PREDICTORS OF ATTRITION IN LATINO ALZHEIMER’S DISEASE CAREGIVERS IN THE REACH TRIAL: AN ARCHIVAL INVESTIGATION

By

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To my parents, mami & papi, with love
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Progressive memory disorders are becoming a national epidemic. It is estimated that 75% of persons with memory disorders are cared for informally, at home, by a friend or family member. Caring for someone with cognitive impairment is a demanding and challenging responsibility that places tremendous strain on families. Due to the changing demographics in the composition of the U.S. population, it is expected that a significant proportion of elders with dementia and their caregivers will be of diverse backgrounds.

Latinos, the largest and fastest growing segment of the U.S. population, are expected to account for 25% of the dementia-affected cohort; however, little is known about Latino dementia caregivers. Recruiting and retaining Latinos into research studies continues to be a challenge for investigators. This study was a secondary analysis of the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) trial, a multi-site randomized trial that developed and tested the effectiveness of multiple interventions for family caregivers of persons with Alzheimer’s disease and related disorders. The focus of this study was to identify variables associated with attrition from the REACH trial in Latino participants at the Palo Alto and Miami sites. Six variables (i.e., age, educational level, income, depression score, social support, and health status) believed to predict attrition (i.e., drop-out status) of Latino dementia caregivers from the REACH trial were
examined. None of these variables were predictive of attrition for these two samples. Although the outcomes of this study did not contribute new information concerning which socioeconomic, demographic, and client factors are associated with the attrition of Latino dementia caregivers from the REACH trial, these findings indicate some trends and thus contribute to the existing literature on Latino dementia caregivers and serve to inform future research studies.

The understanding of the variables examined in this study are embedded in the cultural context, thus, it is recommended that future inquiries into Latino dementia caregivers allow for the measurement of cultural considerations. Due to the archival nature of this inquiry, the hypotheses in this study were not powered sufficiently to test the relationship of the variables of inquiry and data were not purposefully collected.
Progressive memory disorders, such as Alzheimer’s disease (AD), cardiovascular dementias, and many other related disorders, are becoming a national epidemic. Progressive memory disorders refer to a cluster of conditions that worsens over time, negatively impacts the brain, and impairs the functioning of individuals. Currently, it is estimated that there are more than 5 million people living with Alzheimer’s disease in the United States (Alzheimer’s Association, 2007; USA Today, 2007) and this number is expected to more than double in the coming years. In Florida, over 479,875 individuals are believed to suffer from Alzheimer’s disease (Department of Elder Affairs, 2006). As Alzheimer’s disease and related disorders continue to affect increasing numbers of people, it is estimated that a larger proportion of those will be culturally or ethnically diverse. Many of these individuals will be of Latino origin.

The terms Hispanics and Latino are frequently used interchangeably and refer to a heterogeneous group that share Spanish as a common language. This study used the term Latino rather than the term Hispanic, as Latino is an inclusive term that has been used by people of Latin/Hispanic descent to empower themselves in political arenas, humanities, and literature (Oboler, 1995; Shorris, 1992; Torres, 2004; Torres-Rivera, Wilbur, Roberts-Wilbur, & Phan, 1999).

Perhaps the biggest impact of Alzheimer’s disease (AD) is on the family and other caregivers. Due to the debilitating nature of progressive memory disorders (e.g., AD), individuals affected by these types of ailments require increasing assistance with daily living skills and close supervision. The majority of individuals suffering from Alzheimer’s disease receive care at home. The Family Caregiving Alliance (2001) reports that 34 million adults, or 16 percent of the population, provide care to adults 50 years of age or older. This type of unpaid
caregivers is referred to as informal or family caregivers. Statistical data provided by the Alzheimer’s Association (2005) indicate that seven out of ten people with Alzheimer’s disease live at home in the care of family or friends. According to Schulz (2000), this translates into over 5 million households in the U.S. providing care for a loved one with dementia.

A review of the caregiving literature shows that the terms caregivers and caregiving are broadly defined and refer to providing a wide range of care and assistance. These range from providing care with activities of daily living such as personal hygiene, toileting, eating, assisting with other routines such as managing money or assets, to providing total care to individuals who are not able to function independently (Gallagher-Thompson, Coon, Solano, Amber, Rabinowitz, & Thompson, 2003; National Alliance for Caregiving & American Association of Retired Persons, 2005; Family Caregiver Alliance, 2001; Shultz, 2000).

