are not expected to restore their physical health from their primary diagnosis (i.e., hip replacement, stroke, etc.). Therefore, the formal caregivers may act on the assumption that the primary diagnosis does not matter because “they don’t belong here.” This message may in turn be conveyed to patients and family even when it is not explicitly stated.

**Patient Outcomes**

The subtheme of patient outcomes represented an uncertainty of whether or not older adults with ADRD would in fact benefit from rehabilitation interventions. Patients with low cognitive function are not accepted in many rehabilitation facilities because they
are not considered good candidates for acute rehabilitation programs and are expected to have poor outcomes (Green, Forster, Bogle, & Young, 2002). Formal caregivers shared their views on patient outcomes:

Yeah like he said they're preparing for their loved ones to go home. Are they gonna be able to continue caring for them or determine whether they have they progressed any further? Are they thinking they need to be living in assisted living, group home, hospice, you know?

Our goals for them [non-ADRD patients] at rehab is for them to get ready for discharge, either home, hospice, or extended care, this [extended care] is where most of the patients with dementia go.

…the outcome, the rehab outcome is to return home. The needs for ADRD and those without [ADRD] differ in medical surgical because in rehab they are more stable, but on medical surgical units they are sicker. We prepare for life, for life the way it is going to be, even if it means going to a nursing home for those [ADRD] patients.

One informal caregiver shared her perceived outcome plan for her sister:

Of course I have seen the outcome, it is a hard call...but there is hope. They, my sister’s family, need to…are going to have to make a lot of adjustments. All families going through these situations may need to make an adjustment. They can’t get hotheaded. They are going to have to keep their cool, because if they blow up, they are going to blow off (the patient)….
I can’t speak for others, but there is hope for my wife. She will be coming home with me.

**Barriers.**

Most of the formal caregivers’ descriptions of a rehabilitation patient outcome did not align with older adults with ADRD in a rehabilitation setting. Although the expectations of rehabilitation nurses are to allow the patient to maintain optimum health and adapt to an altered lifestyle, formal caregivers shared beliefs ranging from removing the ADRD person from the rehabilitation setting to placing them directly in a nursing facility. As stated earlier, one reason was because of the formal caregivers’ lack of understanding of the disease. Other reasons were due to poor communication and a lack of information regarding the specific patient and the involvement of their family.

Informal caregivers enter rehabilitation settings with perceived “hope” and different expectations. Their expectation aligns with the goals and expectations of all rehabilitation patients: achieving and maintaining an acceptable QoL.

**Summary of the Findings**

In summary, discordant perceptions and expectations characterized formal and informal caregivers’ understanding of the needs of older adults with ADRD, as well as ways to meet those needs. In addition, feelings of not being understood by one another seem to stem from these perceptions. The subthemes demonstrate caregivers’ perceptions of identifying the needs of older adults with ADRD in rehabilitation facilities. Formal caregivers highlighted communication, family involvement, belonging, and patient outcome as ways to assist them in meeting the needs of ADRD patients. They identified barriers such as lack of communication, family lack of understanding of the expected
level of involvement, ADRD persons not belonging, and expected outcomes were also mentioned. Informal caregivers highlighted the importance of communication, family involvement, nursing care, and patient outcome, whereas their perceived barriers included lack of communication, personal involvement with the ADRD person, understanding of rehabilitation nursing care, and expected positive patient outcome.

All of the participants stated that the older adults with ADRD had unmet needs in the rehabilitation facilities. This finding is consistent with studies in other settings and the needs of patients in a rehabilitation setting from the patient’s perspective.

The majority of the caregivers stated that they had very little interaction with each other, but their perceptions of the needs of older adults with ADRD were similar. Due to the ability of wanting to meet these needs, many of the caregivers expressed a desire to understand the disease in order to provide better care.
CHAPTER 5:
DISCUSSION AND RECOMMENDATIONS

This chapter discusses the findings including the overall theme of discordant perceptions and expectations, as well as the emergent subthemes from the study, and it highlights the discordance and similarities between the formal and informal caregivers. It puts emphasis on caregiving characteristics in a rehabilitation setting and associates the findings with the related literature. Formal and informal caregivers’ perceptions led the researcher to explore recommendations that may influence ADRD caregivers and other interdisciplinary team members in rehabilitation settings.

Rationale for Focusing on Discordant Perceptions and Expectations

The study findings suggest key needs seem to be driven by one overarching theme: discordant perceptions and expectations between formal and informal caregivers due to misunderstanding and disconnection. The link between perceptions and expectations was communicated by Asch (1987). Although they are two different concepts, perceptions and expectations greatly influence one another. Perceptions involve the process used to create meaning for others, objects, occurrences, and other events (Wood, Harms, & Vazire, 2010, p. 68). This process of perception is used by selecting what is noticed, organizing it by assigning meaning, and interpreting these meanings. For example, Watson, Lewis, Moore, and Jeste (2011) explored the perception of depression among family caregivers by asking them to describe what was known about depression and dementia; having them give it meaning by answering a single question, “Do you believe you are depressed?” and allowing them to interpret the meaning. In contrast, expectations are beliefs that something will occur; this is referred to as probability
expectations (Kravitz, 1996; Uhlmann, Inui, & Carter, 1984). Although expectations are sometimes used to measure expectancies regarding what will be done, they are more frequently employed to detect expectancies regarding outcomes or what will be the result of some action or behavior. For example, in the current study, family members who did not fully understand rehabilitation care expected their loved ones to regain total function, comparing them to non-ADRD patients, despite the ADRD patient’s cognitive dysfunction. As one family member stated, “I know my sister will be back to ‘normal’ because this facility provides the best care.” This statement was similar to findings reported in a study by Tielsch, Javitt, Coleman, Katz, and Summer (1995) that employed the probability expectations approach and asked patients to predict their expected functional outcomes following eye surgery along specific functional domains, such as watching television and reading the paper.

Expectations can obscure a person’s perceptions and vice versa. For example, in the current study, formal caregivers often expected patients with ADRD to have poor outcomes because of how they perceived them (i.e., as unable to learn, follow therapeutic instructions, and function independently). In addition, the accountability that nurses hold for family members greatly affects the way they perceive the family members’ role as caregivers. A common expectation is that family members instinctively know how to care for their loved ones with cognitive impairment, while the reality often is that they need to be taught how to care for them. Expectations that come from the family caregivers’ understanding of nursing can also greatly influence their expectations and perceptions. For example, prior to their loved one’s admission to the rehabilitation facility, nursing staff can provide literature to inform the family caregiver of each team member’s role and
responsibilities within the rehabilitation facility. Family members also hold the rehabilitation staff members accountable for their roles. The gap that separates perceptions from expectations can be applied to the nurses’ care (nurses’ perceptions and family members’ expectations), family members’ care (family members’ perceptions and nurses’ expectations), and the health care system (both the nurses’ and the family members’ perceptions and expectations). In the current study, miscommunication was regarded as discordant nurse-family expectations about the perceptions of needs of ADRD patients, with feelings of misunderstanding arising from these discordant perceptions. For example, the nurse expected the family to provide information about their loved one, while the family expected the nurse to give regular updates regarding medication and treatment. In the case of family involvement, family members have been observed doing too much or not enough, yet, nursing staff disagree with the family member’s perception of involvement and see it as not being effective either way (i.e., too much or too little). Most formal caregivers felt that placement of ADRD patients in the rehabilitation facility was not appropriate because they perceived that these patients would be disruptive and uncooperative even prior to assessment. Conversely, most of the informal caregivers believed that rehabilitation was the best place for the ADRD patient prior to returning to the community setting. The overall theme of discordance generated a variety of subthemes related to discordant perceptions, including communication and information, family involvement, rehabilitation nurse philosophy, nursing care, belonging, and patient outcomes.

**Recommendations of discordant perceptions and expectations.**

The consensus of shared perceptions and expectations form the foundation of
social interaction (Asch, 1990). As in caregiving described in this study, several factors such as communication and information, family involvement, rehabilitation nurse philosophy, nursing care, belonging, and patient outcomes may influence the ability to maintain interpersonal consensus or make it difficult to carry out the role as a caregiver meeting the needs of the ADRD patient in a rehabilitation setting. The ability to reach interpersonal consensus may depend on these factors and the formal and informal caregivers’ capacities to understand the ADRD patients’ needs through each other’s perceptions. A consensus should be reached for each individualized factor based on the understanding of caregiving to meet the need of the ADRD patient; the communication may be more involved than that needed for reaching interpersonal consensus for regular nursing care. Finally, additional research is needed to identify the bases of dissonance between perception and expectations regarding the consequences of caring for ADRD patients in a rehabilitation setting.

**Communication**

A lack of communication and information emerged as a key subtheme. Negative approaches to communication and information while caring for ADRD persons was the “norm.” Both formal and informal caregivers expressed concerns about what they considered the key evidence. For example, formal caregiver participants in one of the facilities whose informal caregiver participants appeared the most satisfied with patient care still stated that there was a serious lack of communication between family and nursing staff. They had this belief because communication was most often initiated by the therapists, and discourse between the family members and nursing staff involved asking the therapists’ questions or by formal caregivers reading the therapists’ notes.
Communication gaps between formal and informal caregivers have been known to affect patient care (Ward-Griffin & McKeever, 2000), with discordant expectations between formal and informal caregivers leading to decreased satisfaction, communication breakdowns, and missed opportunities to address caregiver and patient needs. In this study, most of the participants shared they did not know how to initiate conversation to each other about the patients’ needs. Formal caregivers stated that if the patient or their family needed something, they would ask. Informal caregivers stated that they would wait on the nursing staff to inform them of their loved ones’ medical needs. Supporting that conclusion, formal caregivers may overlook the informal caregivers’ integral role of providing care (Simon, 2001).

Research surrounding communication as it relates to patients with dementia has been seen as a dynamic, complex, and ongoing process during which participant experiences are shared (McKillop & Petrini, 2011); however, a more consistent and concrete definition was required to provide a better understanding for this study. Communication is a process of words to exchange information with someone else. This definition allowed the researcher to depict the process of communication and information to enhance the understanding of the communication process. Participants in this study varied from nursing staff to family members/friends, had diverse ethnic backgrounds, and had experience with different rehabilitation facilities, yet, they shared similar experiences when communicating with each other. Communication seldom results in complete understanding because of the many environmental and personal barriers to effective communication (Shortell, 1988).
Recommendations to increase effective communication.

Effective communication between formal and informal caregivers is crucial to providing the best possible care for ADRD patients in rehabilitation facilities. Particularly since these patients may be unable to effectively express their own concerns and needs. Therefore, strategies such as assertive communication between the formal caregiver, informal caregiver, and the patient with ADRD should enhance the ADRD person’s capacity to understand language related to rehabilitation care designed to meet their needs. Although informal caregivers must depend on formal caregivers, they also have information about their loved ones’ physical, psychosocial, and emotional needs that is important in developing appropriate individualized care (Port et al., 2001), and rehabilitation settings are no different. Family caregiver support and involvement can assist RNs and CNAs in reducing the behavioral symptoms of the older adults with ADRD by helping to identify their various needs (Foley, Sudha, Sloane, & Gold, 2003). In addition, increasing informal caregivers’ participation also enhances patient involvement in activities (Dobbs et al., 2005). For example, in rehabilitation sessions, family members would often state they were present to support their loved ones. They found that when they were encouraging the patient during therapy and performing tasks, the patient seemed to do better. In this study, Angela, an informal caregiver, shared how she was very pleased with the facility, but it was not the facility or staff that gets her husband to do better, it is her presence. The study findings are all in line with other research reporting that informal caregivers express a desire for more and improved communication with formal caregivers (Port et al., 2005). Clearly, communication between formal and informal caregivers of older adults with ADRD in a rehabilitation
setting is essential for meeting the needs and achieving the shared goal of optimal QoL both within the rehabilitation facility and after return to the community.

**Family Involvement**

Family caregivers saw their key role in rehab as participating in their loved one’s care by providing emotional and social support. The formal caregivers perceived the informal caregivers’ involvement to be either “too much” or “not enough.” However, this may be result of the assumption that that the inability to restore functioning in one area (cognitive) indicates an inability to restore functioning in other areas (physical), which leads informal caregivers to carry out greater activities for their loved one with ADRD than necessary (Resnick & Remsburg, 2004). This can create challenges in rehabilitation when dependent behavior is displayed and the result is support and care, thereby reinforcing dependency and subsequently increasing the likelihood of the person becoming more dependent (Edwards & Burnard, 2003). This may in fact reduce the participation of the older adult with ADRD in their ADLs and contribute to increased functional deficits due to a lack of rehabilitation training (Resnick & Remsburg, 2004). On the other hand, some nurses and CNAs have been noted to discourage family member participation. These older adults with ADRD are more likely to function dependently, rather than being encouraged toward independent practices. As a result, informal caregivers were seen as being “under” involved, perhaps due to discouragement by the formal caregivers or perceptions of not being needed, because the nursing staff was providing the care. This can also cause concern regarding informal caregiver participation even after discharge.

There is a fine line between family providing and maintaining too much or too
little care for the older adult with ADRD (Secker, Hill, Villeneau, & Parkman, 2003). There needs to be a key focus on addressing the needs of the ADRD person in terms of helping them maintain independence and safety.

Formal caregivers perceived informal caregivers as not being part of the interdisciplinary team. The definition of an interdisciplinary team varies widely according to setting and purpose, yet is typically made up of a core group of members who consistently work together with support team members or “consultants” (Rothberg, 1992). Family involvement in the rehabilitation setting takes on an interdisciplinary approach.

A model interdisciplinary rehabilitation team was formulated by a group of practitioners and researchers (American Congress of Rehabilitation Medicine, 1992) that provided a framework for examining family integration into teams and even greater involvement of the patients and family members (Velji et al., 2008). The outcome of this study examined the impact on team functioning of situations where family caregivers’ input was critical but missing (e.g., if a patient inaccurately represents themselves due to cognitive impairment). In addition, family input rather than presence was important in the maintaining optimal team function in formal meetings.

**Recommendations regarding family involvement.**

In several rehabilitation studies, the success of a person returning home appears to be affected by how involved the informal caregiver is in the rehabilitation setting during and after their loved one’s stay (Meijer et al., 2005; Morris, Grant, & Lynch, 2007). Family is often involved when they feel as though they are part of the rehabilitation team. In this study, family members described having a task or role as a “companion” caregiver
and as being part of the team. They felt like they were needed. In addition, family input rather than presence was important in maintaining optimal team functioning in formal meetings. Ultimately, the interdisciplinary model implies active involvement, communication, and cooperation among the various professional disciplines and family members (Melvin, 1980). Such team cooperation is critical in ensuring that family goals are appropriately addressed (Weber et al., 1995).

Family members and friends are most often the informal caregiver(s) in our society; they provide 85% of help provided to all older adults in United States (Gitlin & Schulz, 2012). In the three rehabilitation facilities, all of the informal participants were the primary or the only unpaid direct caregiver. Each shared their experience as caregivers and stated that a lack of support outside of the facility causes them to be too involved, whereas some formal caregivers expressed that the informal caregiver’s increased involvement was helpful or at times “doing too much.” Both types of caregivers perceived family involvement as a strategy for meeting the needs of ADRD patients, but neither identified how this strategy could be implemented. The concept of family-centered care requires shared knowledge, goal-setting, and decision-making with the informal caregiver. For years the concept of family-centered care has been identified in the health care system as the collaboration between these two types of caregivers. The Institute of Family-Centered Care (2006), describes family-centered care as an innovative approach for planning, delivering, and evaluating health care that is grounded in a mutually beneficial partnership among patients, families, and providers.

There are several opportunities for improving the capacity of informal caregivers to assist with rehabilitation care: inform both caregivers and the patient about all aspects
of the ADRD and its consequences for the patient’s abilities; nursing staff, family
members, and patients practicing rehabilitation nursing caregiving skills taught by
rehabilitation nurse educators; and involve the formal and informal caregivers as well as
the patient in setting rehabilitation goals. These may seem like common practices in a
rehabilitation setting, but according to a study involving stroke patients, very few
informal caregivers (4%–20%) were involved in their loved one’s rehabilitation goals
(Monaghan et al., 2005); the participants’ stated goals were not discussed or agreed to by
them. Therefore, establishing this role with the informal caregiver may enhance the
ADRD patient’s QoL. Rehabilitation offers a unique setting that differs from acute care
regarding the types of clinical issues faced, the make-up of the team and their interaction,
and the involvement of the rehabilitation professionals and family members.

Rehabilitation Nursing Philosophy

Rehabilitation nurses share a belief system about disability and the rights of the
individual with disabling conditions and chronic illness. According to the American
Nurses Association & the Association of Rehabilitation Nurses (1988), rehabilitation
nurses believe that a person with a disability has intrinsic worth that transcends the
disability and that each person is a unique holistic being who has both the right and
responsibility to make informed personal choices regarding their health and lifestyle.

In this study, the role and associated activities of formal caregivers regarding the
philosophy of rehabilitation nursing did not seem to be aligned with that of older adults
with ADRD and their informal caregivers. However, the informal caregivers described
thoughts, behaviors, and feelings that were closely aligned with the rehabilitation nursing
philosophy as it related to their loved one’s care. Family caregivers shared that nursing
caregivers lacked an understanding of how to apply this philosophy. Overall, the approach towards the philosophy of rehabilitation nursing when working with older adults with ADRD was seen as lacking by informal caregivers and even in application by formal caregivers. One informal participant may have summed it up best by sharing her experience in comparing rehabilitation nursing versus intensive care nursing, highlighting the significance of patient care and attentiveness in the intensive care setting and stressing the lack of attention and the need to increase nursing care and education of ADRD patients in the rehabilitation setting.

**Recommendations related to rehabilitation nursing philosophy.**

While not clearly defined by the formal caregiver, the philosophy of nursing and its related actions should be readily apparent to all formal and informal caregivers in a rehabilitation setting. Through rehabilitation, people with disabilities are enabled to mobilize their own resources, decide what they wish and are able to be, and achieve goals through their own efforts and their own way (Wright, 1983) with the support of their family and the guidance of the interdisciplinary team. AD and related diseases are seen as disabilities caused by progressive neurological illness. Developing a better understanding of the psychology of dementia, the related stages of the disease progression, and the role of ADRD caregivers and their family could improve the rehabilitation care of patients with ADRD. Rehabilitation therapy may be a better way of approaching the care of persons with ADRD than a model, such as the NDB model that served as a guiding framework in the current study.

The aim of “habilitation therapy” is to maximize the functional independence and morale of individuals with dementia (Raia & Koenig-Coste, 1997). This therapy can be
defined as a preemptive behavior therapy triggered by six “domains”: physical environment, social, communication, functional, perceptual, and behavioral. Physical environment makes up for the lack of cognition promoting mastery of the environment (e.g., caregivers should provide limited choices when setting up meals). The communication domain uses strategies such as body language, repeated demonstration, redirecting, cueing, and pictures. The social domain should allow caregivers to help patients maintain social and cognitive skills through skill practice during activities such as developing a week-long calendar that includes interactive activities (e.g., puzzles, art, singing, etc.) for both the patient and their family. Functional assistance should be used to promote increased independence through modifications such as giving showers at night instead in the morning. The perceptual domain would focus on sensory cues recognized to decrease confusion, such as touching the person on the shoulder before providing care. The behavioral domain is based on the ADRD person’s behavior and whether or not the caregivers can directly modify the behavior or if they need to use strategies to change them indirectly, such as assessing when a patient behavior becomes inappropriate before intervening. The principal learning task becomes how to value what ADRD people can do rather than dwelling on what they have lost. This behavioral approach is aligned with the philosophy of rehabilitation nursing and benefits both the ADRD patient and their caregivers.