The demands associated with providing care to a person with chronic medical conditions such as Alzheimer’s disease and related disorders may place a significant burden on caregivers. Research findings show that due to the complex deficits of a person with dementia (i.e., declines in intellectual functioning and self-care behaviors, personality changes, and problematic behaviors), caregivers of persons with Alzheimer’s disease and related disorders experience higher levels of stress and a number of additional negative outcomes such as poor health, depression, and emotional strain (Argimon, Limon, Vila, & Cabezas, 2004; Family Caregiver Alliance, 2001; Haley, Levine, Brown, & Bartolucci, 1987; Gallagher-Thompson, Coon, Solano, Ambler, Rabinowitz, & Thompson, 2003; Gallagher-Thompson et al., 2003; Mitrani et al., 2006; Schulz & Beach, 1999).

**Scope of the Problem**

The Alzheimer’s Association (2004) reports that Latinos have a greater risk of developing Alzheimer’s disease and related disorders. In Florida, the Department of Elder
Affairs estimates that there are currently over 34,000 Latinos diagnosed with Alzheimer’s disease (electronic communication, September 29, 2006). By 2050 the Alzheimer’s Association (2004) estimates that over one million Latinos nationwide will be afflicted with this devastating illness. Alzheimer’s disease, the most common progressive memory disorder, is an irreversible condition that adversely affects the intellectual functioning of the brain and eventually results in major thinking and physical impairments as well as changes in personality. As the number of persons affected with this devastating illness increases, so does the number of informal caregivers helping a loved one with Alzheimer’s disease.

Two demographic trends contribute to the growing numbers of people with Alzheimer’s disease in the Latino population. First, the natural chronological process of aging appears to be a strong risk factor for Alzheimer’s disease. There has been a remarkable increase in life expectancy over the last century. In addition, the number of older individuals is steadily rising. By 2011, the first wave of adults in the baby boomer generation (born between 1946 -1964) will turn 65 years of age (Center for Health Communication Harvard School of Public Health & MetLife Foundation, 2004). As the U.S. population ages, the Alzheimer’s Association (2004) estimates that by age 65, one out of every ten persons will develop Alzheimer’s disease. Additionally, by age 85, one out of every two persons will develop Alzheimer’s disease (Evan et al., 1989). As the incidence of Alzheimer’s disease rapidly increases with the numbers expected to more than double by the year 2050, upwards of sixteen million people will be affected (Alzheimer’s Association, 2004). If these predictions come true, Alzheimer’s disease is likely to become a devastating clinical and public health issue over the next 20 years.

The second change is the sudden increase of Latinos in the United States. The recent growth of the Latino population in the United States is one of the most dramatic demographic
increases that has taken place in the history of the United States. No other racial or ethnic groups have had as great an impact on the demography of the United States over the last century as Latinos. The Pew Hispanic Center (2005) reports that “the 2000 Census marked the [Latino] population at 35.3 million people, an increase of 58 percent over 1990 (p.2).” Moreover, they predict that by the end of this decade, there will be over 47 million Latinos in the U.S. and over 60 million by 2020. Furthermore, it is estimated that by the year 2050, one out of every four Americans will be of Latino heritage.

The combination of these two changes is significant because according to the 2000 census, Latinos are the fastest growing segment of the general population as well as the fastest growing group of elders 65 years of age and older. Latinos make up almost ten percent of the total baby boomer generation (Metropolitan Life Insurance Company, 2005). Projections indicate that by the year 2050, there will be 12.5 million Latinos elders 65 and older in the U.S. (Gallagher-Thompson, Solano, Coon, & Areán, 2003). These numbers are significant due to the growing needs of elders and the higher risk of developing Alzheimer’s disease in the elder population. Thus, the health care community will need to be able to meet the needs of this growing segment of the population, especially the needs of caregivers, in order for them to continue providing the vast majority of care for their elders suffering from Alzheimer’s disease.