Overall, the current study findings suggest that the NDB framework is less aligned with rehabilitation than “habilitation therapy”. Consideration should therefore be given to working with a rehabilitation model to identify and help address the needs of older adults with ADRD.
Nursing Care

The schedule of care in rehabilitation facilities is often made up of structured routines (Bowers et al., 2000) that are highly task oriented. There is very limited time to spend on the psychosocial needs of ADRD patients (Younger & Martin, 2000). Consequently, despite efforts to provide individualized care, the results of the current study indicate that rehabilitation facilities continue to embrace task-oriented methods of care. Formal caregivers were expected to provide a basic set of nursing tasks such as bathing, toileting, and eating at set times. Numerous tasks were juxtaposed with concerns by both formal and informal caregivers regarding staff shortages. Their concern with the number of staff members also played a role in lack of care and attention beyond basic care needs. In addition, informal caregivers made the assumption that formal caregivers would be involved in the well-being of care of their loved one while in the rehabilitation facility, while informal caregivers only concentrated on emotional support and social activities or interactions with their loved ones.

Caregiver differences are common regarding the respective roles and approaches when caring for the ADRD patient (Bauer & Nay, 2003; Butcher, Holkup, Park, & Maas 2001). Informal caregivers may withhold their recommendations for improving care or complaints about QoL, fearing negative repercussions for their loved ones with ADRD (Hertzberg & Ekman, 1996). Conversely, formal caregivers often have inadequate time for meaningful discussions with informal caregivers (Pillemer, 1996). According to Bamm & Rosenbaum (2008), families view nurses’ lack of availability, accessibility, and communication as critical barriers to providing them with education, counseling, and information. The formal and informal caregivers surveyed in this study discussed a
variety of similar challenges as captured by Lawrence, an informal participant, whose wife was recently discharged from the rehabilitation facility: “they [nurses] are so focused on what they are doing and not who they are doing it to.” A formal participant shared how she wished she had the time to provide the type of care “they” [the ADRD patient] needed, but she could not. Therefore, it is imperative that formal and informal caregivers share those challenges to develop a better working relationship.

**Recommendations for nursing care.**

Despite the difference in the perceptions of care and the lack of staffing, formal and informal caregivers can benefit from additional nursing staff and ADRD training. In a study by Zimmerman et al. (2005), patients with dementia received better nursing care because the facility provided additional staff members who were trained in domains central to dementia care; and encouraged activity participation. Providing staff based on the acuity (severity) of the patient appeared to be the greatest concern of both types of caregivers. Modifying the nurse-to-patient ratio based on the nursing hour per care would benefit both the staff and family members, and more importantly, the ADRD patient. These changes are likely to lead to improved QoL in older adults with ADRD.

**Education**

Education emerged from the nursing care subtheme. To distinguish between education and information, the researcher operationalized education as the act or process of imparting knowledge or skills to another; the understanding of information being gained from being educated (Education, Merriam-Webster’s online, n.d.). Informal caregivers who possessed information and were educated about the illness felt empowered to provide broader care and assistance to their family member or loved one.
suffering from ADRD. During an informal focus group, Mr. Savage shared his experience on AD and how learning about it helped him take care of his wife. Several family caregivers felt that formal caregivers were not sufficiently knowledgeable about the disease and therefore concluded that the formal caregiver lacked the ability to properly care for and meet the needs of their loved one. Informal caregivers expressed concern that the education they received from the formal caregivers was limited compared to information provided from their loved one’s physical therapist. They also expressed concern regarding receiving little information on medication, especially new medication prescribed during the rehabilitation stay. Some informal caregivers stated that formal caregivers were not educated on scheduled toileting or feeding of their loved one.

In contrast, other than toileting, formal caregivers stated that their role as a nurse was to educate the patient and the family and shared that this goal was being met even though some nursing staff expressed a concern that family members were not available or receptive to important information/guidance. Prior research has shown that formal caregivers may ration information to informal caregivers based on their perceptions of how readily the informal caregiver can absorb it (McGown & Brathwaite, 1992). It is possible that staffing miscommunication and challenges exacerbated these issues in the current study.

**Recommendations for education.**

Nurse care in any setting begins with care, compassion, and more importantly, education. Whether one is a formal or informal caregiver, information and education are critical to the coordination of care (Weinberg et al., 2007). Education and understanding of the disease are essential to effective caregiving. Each facility provides a package that
includes but is not limited to information on stroke and hip and knee replacements. All three facilities have stroke support groups and hip and knee training for those who chose to have elective surgery. Each facility could provide information about ADRD in the existing package and offer established ADRD support groups that can be attended during and after discharge from the rehabilitation facility. In addition, rehabilitation facilities could create a strategic interdisciplinary steering team whose task is to develop a training model to educate all disciplines in understanding and caring for ADRD patients and their family members. The benefits to providing training to nursing staff and education to family members of older adults with ADRD could enable nursing staff and family members to better understand each other’s perspective and desired outcomes (Christ & Blacker, 2005).

**Belonging**

From the formal caregivers’ point of view, patients in the rehabilitation setting with cognitive impairment such as ADRD required more attention. As a CNA stated “…it takes more time to take care of one [ADRD] patient than it takes to take care of my whole assignment [other assigned patients].” In addition, formal caregivers viewed the ADRD patient as not belonging in a rehabilitation setting. Another formal caregiver, whom I had observed receiving a compliment from an informal participant, stated “they do not ‘fit’ in a rehabilitation setting.” Interestingly enough, their responses emerged from the question “Why do you think these needs go unmet?” Professional caregivers of people with ADRD often ask why they should support the rehabilitation efforts of an ADRD person when they know that the person is only “going to get worse anyway” (Hopper, 2003, p. 345). Yet, the interesting point in this study was that the formal
caregivers’ perceptions of ADRD patients “not belonging” was based on the fact that they did not understand how to identify and address these patients’ needs. Many of the informal caregivers felt as though their loved ones belonged in the rehabilitation facility and perceived that as part of them “getting better.” A husband whose spouse was transferred from another facility shared his thoughts on her stay at the rehabilitation facility, “this facility is better than any other facility…that is why we were flown here, so that she could be rehabbed.”

**Recommendations of belonging.**

Belonging is the experience of personal involvement in a system or environment, so that the individuals feel themselves to be an integral part of that system or environment (Hagerty, Lynch-Sauer, Patusky & Bouwsema, 1993). Several studies have shown the efficacy of structured behavioral treatments that decrease demands on persons with dementia. Specifically, older adults with ADRD have benefited from interventions including reduced wandering behavior (Robison et al., 2007), more active engagement with their environment (Judge, Camp, & Orsulic-Jeras, 2000) and improved ability to carry out specific tasks (Zanetti et al., 1997). In 2007, Robison et al. published an article on the Partners in Caring program (PIC) used in a structured environment. The PIC program revealed positive outcomes for families, staff, and patients; families’ experienced significant improvement in communication with staff, spouses were more involved, and the patients’ behavioral symptoms decreased. Robison and colleagues (2007) also reported that after education and training, the program had a positive effect on the family and staff. Formal and informal caregivers in the current study shared how they believe that the implementation of education, training, and an established program
may help them care for older adults with ADRD.

**Patient Outcomes**

According to formal caregivers, most older adults with ADRD are expected to have a poorer outcome than those without ADRD. This theme emerged from the question “How does the need differ between ADRD and non-ADRD patients?” Throughout their individual statements, formal and informal caregivers’ response to older adults with ADRD and their expected outcome were different. Nursing caregivers expressed how family caregivers, especially those who were older, were not able to care for their loved ones and should not expect them to return home. Typically in a rehabilitation setting, the outcome is not determined by one’s cognitive status, but by their pre- and postevaluations. Yet in this study, formal caregivers would often determine the ADRD patients’ outcomes based on their secondary diagnosis. During her individual interview, Barbara, who represented several of the rehabilitation nurses, expressed her feelings toward ADRD patients and their outcomes: “They [nurse liaisons] should know that once the patient [ADRD] is admitted to rehab, they will not be returning home [referring to nursing home].” That speaks volumes about the ADRD patients’ expected outcomes from this nurse’s perspective. According to Graff et al. (2007), dementia patients and their informal caregiver dementia QoL (DQoL) scores were significantly better after working with an occupational therapist over a 6-week period compared to those who did not receive therapy. Informal caregivers provided expressions of “hope” for their loved ones outcomes. Although informal caregivers shared a range of expected outcomes (e.g., full recovery to partial recovery), they expected an overall improvement.
Recommendations regarding patient outcomes.

Patient outcome is extremely important in the rehabilitation setting. Patient outcome begins on the first day of evaluation by the interdisciplinary team, which helped determine the patient’s length of stay. If nursing staff is part of that team and has predetermined the ADRD patient’s outcome as “negative,” these decreased expectations may also be taken on by the other team members. There is some evidence that older adults with cognitive impairment who receive intensive inpatient rehabilitation after impairment may be able to gain benefits in physical function that are comparable to those of their cognitively intact counterparts (Muir & Yohanna, 2009). This evidence suggests there is opportunity for outcomes that are better than expected by some formal participants in the current study. The importance of this recommendation lies in the strength of the education and training for both formal and informal caregivers. Formal caregivers will benefit from recognizing the possibility that patients with ADRD can return to their preadmission setting. Informal caregivers will benefit from education and external resources to provide the best outcome for their loved ones.

Similarities

Though discordant perceptions and expectations were identified as the overarching theme, there were similarities as it related to the subthemes. Both formal and informal caregivers shared concerns about education and training. In this study, education emerged as necessary to understand and meet the needs of ADRD patients in rehabilitation settings. In all of the focus groups, both caregivers expressed a need for education. When asked what changes were needed to enhance functional recovery for ADRD patients, one nurse stated “we need more education nurses, therapists, family, and
patients.” Everyone in the group agreed. In another focus group, a CNA shared this about family caregivers, “I think they need education about what to do and to show them the way to do it, whatever way is easy for them.” A nurse shared this, “They have just started [taking care of their loved one] and since someone’s [nursing staff] there to take care of the people [ADRD patients]...they just don't know how to approach us [nursing staff].”

During a focus group meeting with family caregivers, education became a part of the conversation. Family caregivers expressed their concerns regarding the lack of education for both the staff and family. One family caregiver shared this, “When asked ‘what else you would like to add?’ I think more education, if we [nursing and family caregivers] are going to be dealing with dementia and Alzheimer’s patients. We must be ready for them.” Fessey (2007) discussed the need for nursing caregivers to obtain knowledge through educational opportunities such as cascade training where a small group of nursing staff are trained to train other staff in acute care settings similar to rehabilitation facilities. The importance of knowing about the disease and the patient’s other comorbidities provide both groups of caregivers’ better opportunities to provide quality care within the rehabilitation timeframe. Packer (2000) suggests that knowledge about ADRD along with care is not enough. There is a need to educate formal and informal caregivers about cognitive impairment and the stages of AD, as well as a need to emphasize how care practices can influence an increase or decrease in symptoms (Aveyard, 2001).

Communication was also a noticeable issue shared by both the formal and informal caregivers. Communication was lacking between both groups. According to Porter and Kearns (2005), families reported a need for staff to increase communication
and provide more information, whereas staff reported not having enough time to communicate or provide information to families (Pillemer, 1996). Communicating and sharing information were necessary to identify and address the needs of ADRD patients. In some instances, they held each other accountable for not sharing information that was pertinent to the patient. Other areas in which both caregivers made similar statements were related to problems with communication, nursing staff spending too much time on computers, understaffing, nursing staff having problems with scheduling tasks for patients (e.g., not providing scheduled toileting time), and a lack of understanding of each other’s role. Formal and informal caregivers agreed that family involvement could have been defined better. This may be related to the cultural differences between the formal and informal caregivers as there was a significant difference in age between the two groups.

**Summary of Discussions and Recommendations**

ADRD and rehabilitation caregiving is an area where both nursing staff and family caregivers had concerns regarding discrepancies of how needs were met and how they should be met in the future. The recommendations of the current study include the need to: understand interpersonal perceptions and expectations of nursing staff and family caregivers to identify and meet the needs of the ADRD patient in rehabilitation settings, improve communication between the nursing staff and family caregivers, provide education and training opportunities for both the nursing staff and the family members of patients with ADRD, identify access to information about ADRD and caregiving resources, describe the roles of the nursing staff and family caregivers, examine the roles that the ADRD patient and their family caregivers play within the
rehabilitation setting, and modify the environment to accommodate the ADRD patient and their family caregivers.

In an ideal rehabilitation facility, nursing staff, patients, and their families would work together to meet the needs of the patients and each other. As a formal caregiver stated, “We are all in this together to help each other understand how to take care of the [ADRD] patient.” In the ideal setting, staff would take time to communicate to the patient and their family members, family would be available to ask and receive questions, and the nursing staff would be flexible enough to accommodate the ADRD patient’s behavior to provide the additional effort required for their care. In this scenario, the nurses, family members, and patients would know about the philosophy of rehabilitation nursing and be in agreement or at least on the same page regarding expected outcomes for patients with ADRD.

**Study Limitations**

In this study, it was imperative that data be gathered to provide a clear understanding of the needs of older adults with ADRD in a rehabilitation setting. Although this research presented diverse and pertinent information related to the formal and informal caregivers’ perceptions of the needs of ADRD patients in three rehabilitation facilities, several limitations must be acknowledged. Participants’ recognition of ADRD patients was based on their knowledge of a health care professional’s diagnosis regarding their patients; therefore, no formal written diagnosis or assessment of ADRD was required. Cognitive stages of ADRD patients were not measured in this study. It is important to note that data was collected from formal and informal caregivers’ perspectives, not those of the ADRD patients. While the data
collected from the participants was very helpful in understanding how to identify ADRD patient needs, additional research is required to gain a more comprehensive understanding of how behavioral, psychosocial, physical, and environmental factors impact the care of the ADRD patient in the rehabilitation setting.

With respect to formal and informal caregivers, there was significantly more ethnic diversity among the former group. The sample was limited to nursing staff and lacked representation from other rehabilitation health care professionals. In addition, these findings are not necessarily generalizable to other rehabilitation settings or health care systems due to a relatively small sample size in one health care setting. The physical location of the interviews and the timeline also may have impacted the data and related factors. Because data was collected on campuses of the rehabilitation facilities, this may have caused the participants to be less forthcoming (e.g., formal caregivers may have associated the meetings with work). Moreover, meetings took place across a 6-month period, which included the adoption of a national health insurance plan (Affordable Care Act) and several major holidays. Because of this, the census in each facility was lower than expected. Nurses’ and family members’ broad schedules and some participants not wanting to share their information with others created challenges in developing focus groups. Although steps were taken to monitor the data validity and credibility, the researcher does acknowledge that her professional experience in rehabilitation nursing and personal experience with family members with ADRD in remay have shaped the study findings; therefore, it is important for others to examine these needs through additional research. The study was completed in one health care system and is not applicable to other rehabilitation settings. Even so, three facilities provided data from
formal and informal caregivers to help identify the potential needs of ADRD patients in rehabilitation. The research yielded a considerable amount of rich and meaningful data that can be drawn on to inform the practice of the interdisciplinary teams and family caregivers.

As researchers continue to seek a better understanding of ADRD patient needs, it is important for both types of caregivers to provide the best quality of care. Because studies have shown that identifying the needs of ADRD patients can lead to positive outcomes for the patients and their families, it is this researcher’s assertion that future studies can help achieve this goal if they are designed to assess the points discussed below.

**Research and Practice Implications**

There are several areas for future research pertaining specifically to persons with ADRD in rehabilitation settings. First, additional studies are needed to gain a better understanding of the actual needs of the ADRD patients through their voices and other networks as opposed to the needs of their caregivers. Also, it is important to evaluate the roles of the person with ADRD and formal and informal caregivers within rehabilitation settings. Further exploration of a more ethnically diverse population is needed to reflect the impact of the perceived needs of persons with ADRD and their families. Further research could explore the perceptions of formal and informal caregivers in other rehabilitation settings throughout the country by administering a more structured survey or employing other research methods within a national rehabilitation organization. This may provide insight for dementia care programs in a variety of health care settings.

The current study and future research of rehabilitation settings with older adults
who have some form of cognitive impairment have the potential to assist staff and family with ADRD health literacy tools. ADRD health literacy is the capacity to learn the cardinal symptoms of ADRD (as summarized in the Alzheimer’s Association’s 2013 “Know the 10 Signs” publication) to make appropriate health decisions when trying to meet the needs of persons with ADRD. Future work should develop dementia modules for staff and guide them to resources such as dementia support groups and associations for family and patients during and after their stay at rehab. Additional research could explore the perceptions of other formal disciplines and informal caregivers in other clinical settings, such as acute care, intensive care, and emergency rooms. Future studies that assess the interdisciplinary team, including the family, have the potential to help develop a systemwide approach related to other health care settings. Further examination of a rehabilitation model, such as “habilitation therapy” specific to dementia care has the potential to positively impact opportunities to develop a program within health care systems. For example, “habilitation therapy” seeks to restore external function by emphasizing internal emotion. This model was developed to involve both the family and the interdisciplinary team.

In practice, future research would involve the interdisciplinary team, including the family, coming together to identify innovative models of best practice services and models of care for people with dementia rehabilitation settings. This would include supporting the development of clinical guidelines related to dementia and research outcomes for ADRD patients in the rehabilitation setting. More best practices in the care of older adults with ADRD in rehabilitation settings require more attention.

Unfortunately, the overall theme and subthemes derived from this study are not in
accordance with the philosophy of rehabilitation practice, which includes family involvement and nursing care. Family caregivers often have the capacity to develop the skills to work within an interdisciplinary setting that focuses on a family-centered approach with their loved ones with ADRD. Nursing caregivers have the capacity to develop the skills to work within an interdisciplinary team to ensure that ADRD patients and their family caregivers are receiving quality care in rehabilitation settings. Collectively, both caregivers emphasized a need for changes in the areas of education, training, and resource development as they relate to meeting the needs of ADRD patients.

Most rehabilitation studies focus on the physical disorders of older adults related to strokes and hip or knee replacements. Few researchers have assessed cognitive impairment and related rehabilitation outcomes. Re-evaluating the ADRD patients’ status in rehabilitation facilities and modifying the environment to accommodate and meet their needs requires meaningful and effective education, training, and resource development strategies. There is clearly a need for interdisciplinary team-focused models that incorporate ADRD health education, training, and resources that involve patients with ADRD to the best of their ability, as well as their informal caregivers. In the near future, the researcher intends to contribute to the knowledge of psychosocial, physical, and behavioral needs of ADRD patients in a rehabilitation setting by developing dementia care training programs for rehabilitation nursing.
REFERENCES


Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. Archives of
Physical Medicine and Rehabilitation, 89(8), 1618–1624.


Clay, M., & Wade, S. (2003). Rehabilitation and older people. Nursing Older People, 15,


research: some thoughts and an invitation to dialogue. *Qualitative Social Work, 1*(1), 39–55.


Lincoln, Y.S., & Guba, E.G. (2000). Paradigmatic controversies, contradictions, and


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Morgan, D. G., & Stewart, N. J. (1999). The physical environment of special care units: needs of residents with dementia from the perspective of staff and family caregivers. *Qualitative Health Research, 9*(1), 105–118.


rehabilitation setting. *Healthcare Quarterly (Toronto, Ont.),* 11(3 Spec No.), 72–79.