**Statement of the Problem**

Due to the high incidence of Alzheimer’s disease in ethnic minority elders, the prevalence of informal caregivers is on the rise. The Alzheimer’s Association (2004) reports that Latinos are believed to be at a greater risk of developing progressive memory disorders due to a higher incidence of cardiovascular disease, believed to be a significant risk factor for cardiovascular dementia and Alzheimer’s disease. Sociodemographic factors such as lower education and limited access to health care, also are believed to be risk factors for Alzheimer’s
disease. As the numbers of Latino elders continue to climb, so does their need for care. Although reliable estimates are difficult to find, current estimates by the Alzheimer’s Association (2004) indicate that close to 200,000 Latinos nationwide suffer from Alzheimer’s disease and related disorders. These data illustrate the importance of continuing efforts to advance knowledge about the sequelae of Alzheimer’s disease and underscore the need to include culturally diverse groups in the investigation in order to develop effective methods to meet their needs. However, a review of the literature shows that although minorities, specifically Latinos, are the fastest growing segment of the population, they continue to be underrepresented in research studies. Furthermore, the studies that have been successful at recruiting and retaining Latino caregivers show mixed results.

Although there has been a boom in research studies on Alzheimer’s disease over the last decades and efforts have been put forward to include culturally diverse populations, there continues to be a gap in the literature on how this disease affects minority populations and their families. One of the main problems associated with the paucity in research studies with minority populations involves failures to recruit and retain older members of minorities into research studies. Researchers maintain that this is particularly true for Latino caregivers due to the stigma associated with mental illness and the time consuming and labor intensive burden placed on them (Areán, Alvidrez, Nery, Estes, & Linkins, 2003; Gallagher-Thompson, Solano, Coon, & Areán, 2003). The steady increase of Latinos in the U.S. warrants the need to examine the Alzheimer’s disease caregiving experience of this segment of the population as well as the barriers to accessing services.

As the prevalence of Alzheimer’s disease and other progressive memory disorders grows exponentially over the next decades, it will compromise the already strained healthcare system,
the long-term care system, and the economy. Due to the high incidence of Alzheimer’s disease in the Latino community and the lower rates of health insurance coverage and healthcare-seeking behaviors in this community, it is imperative for health care professionals to understand how cultural values and beliefs affect the willingness of family caregivers to seek and maintain connections for help in order to minimize the negative impact of Alzheimer’s disease on patients, families, the healthcare system, and society at large. Though seeking help is an important research issue, this study focused on the problem of barriers to retention, more specifically, the barriers of retaining informal Latino Alzheimer’s disease caregivers in research studies.

**Need for the Study**

Research studies persistently show that while the numbers of Latino families affected by Alzheimer’s disease continue to grow, researchers have not been able to recruit and retain proportional numbers of Latino Alzheimer’s disease patients and caregivers in studies. By 2010, it is expected that “ethnoculturally diverse persons will represent 25% of the dementia-affected cohort and by 2050 they will number 33%, as compared to 16.7 % of the total dementia-affected elderly population in 2000” (Valle & Lee, 2002, p. S64). If the predictions come true, this illness is likely to become a devastating clinical and public health issue over the next decades.

Studies show that Latinos seek health services at a much lower rate compared to other groups despite their high incidence of cardiovascular disease and related illnesses (Alzheimer’s Association, 2004; Larkey, Hecht, Miller, & Alatorre, 2001; Liao, Tucker, & Giles, 2004). Despite the rapid growth of the Latino population, public sector responses to the health service needs of this population have developed slowly and do not commensurate with the growth, needs, and grim circumstances of the population. In addition, the Kaiser Family Foundation (2003) reported that Latinos have the lowest insurance rates when compared to other racial groups in the U.S. The gap in health insurance coverage is due in part to the disadvantaged
economic position of ethnic groups with a greater toll on Latinos (Center for Studying Health System Change, 2004). Research findings show that the Latino population in the U.S. is not receiving appropriate health care necessary to reduce the risk or manage progressive memory disorders. Professional groups, such as the Alzheimer’s Association (2004) warn that ignoring the threat of dementia in the Latino community may lead to a health crisis for this segment of the population in the United States. These discrepancies have maintained the vast racial and ethnic disparities in Latino access to health care.