APPENDIX A

RECRUITMENT AND ENROLLMENT PROCESS
Step 1

Researcher schedules a meeting with the nurse administrator and the social worker and/or other appropriate staff to discuss study and review inclusion criteria

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<th>Step 2</th>
<th>Formal Caregiver</th>
<th>Informal Caregiver</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Nurse administrator to help to identify formal caregivers to recruit for the study and other appropriate staff</td>
<td>Social worker will identify informal caregivers to recruit for the study</td>
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<table>
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<tr>
<th>Step 3</th>
<th>Formal Caregiver</th>
<th>Informal Caregiver</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Researcher will approach formal caregivers individually or in a group setting to discuss and give information about the study</td>
<td>Social worker will approach informal caregiver to discuss and give information about the study</td>
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<tr>
<th>Step 4</th>
<th>Formal Caregiver</th>
<th>Informal Caregiver</th>
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<tr>
<td></td>
<td>If interested, a request to contact them in person or on the phone to collect information</td>
<td>If interested, a request that the researcher contact them in person or on the phone to collect information (pre-screen)</td>
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<th>Step 5</th>
<th>Formal Caregiver</th>
<th>Informal Caregiver</th>
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<tr>
<td></td>
<td>Informed of date and time of Focus Group meetings</td>
<td>Informed of date and time of Focus Group meetings</td>
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APPENDIX B

RECRUITMENT SCRIPT TO FORMAL CAREGIVERS
Formal Caregiver Recruitment Script

This script is an example of what might be said by the principal investigator when approaching the formal caregivers who may be identified by the nurse administrator as meeting the inclusion criteria in this project.

Recruitment Script (in person):
“Hello, my name is Angela Marie Allen. I am a nurse at Banner Health. I received information from (an individual/a contact sheet) indicating that you might be interest in taking part in a project Identifying the Needs of Older Adults with Alzheimer’s Disease and Related Dementias in the Rehabilitation Setting. This research project will be occurring within the next few weeks. It involves collecting information from you by way of participating in a focused group. This focus group/interview will be a semi-structured group session, moderated by me, held in an informal setting, for the purpose of collecting information related to identifying the needs of Alzheimer’s disease and related dementias patients in the rehabilitation setting through your perceptions. The information will also help guide the development of future nurse-lead intervention for Alzheimer’s disease and related dementias patients in the rehabilitation setting. If you would like more information about the project, I can discuss further, supply you with an information package or meet with you at a time that is convenient for you.”

*Individualized focused interviews will be held for those who are unable or uncomfortable to meet in groups.

Recruitment Script (by telephone):
“Hello, my name is Angela Marie Allen. I am a nurse at Banner Health. I received information from (an individual/a contact sheet) indicating that you might be interest in taking part in a project Identifying the Needs of Older Adults with Alzheimer’s Disease and Related Dementias in the Rehabilitation Setting. This research project will be occurring within the next few weeks. It involves collecting information from you by way of participating in a focused group/individual. This focus group will be a semi-structured group session, moderated by me, held in an informal setting, for the purpose of collecting information related to identifying the needs of Alzheimer’s disease and related dementias patients in the rehabilitation setting through your perceptions. The information will also help guide the development of future nurse-lead intervention for Alzheimer’s disease and related dementias patients in the rehabilitation setting. If you would like more information about the project, I can discuss further and supply you with an information package or meet with you at a time that is convenient for you.”

*Individualized focused interviews will be held for those who are unable or uncomfortable to meet in groups.

[Pause]

[If no:] “When would be a better time for you?”
[If yes:] “There is certain criterion that needs to be met in order to ensure that you are eligible to participate, therefore I need to take a couple of minutes to ask you some questions related to eligibility. Please know that I understand that the answer to some of these questions will be obvious, however, to ensure the validity of the research project, I must ask these questions.”

“Before we begin let me assure you that anything you say will be strictly confidential. Also, there is no cost to participate in this study.”

**Formal Caregiver Participant Script to Determine Eligibility**

This script is an example of what might be said by the principal investigator after determining whether the potential formal caregiver is eligible to participate in this research project.

**Eligibility Script**

I really appreciate you taking the time to answer my questions. At this time it appears that this project is a good fit for you. Let me tell you a more about the project.

As mentioned before, if you choose to participate in this project, you will be asked to participate in a focus group. This is a group of people with similar backgrounds and experiences, with issues that affect them. This group will meet for about 60-90 minutes and will include 7-10 rehabilitation registered nurses, certified nurse assistants or appropriate staff. Everyone in the group will be asked to describe the needs of the patients with Alzheimer’s disease and related dementias in the rehabilitation setting. This focus group will be a semi-structured group session, moderated by me, and held in an informal setting. The discussion will be audiotape recorded, and I will also take notes. All names will be anonymous by way of a pseudonym (false name), which will be issued during the session. All information gathered will be kept confidential, and participants will be asked not to discuss the group with others after it ends. Prior to the session you will be asked to fill out an individual demographic questionnaire about yourself and the facility in which you work.

You will be contacted within the next (TBD) weeks with a date/time and location. I will also place a letter that will list the date/time and location as a reminder, in your employee mailbox.

If for any reason you are not able to meet on the assigned date or wish to meet with me individually to discuss the needs of Alzheimer’s disease and related dementias patient in the rehabilitation setting, please let me know.

Taking part in the study is voluntary. You may refuse to take part or withdraw at
any time. A $10 gift card will be provided to you for participating in the project.

Thank you very much for speaking with me. If you have questions or if anything arises prior to the session, please call me at 602-496-0786.
APPENDIX C

STUDY FLYER FOR FORMAL CAREGIVERS
Needs of Older Adults with Alzheimer’s Disease and Related Dementias in a Rehabilitation Setting

Are you:

- At least 18 years of age?
- A registered nurse and certified nurse assistant of a patient with Alzheimer’s disease and related dementias placed in a rehabilitation setting?
- A registered nurse and certified nurse assistant who have worked in a rehabilitation setting for greater than 90 days and provide direct care or supervision to the patient during their stay at the rehabilitation facility?
- Speak and understand English

If you have answered yes to all four questions and are willing to share your experiences, Needs of Older Adults with Alzheimer’s Disease and Related Dementias in a Rehabilitation Setting Project requests your participation.

What are the Needs of Older Adults with Alzheimer’s Disease and Related Dementias in a Rehabilitation Setting project?

Through your participation, this study hopes to identify the needs of older adults with Alzheimer’s disease and related dementias placed in a rehabilitation setting, as well as recognizes the similarities and differences of the nursing staff as opposed to family/friend. This information will help guide the development of future nurse-lead intervention for Alzheimer’s disease and related dementias in a rehabilitation setting.

What do I have to do if I am part of the project?

You will be asked to participate in a one-time focus group, which is a like a group interview. There will be 7-10 nursing staff of patients with Alzheimer’s disease and related dementias in the group. Everyone will be encouraged to respond to questions about the needs of Alzheimer’s disease and related dementias patients in a rehabilitation setting. Your name will not be recorded.
during the group interview. You will receive a $10 gift card for your participation.

Who should I contact to take part in this project, or get more information?

Please call: Needs of Older Adults with Alzheimer’s Disease and Related Dementias in a Rehabilitation Setting project?
Angela Marie Allen, RN, Co-Investigator
Phone: 602-496-0786
Contact Form

Permission

By completing this form, I am giving the co-investigator the permission to contact me to discuss the research project.

Name: __________________________________________

Telephone number: (Primary) _____________________

(Secondary) ______________________

Best times to call: ____________________________________
APPENDIX E

RECRUITMENT SCRIPT TO INFORMAL CAREGIVERS
Informal Caregiver Recruitment Script

This script is an example of what might be said by the social workers and/or other appropriate staff when approaching the informal caregivers who may be identified as meeting the inclusion criteria in this study.

Recruitment Script

“I would like to know if you may be interested in participating in a research project that will be occurring within the next few weeks. It involves collecting information from you by way of participating in a focused group. This is a group of people with similar backgrounds and experiences, with issues that affect them. This group will have 7-10 family members/friends/neighbors. Everyone in the group will be asked to describe the needs of their loved one/friend/neighbor with Alzheimer’s disease and related dementias in the rehabilitation setting. This focus group will be a semi-structured group session, moderated by a Banner Health nurse, held in an informal setting. If you would like more information about this project, I can put you in touch with Angela Marie Allen, the Banner Health nurse who will be conducting the research project.”

This script is an example of what might be said by the principal investigator after collecting the informal caregivers’ contact information from the social workers and/or other appropriate staff after they have approached the informal caregivers who may been identified as meeting the inclusion criteria in this study.

Recruitment Script (in person):

“Hello, my name is Angela Marie Allen. I am a nurse at Banner Health. I received information from (the social workers and/or other appropriate staff or contact sheet) indicating that you might be interest in taking part in a project Identifying the Needs of Older Adults with Alzheimer’s Disease and Related Dementias in the Rehabilitation Setting. This research project will be occurring within the next few weeks. It involves collecting information from you by way of participating in a focus group/individualized focused interview*. This focus group will be a semi-structured group session, moderated by me, held in an informal setting, for the purpose of collecting information related to identifying the needs of Alzheimer’s disease and related dementias patients in the rehabilitation setting through your perceptions. This information will also help guide the development of future nurse-lead intervention for Alzheimer’s disease and related dementias patients in the rehabilitation setting. If you would like more information about the project, I can discuss further, supply you with an information package or meet with you at a time that is convenient for you.”

*Individualized focused interviews will be held for those who are unable or uncomfortable to meet in groups.

Recruitment Script (by telephone):

“Hello, my name is Angela Marie Allen. I am a nurse at Banner Health. I received
information from (an individual/a contact sheet) indicating that you might be interest in taking part in a project Identifying the Needs of Older Adults with Alzheimer’s Disease and Related Dementias in the Rehabilitation Setting. This research project will be occurring within the next few weeks. It involves collecting information from you by way of participating in a focused group/individual. This focus group will be a semi-structured group session, moderated by me, held in an informal setting, for the purpose of collecting information related to identifying the needs of Alzheimer’s disease and related dementias patients in the rehabilitation setting through your perceptions. The information will also help guide the development of future nurse-lead intervention for Alzheimer’s disease and related dementias patients in the rehabilitation setting. If you would like more information about the project, I can discuss further, supply you with an information package or meet with you at a time that is convenient for you.”

*Individualized focused interviews will be held for those who are unable or uncomfortable to meet in groups.

[Pause]

[If no:] “When would be a better time for you?”

Date: __________________  Time: ______________________

[If yes:] “There is certain criterion that needs to be met in order to ensure that you are eligible to participate; therefore I need to take a couple of minutes to ask you some questions related to eligibility. Please know that I understand that the answer to some of these questions will be obvious, however, to ensure the validity of the research project, I must ask these questions.”

“Before we begin let me assure you that anything you say will be strictly confidential. Also, there is no cost to participate in this study.”

Script to Eligible Informal Caregiver Participants

This script is an example of what might be said by the principal investigator after determining whether the potential informal caregiver is eligible to participate in this research project.

Eligibility Script

I really appreciate you taking the time to answer my questions. At this time it appears that this project is a good fit for you. Let me tell you a more about the project.

As mentioned before, if you choose to participate in this project, you will be asked to participate in a focus group. This is a group of people with similar backgrounds
and experiences, with issues that affect them. This group will meet for about 60-90 minutes and will include 7-10 family members/friends/neighbors. Everyone in the group will be asked to describe the needs of their loved one/friend/neighbor with Alzheimer’s disease and related dementias in the rehabilitation setting. This focus group will be a semi-structured group session, moderated by me, and held in an informal setting. The discussion will be audiotape recorded, and I will also take notes. All names will be anonymous by way of a pseudonym (false name), which will be issued during the session. All information gathered will be kept confidential, and participants will be asked not to discuss the group with others after it ends. Prior to the session you will be asked to fill out an individual demographic questionnaire about yourself and your loved one/friend/neighbor with Alzheimer’s disease and related dementias in the rehabilitation setting.

You will be contacted within the next (TBD) weeks with a date/time and location. I will also mail you a letter that will list the date/time and location as a reminder. If you would like me to do that please provide me with your mailing address:

__________________________________________________________________________

If for any reason you are not able to meet on the assigned date or wish to meet with me individually to discuss the needs of your loved one/friend/neighbor with Alzheimer’s disease and related dementias in the rehabilitation setting, please let me know.

Taking part in the study is voluntary. You may refuse to take part or withdraw at any time. A $10 gift card will be provided to you for participating in the project.

Thank you very much for speaking with me. If you have questions or if anything arises prior to the session, please call me at 602-496-0786.
Needs of Older Adults with Alzheimer’s Disease and Related Dementias in a Rehabilitation Setting

Are you:

- At least 18 years of age?
- A family/friend of a patient with Alzheimer’s disease and related dementias placed in a rehabilitation setting?
- A family/friend who has provided at least four hours of direct care or supervision to the patient before their stay at the rehabilitation facility?
- Speak and understand English

If you have answered yes to all four questions and are willing to share your experiences, the Needs of Older Adults with Alzheimer’s Disease and Related Dementias in a Rehabilitation Setting Project requests your participation.

What are the Needs of Older Adults with Alzheimer’s Disease and Related Dementias in a Rehabilitation Setting project?

Through your participation, this study hopes to identify the needs of older adults with Alzheimer’s disease and related dementias placed in a rehabilitation setting, as well as recognizes the similarities and differences of the family/friend and nursing staff. This information will help guide the development of future programs to meet the needs of patients with Alzheimer’s disease and related dementias in a rehabilitation setting.

What do I have to do if I am part of the project?

You will be asked to participate in a one-time focus group, which is a like a group interview. There will be 7-10 family members/friends of patients with Alzheimer’s disease and related dementias in the group. Everyone will be encouraged to respond to questions about the needs of Alzheimer’s disease and related dementias patients in a rehabilitation setting. You will not need to give your name in the group interview. You will receive a $10 gift card for your participation.
Who should I contact to take part in this project, or get more information?

Please call:  Needs of Older Adults with Alzheimer’s Disease and Related Dementias in a Rehabilitation Setting project?
Angela Marie Allen, RN, Co-Investigator
Phone: 602-496-0786
APPENDIX G

FORMAL CAREGIVER DEMOGRAPHIC FORM
Formal Caregiver Demographic Form

Demographic Profile

The principal investigator will ask the following questions to the formal caregivers prior to the focus group meeting.

A. Would you describe yourself as Hispanic or Latino/a or of Spanish origin?
   1. ( ) No
   2. ( ) Yes

B. How would you describe your primary racial group?
   1. ( ) White, Caucasian
   2. ( ) Black, African-American
   3. ( ) Native American or Alaska Native
   4. ( ) Asian
   5. ( ) Native Hawaiian or other Pacific Islander
   6. ( ) No Primary Group
   7. ( ) Other: Specify ____________________

C. What is your gender?
   1. ( ) Female
   2. ( ) Male
   3. ( ) Transgender

D. What is your current age? ______________

E. What is your highest level of education?
   a. ( ) Less than high school education
   b. ( ) Some high school education
   c. ( ) High School Diploma/GED
   d. ( ) Trade School education
   e. ( ) Some college education
   f. ( ) Associate’s Degree
   g. ( ) Bachelor’s Degree
   h. ( ) Master’s Degree
i. ( ) Doctorate Degree
j. ( ) Other: Specify ____________________

F. What is your current title while working in the rehabilitation facility?
   1. ( ) NA
   2. ( ) Certified Nurse Assistant
   3. ( ) Licensed Practical/Vocational Nurse
   4. ( ) Registered Nurse

G. How long have you worked in Rehabilitation settings?
   Years ________ Month ________

H. Which of the following best describes your employment?
   1. ( ) NA
   2. ( ) Casual (<20 hours per week)
   3. ( ) Part-time (at least 20 hours per week)
   4. ( ) Full-time (37 or more hours per week)

I. How many years or months have you worked at xxxxxxx?
   Years ________ Month ________

J. How long have you worked in settings where you have provided care for patients who have been identified with having Alzheimer’s disease or some form of related dementia or serious memory problems?
   Years ________ Month ________

K. How long have you provided direct patient care to patients with Alzheimer’s disease or some form of related dementias or serious memory problems?
   Years ________ Month ________

L. How many hours a day do you spend providing direct patient care to patients with Alzheimer’s disease or some form of related dementias or serious memory problems?
   1. ( ) <1 hour
   2. ( ) 1-3 hours
   3. ( ) 4-6 hours
   4. ( ) 7-9 hours
   5. ( ) >10 hours
APPENDIX H

FORMAL CAREGIVER INFORMATIONAL LETTER
Formal Caregiver Informational Letter

Date

Study Information Letter

(Formal Caregiver)

Title of the Research Project: Identifying the needs of older adults with Alzheimer’s disease and related dementias in a rehabilitation setting: Perceptions of formal and informal caregivers.

Dear Sir or Madam,

Angela M. Allen, a nurse at Banner Health facilities, is conducting a project about exploring the needs of older adults with Alzheimer’s disease and related dementias through the perceptions of the nurses, nurses’ assistants, and family/friends.

What will you be asked to do?

You will be participating as a rehabilitation registered nurse/certified nurse assistant in a project which will take 60-90 minutes of your time. You will spend your time in a focus group with other staff members or an individualized focused interview. The focus group or individualized focused interview will be facilitated by Angela M. Allen, the co-investigator (Co-I).

The questions you will be asked are about the key needs of the Alzheimer’s disease and related dementias patients in the rehabilitation setting. The Co-I will be requesting your permission to audio-tape the interview. You have the right to stop the recordings at any time. After the group interviews are audio-taped, the words will be typed out to produce a transcript.

The focus group/interview will take place in a confidential meeting room on
campus. Prior to the focus group/interview, you will be asked questions to determine if
you are eligible to participate. If you have answered all the questions that determine your
eligibility, the Co-I will ask that you complete an anonymous questionnaire about
yourself including your professional designation, age, gender, ethnicity, education, and
the number of years and the length of time you have worked in the facility. The questions
will take about ten minutes to answer. You will be asked to reflect on the times you have
cared for a person you believed to have some memory problems related to dementia.

Completion of the focus group/interview and participation in this research project
is voluntary. If you complete the focus group/interview you are confirming that you
voluntarily consent to participate in this research project and you understand that
participation in this project is not a condition of employment at Banner Health. All focus
group/interviews will take place during your off-working hours, in which you will not be
paid your salary for participating in the focus group/interview.

What are the risks and benefits of the project?

The level of risk related to the study is very minimal. There is a minimal risk that
participating in a group, audio recording or identifying with some of the questions may
make you feel uncomfortable. The results of this project could help me understand the
needs of the Alzheimer’s disease and related dementias patient in the rehabilitation
setting, how to address those needs, and promote a better quality of life.

Will it cost you anything to be in the project?

No, you pay nothing to participate in this voluntary study.

Will I be compensated for my time?
Upon completion of this project, you will be provided with a $10 gift card by the principal investigator.

**Is the project confidential?**

Yes, the decision to participate or not is voluntary and kept confidential. You can withdraw from the project at any time without an explanation or consequences. Your name will never be used to ensure privacy. You will be asked to use a pseudonym (false name) so that none of the demographic information or typed notes from the focus group/interview will have your name on them. All of the notes that are collected from our focus group/interview will be kept on a safe computer and access to the computer will be secured by a specific password that nobody except me knows. The written data and audio tapes will be kept in a locked file cabinet in an assigned area. After the notes are typed up from the taped interview, all of the audiotapes will be destroyed. If at any time while we are talking during the focus group/interview, you feel you have said something that you do not want to be used for the project, that part will be removed when the notes are typed. In addition, the Co-I asks that all group participants maintain confidentiality from group interviews. The Co-I cannot guarantee that complete confidentiality will be maintained.

**What will this information be used for?**

Some of the information that you share in the focus group and observations may result in projects that become talks, reports, presentations and publications by the Co-I or author. In addition, a brief summary of the results will be submitted to all participants. Your name will never be used in these talks, reports, presentations and publications. Your participation is important in helping the Co-I to understand what is required to meet the needs of older adults with Alzheimer’s disease and related dementia. Thank you for your
interest in this project.

If you have any questions concerning the project, please contact Angela M. Allen, Co-Investigator, at 602-496-0786.

Thank you again for your willingness to participate and I look forward to meeting with you in the near future.

Sincerely yours,

Angela M. Allen

Angela M. Allen, RN
Staff Nurse
Banner Boswell Medical Center
10601 Sante Fe Dr.
Sun City, Arizona 85351
Angela.Allen@bannerhealth.com

Please keep this information letter for your own records.

The Institutional Review Board (IRB) reviews human research studies. It protects the rights and welfare of people taking part in those studies. You may contact the IRB if you have any questions about your rights as a participant in this project or if you feel you have been placed at risk. The Banner Health Institutional Review Board number is --- --- ----

By signing below you are agreeing to participate in this study.
By signing below, you are agreeing to be taped.

NOTE: A COPY OF THE SIGNED AND DATED INFORMATION LETTER MUST BE KEPT BY THE PRINCIPAL INVESTIGATOR AND A COPY MUST BE GIVEN TO THE PARTICIPANT.
APPENDIX I

INFORMAL CAREGIVER SCREENING FORM
Informal Caregiver Screening Form

Date: _____________________  Time: _____________

A. What is your current age? ______________

B. What is your relationship with the person in the rehabilitation facility? “You are the…”
   0. ( ) Husband
   1. ( ) Wife
   2. ( ) Son/Son-in-Law
   3. ( ) Daughter/Daughter-in-Law
   4. ( ) Brother
   5. ( ) Sister
   6. ( ) Other relative, specify: ________________
   7. ( ) Neighbor
   8. ( ) Friend

C. What is the current age of your loved one/neighbor/friend? ______________

D. Have you been told that your loved one/neighbor/friend has Alzheimer’s disease or some form of dementia or serious memory problem?
   0. ( ) Yes
   1. ( ) No
   If “no” to #4, please explain your purpose of participating:
   __________________________________________

E. How many hours a day would you say you have provided direct or supervised care to your loved one/neighbor/friend with Alzheimer’s disease or some form of dementia or serious memory problem prior to their rehabilitation stay?
   0. ( ) <1 hour
   1. ( ) 1-3 hours
   2. ( ) 4-6 hours
   3. ( ) 7-9 hours
   4. ( ) >10 hours
F. How many hours a day would you say you have provided direct or supervised care to your loved one/neighbor/friend with Alzheimer’s disease or some form of dementia or serious memory problem during their rehabilitation stay?

0. ( ) <1 hour
1. ( ) 1-3 hours
2. ( ) 4-6 hours
3. ( ) 7-9 hours
4. ( ) >10 hours

G. Determine if the informal caregiver can speak and understand English?

0. ( ) Yes
1. ( ) No

If the potential informal caregiver is not eligible, thank them for answering the questions and inform them that based on the answer(s) given, that they do not appear to be a best fit for this project.

If the potential informal caregiver has answered all inclusionary questions, proceed to the script for eligible participants.
APPENDIX J

INFORMAL CAREGIVER DEMOGRAPHIC FORM
ID # _________________________________

Pseudonym: ________________________________ Date: ________________

Informal Caregiver Demographic Form

Demographic Profile

The principal investigator will ask the following questions to the informal caregivers prior to the focus group meeting.

A. Would you describe yourself as Hispanic or Latino/a of Spanish origin?
   1. ( ) No
   2. ( ) Yes

B. How would you describe your primary racial group?
   1. ( ) White, Caucasian
   2. ( ) Black, African-American
   3. ( ) Native American or Alaska Native
   4. ( ) Asian
   5. ( ) Native Hawaiian or other Pacific Islander
   6. ( ) No Primary Group
   7. ( ) Other: Specify ____________________

C. What is your highest level of education?
   1. ( ) Less than high school education
   2. ( ) Some high school education
   3. ( ) High School Diploma
   4. ( ) Trade School education
   5. ( ) Some college education
   6. ( ) Associate’s Degree
   7. ( ) Bachelor’s Degree
   8. ( ) Master’s Degree
   9. ( ) Doctorate’s Degree
   10. ( ) Other: Specify _______________________

D. What is your gender?
   1. ( ) Female
   2. ( ) Male
   3. ( ) Transgender
E. What is your current age? ___________

F. What is your relationship with the person identified as having some form of dementia in the rehabilitation facility? “You are the…”

1. ( ) Husband
2. ( ) Wife
3. ( ) Son/Son-in-Law
4. ( ) Daughter/Daughter-in-Law
5. ( ) Brother
6. ( ) Sister
7. ( ) Other relative, specify: ___________________
8. ( ) Neighbor
9. ( ) Friend

G. How many years or months have you cared for your loved one/neighbor/friend who has Alzheimer’s disease or some form of dementia or some form of serious memory problem?

Year(s) ________ Month(s) _______

H. Did you live with your loved one/neighbor/friend who has Alzheimer’s disease or some form of dementia or some form of memory problem prior to their rehabilitation stay?

1. ( ) No
2. ( ) Yes

(If “yes” to # H, skip # I)

I. How often did you usually see your loved one/neighbor/friend with Alzheimer’s disease or some form of dementia serious memory loss prior to their rehabilitation stay?

1. ( ) At least once a day
2. ( ) At least once a week
3. ( ) At least twice a month
4. ( ) At least once a month
5. ( ) Don’t know

J. How many hours a day would you say you provide direct or supervised care to your loved one/neighbor/friend with Alzheimer’s disease or some form of dementia serious memory loss prior to their rehabilitation stay?
1. ( ) <1 hour
2. ( ) 1-3 hours
3. ( ) 4-6 hours
4. ( ) 7-9 hours
5. ( ) >10 hours

K. How often did you usually see your loved one/neighbor/friend with Alzheimer’s disease or some form of dementia serious memory loss during their rehabilitation stay?

1. ( ) At least once a day
2. ( ) At least once a week
3. ( ) At least twice a month
4. ( ) At least once a month
5. ( ) Don’t know

L. How many hours a day would you say you provide direct or supervised care to your loved one/neighbor/friend with Alzheimer’s disease or some form of dementia or serious memory loss during their rehabilitation stay?

1. ( ) <1 hour
2. ( ) 1-3 hours
3. ( ) 4-6 hours
4. ( ) 7-9 hours
5. ( ) >10 hours

M. Have you received any education or training on caregiving or caregiving issues related to Alzheimer’s disease or some form of dementia or serious memory loss?

1. ( ) No
2. ( ) Yes

If yes, check all of the following that may apply. I received the following training through….

1. ( ) Conferences
2. ( ) Workshops
3. ( ) 1:1 sessions
4. ( ) Support groups
5. ( ) Training
6. ( ) Books
7. ( ) DVDs
8. ( ) Other, Specify: ________________
9. ( ) More than one training
N. Do you know where you can find educational information or training on
caregiving or caregiving issues related to Alzheimer’s disease or some form of
dementia or serious memory loss?

1. (    ) No
2. (    ) Yes
Study Information Letter

(Informal Caregiver)

Title of the Research Study: Identifying the needs of older adults with ADRD in a rehabilitation setting: Perceptions of formal and informal caregivers.

Dear Sir or Madam,

Angela M. Allen, a nurse at Banner Health facilities, is conducting a project about exploring the needs of older adults with Alzheimer’s disease and related dementias through the perceptions of the nurses, nurses’ assistants, and family/friends.

What will I be asked to do?

You will be participating, in a project, as a family member/friend of someone with dementia in a rehabilitation setting. This project will take 60-90 minutes of your time. You will spend your time in a focus group with other patient’s family members/friends or an individualized focused interview. The focus group or individualized focus interview will be facilitated by Angela M. Allen, the co-investigator (Co-I).

The questions you will be asked are about the key needs of the Alzheimer’s disease and related dementias patients in the rehabilitation setting. The Co-I will be requesting your permission to audio-tape the interview. You have the right to stop the recordings at any time. After the groups are audio-taped, the words will be typed out to produce a transcript.
The focus group/interview will take place in a confidential meeting room on campus. Prior to the focus group/interview, you will be asked questions to determine if you are eligible to participate. If you have answered all the questions that determine your eligibility, the Co-I will ask that you complete an anonymous questionnaire about yourself, including your age, gender, education, ethnicity, relationship with the person with dementia and the number of years you’ve cared for them. The questions will take about ten minutes to answer. You will be asked to reflect on the times you have cared for your loved one/friend who was diagnosed with some form of memory problems related to dementia.

Completion of the focus group/interview and participation in this research project is voluntary. If you complete the focus group/interview you are confirming that you voluntarily consent to participate in this research project and you understand that by participating in this project, information or judgment of your loved one/friend will not be held against you. Whether you choose to participate or not will have no affect on the care your loved one/friend will receive during their rehabilitation stay.

**What are the risks and benefits of the study?**

The level of risk related to the study is very minimal. There is a minimal risk that participating in a group, audio recording or identifying with some of the questions may make you feel uncomfortable. The results of this project could help the Co-I understand the needs of the Alzheimer’s disease and related dementias patient in the rehabilitation setting, how to address those needs, and promote a better quality of life.

**Will I be compensated for my time?**

Upon completion of this study, you will be provided with a $10 gift card by the
Co-I.

**Is the study confidential?**

Yes, the decision to participate or not is voluntary and kept confidential. You can withdraw from the study at any time without an explanation or consequences. Your name will never be used to ensure privacy. You will be asked to use a pseudonym (false name) so that none of the demographic information or typed notes from the focus group/interview will have your name on them. All of the notes that are collected from our focus group/interview will be kept on a safe computer and access to the computer will be secured by a specific password that nobody except me knows. The written data and audio tapes will be kept in a locked file cabinet in an assigned area. After the notes are typed up from the taped interview, all of the audiotapes will be destroyed. If at any time while we are talking during the focus group/interview, you feel you have said something that you do not want to be used for the study, that part will be removed when the notes are typed. In addition, I ask that all group participants maintain confidentiality from group interviews. I cannot guarantee that complete confidentiality will be maintained.

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If you have any questions concerning the project, please contact Angela M. Allen, Co-Investigator, at 602-496-0786.

Thank you again for your willingness to participate and I look forward to meeting with you in the near future.

Sincerely yours,

Angela M. Allen, RN
Staff Nurse
Banner Boswell Medical Center
10601 Sante Fe Dr.
Sun City, Arizona 85351
Angela.Allen@bannerhealth.com

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By signing below, you are agreeing to be taped.

NOTE: A COPY OF THE SIGNED AND DATED INFORMATION LETTER MUST BE KEPT BY THE PRINCIPAL INVESTIGATOR AND A COPY MUST BE GIVEN TO THE PARTICIPANT.
Formal Caregiver Interview Guide

Introduction:
You are being asked to participate in this focus group/individualized focus interview because you are/have been a caregiver of an older adult with Alzheimer’s disease and/or related dementias in a rehabilitation setting. I am interested in learning about the needs of older adult with Alzheimer’s disease and/or related dementias in rehabilitation setting from your perceptions. I would like to ask you how you perceive their needs based on the experiences you have had with them. There is no right or wrong answer. The focus group/interview will last about 90 minutes.

- Before we get started I would like to get some information about you
- I will use this information to describe who participated in the Focus Group/Interview
- If you have not done so, please complete the demographic information
- PLEASE USE A PSEUDONYM (FALSE NAME)
- DO NOT USE YOUR ACTUAL NAME

Key needs of the ADRD patients in a rehabilitation setting

I. Perceptions of Staff
   Probes:
   1. What do you perceive as the key needs of the ADRD patient in a rehabilitation setting?
   2. How does your role differ from the family/friends/neighbor in caring for patients with ADRD?

II. Opportunities for addressing the needs
   Probes:
   3. How are these needs addressed?
   4. Who addresses these needs?
   5. How well are these needs addressed?

III. Needs and unmet needs
    Probes:
    6. What needs go unmet?
    7. Why do you think these needs go unmet?

IV. Experience in a rehabilitation setting
    Probes:
    8. What are the changes needed to enhance functional recovery for ADRD patients?
    9. How do the needs of younger versus older patients with ADRD differ while in an inpatient rehabilitation facility?
10. How do the needs differ between those with or without ADRD in this setting?
11. How do these needs differ in rehabilitation settings compared to other health care settings?

Conclude the focus group by asking the participants the following question:
12. What else that we have not yet discussed regarding meeting the needs of ADRD patients can you share before we conclude the interview?

Thank you for participating in this focus group!
Informal Caregiver Interview Guide

Introduction:
You are being asked to participate in this focus group/individualized focus interview because you are/or have been a caregiver of an older adult with Alzheimer’s disease and/or related dementias in a rehabilitation setting. I am interested in learning about the needs of an older adult with Alzheimer’s disease and/or related dementias in a rehabilitation setting from your perceptions. I would like to ask you how you perceive their needs based on the experiences you have had with them. There is no right or wrong answer. The focus group/interview will last about 90 minutes.

• Before we get started I would like to get some information about you
• I will use this information to describe who participated in the Focus Group/Interview
• If you have not done so, please complete the demographic information
• PLEASE USE A PSEUDONYM (FALSE NAME)
• DO NOT USE YOUR ACTUAL NAME

Key needs of the ADRD patients in a rehabilitation setting?

I. Perceptions of Family/Friend
Probes:
1. What do you perceived as the key need of the ADRD patient?
2. How does your role differ from the nursing staff in caring for patients with ADRD?

Opportunities for addressing the needs
Probes:
3. How are these needs addressed?
4. Who addresses these needs?
5. How well are these needs addressed?

Needs and unmet needs
Probes:
6. What needs go unmet?
7. Why do you think these needs go unmet?

Experience in a rehabilitation setting
Probes:
8. What are the changes needed to enhance functional recovery for ADRD patients?
9. How do the needs differ between those with or without ADRD in this setting?
10. How do these needs differ in rehabilitation settings compared to other health care settings you may have encountered?
Conclude the focus group by asking the participants the following question:
11. What else that we have not yet discussed regarding meeting the needs of ADRD patients can you share before we conclude the interview?

Thank you for participating in this focus group!
Table 1

*Demographic Characteristics of Formal Caregivers*

<table>
<thead>
<tr>
<th>Variable</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>44.7 (13.8)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic or Latino</td>
<td>7 (25.9%)</td>
</tr>
</tbody>
</table>

**Race**

<table>
<thead>
<tr>
<th>Race</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White, Caucasian</td>
<td>17 (63.0%)</td>
</tr>
<tr>
<td>Black, African American</td>
<td>4 (14.8%)</td>
</tr>
<tr>
<td>Native American or Alaskan</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (3.7%)</td>
</tr>
<tr>
<td>Native Hawaiian or/other Pacific Islander</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>No primary group</td>
<td>5 (18.5%)</td>
</tr>
</tbody>
</table>

**Sex**

<table>
<thead>
<tr>
<th>Sex</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>21 (77.8%)</td>
</tr>
<tr>
<td>Male</td>
<td>6 (22.2%)</td>
</tr>
</tbody>
</table>

**Education level**

<table>
<thead>
<tr>
<th>Education level</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High school education</td>
<td>1 (3.7%)</td>
</tr>
<tr>
<td>Trade school education</td>
<td>1 (3.7%)</td>
</tr>
<tr>
<td>Some college education</td>
<td>9 (33.3%)</td>
</tr>
<tr>
<td>Associate’s degree</td>
<td>6 (22.2%)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>8 (29.6%)</td>
</tr>
<tr>
<td>Qualification</td>
<td>Count (Percentage)</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>1 (3.7%)</td>
</tr>
<tr>
<td>Other: specify</td>
<td>1 (3.7%)</td>
</tr>
</tbody>
</table>

**Job title**

<table>
<thead>
<tr>
<th>Title</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered nurse</td>
<td>16 (59.3%)</td>
</tr>
<tr>
<td>Certified nurse assistant</td>
<td>11 (40.7%)</td>
</tr>
</tbody>
</table>

**Hours/day providing direct care**

<table>
<thead>
<tr>
<th>Hours/Day</th>
<th>Count (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1</td>
<td>3 (11.1%)</td>
</tr>
<tr>
<td>1-3</td>
<td>3 (11.1%)</td>
</tr>
<tr>
<td>4-6</td>
<td>2 (7.4%)</td>
</tr>
<tr>
<td>7-9</td>
<td>17 (63%)</td>
</tr>
<tr>
<td>&gt;10 hours</td>
<td>2 (7.4%)</td>
</tr>
</tbody>
</table>

*Note: N = 27.*
Table 2

**Demographic Characteristics of Informal Caregivers**

<table>
<thead>
<tr>
<th>Variable</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>69.5 (13.8)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic or Latino</td>
<td>1 (3.7%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White, Caucasian</td>
<td>24 (88.9%)</td>
</tr>
<tr>
<td>Black, African American</td>
<td>2 (7.4%)</td>
</tr>
<tr>
<td>Native American or Alaskan</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Asian</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Native Hawaiian or other Pacific Islander</td>
<td>1 (3.7%)</td>
</tr>
<tr>
<td>No primary group</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>17 (63.0%)</td>
</tr>
<tr>
<td>Male</td>
<td>10 (37.0%)</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
</tr>
<tr>
<td>High school education</td>
<td>7 (25.9%)</td>
</tr>
<tr>
<td>Trade school education</td>
<td>2 (7.4%)</td>
</tr>
<tr>
<td>Some college education</td>
<td>9 (33.3%)</td>
</tr>
<tr>
<td>Associate’s degree</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>4 (14.8%)</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>3 (11.1%)</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Doctorate degree</td>
<td>2 (7.4%)</td>
</tr>
<tr>
<td>Other: specify</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

Relationship to the ADRD patient

<table>
<thead>
<tr>
<th>Husband</th>
<th>7 (25.9%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife</td>
<td>5 (18.5%)</td>
</tr>
<tr>
<td>Son/son-in-law</td>
<td>2 (7.4%)</td>
</tr>
<tr>
<td>Daughter/daughter-in-law</td>
<td>8 (29.6%)</td>
</tr>
<tr>
<td>Brother</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Sister</td>
<td>2 (7.4%)</td>
</tr>
<tr>
<td>Other relative, specify:</td>
<td>3 (11.1%)</td>
</tr>
<tr>
<td>Neighbor</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Friend</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

Live with ADRD patient prior to Rehab?

<table>
<thead>
<tr>
<th>Yes</th>
<th>20 (74.1%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>7 (25.9%)</td>
</tr>
</tbody>
</table>

Hours/day providing direct care prior to rehab

<table>
<thead>
<tr>
<th>&lt;1</th>
<th>11 (40.7%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>5 (18.5%)</td>
</tr>
<tr>
<td>4-6</td>
<td>2 (7.4%)</td>
</tr>
<tr>
<td>7-9</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>&gt;10</td>
<td>9 (33.3%)</td>
</tr>
</tbody>
</table>
How often did you see the ADRD patient in rehab

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least once a day</td>
<td>23</td>
<td>85.2%</td>
</tr>
<tr>
<td>At least once a week</td>
<td>4</td>
<td>14.8%</td>
</tr>
<tr>
<td>At least twice a month</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Once a month</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>I don’t know</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>

Hours a day providing direct care in rehab

<table>
<thead>
<tr>
<th>Hours Range</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1</td>
<td>4</td>
<td>14.8%</td>
</tr>
<tr>
<td>1-3</td>
<td>12</td>
<td>44.4%</td>
</tr>
<tr>
<td>4-6</td>
<td>3</td>
<td>11.1%</td>
</tr>
<tr>
<td>7-9</td>
<td>5</td>
<td>18.5%</td>
</tr>
<tr>
<td>&gt;10</td>
<td>3</td>
<td>11.1%</td>
</tr>
</tbody>
</table>

Note: N = 27. ADRD = Alzheimer’s disease and related dementias.