Therefore, due to the rapid increase in Latino elders and the alarming incidence of progressive memory disorders (e.g., Alzheimer’s disease), it is imperative that health care professionals identify barriers to recruitment and retention of Latinos into research studies and subsequent treatment protocols necessary for improving the delivery of healthcare services to the Latino population and thus, bridge the gap in health disparities. Unfortunately, research studies tend to place an inordinate burden on already taxed research participants. Therefore, it is necessary to advance the current knowledge about how the burden of measurement and barriers to participation contribute to attrition from existing research studies. Also, it is vital to revise current procedures into culturally sensitive and appropriate new research and applied practices.

Purpose of the Study

Due to the changing demographics of the U.S., especially the fast growing rate of Latinos and the silver tsunami (Fryling, 2006) that is starting to take place, it is imperative to explore these changes and the implications to the health care system and society at large in order to advance our understanding about barriers to providing care in the Latino community. The need for scientific examination about the obstacles in recruiting and retaining minority participants into research studies has been well documented (Areán, Alvidrez, Nery, Estes, & Linkins, 2003; Gallagher-Thompson et al., 2003; Warren-Findlow, Prohaska, & Freedman, 2003). Thus, it is
important to identify the factors that predict the attrition rate from research studies in order to gain a better understanding about how these influence the attitudes of Latino Alzheimer’s disease caregivers on accessing and utilizing services. This knowledge is needed in order to bridge the gap in health and health care disparities among Latino Alzheimer’s disease caregivers.

This study examined the barriers of retention, more specifically retaining Latino Alzheimer’s disease caregivers in research studies. Data collected for the Miami, FL, and Palo Alto, CA, sites of the Resources for Enhancing Alzheimer’s Caregiver Health, also known as the REACH I study, were analyzed to examine and contrast attrition rates among two different sets of Latino Alzheimer’s disease caregivers. This researcher was interested in identifying the factors that may contribute to Latino Alzheimer’s disease caregivers prematurely dropping out of research studies that may yield subsequent treatment approaches to improve the well-being of both the Alzheimer’s disease caregiver and the care recipient.

Theoretical Framework

This study used a combination of two stress process models to guide its inquiry. First, it borrowed the stress process model used in the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) study. The REACH study (Czaja, Schulz, Lee, & Belle, 2003) adapted a stress process model of caregiving to include environmental stressors to health outcomes in dementia caregiving. According to the investigators, this model establishes that the functional limitations and behavioral problems of the care recipient in conjunction with social and environmental stressors make up the primary stressors for dementia caregivers. As caregivers engage in their caregiving responsibilities, they perceive and identify stressors associated with caregiving. Then they evaluate these demands, as well as their ability and resources to meet these demands. If the caregivers feel helpless and unable to cope with these demands, they experience stress. “The appraisal of stress is assumed to contribute to negative emotional, psychological, and behavioral
responses that put the individual at risk for physical and psychiatric disease” (Czaja et al., 2003, p. 386).

The second relevant stress process model is the one advanced by Haley, Levine, Brown, and Bartolucci (1987) that proposed a model adapted from the stress response model to explain caregivers’ help-seeking behaviors. According to the authors, caregivers’ appraisal of stressors, personal coping responses, and social support, mediate between stress and caregiver outcome. “Use of coping mechanisms such as seeking information, using problem solving, and emotional release may also help the caregiver to manage his or her relative more effectively, and lessen emotional distress” (Haley et al., 1987, p. 323). If caregivers have access to and use available resources, they may increase the probability of obtaining better outcomes in coping with the chronic stress of caregiving. These stress and coping models are useful in the conceptualization of the process of dementia caregivers’ participation in research studies and their utilization of services. Once stressors and the caregivers’ assessment of these are identified, they may be changed or modified (Schulz et al., 2003).

**Overview of the Resources for Enhancing Alzheimer’s Caregiver Health Study**

The Resources for Enhancing Alzheimer’s Caregivers Health (REACH) was a 5-year, multi-site research project conducted with support from the National Institutes on Aging and the National Institute of Nursing Research. Six sites, including Birmingham, Boston, Memphis, Miami, Palo Alto, and Philadelphia, developed and tested the effectiveness of multiple interventions for family caregivers of persons with Alzheimer’s disease and related disorders. Each site investigated a different intervention or a combination of interventions. The interventions included (1) individual information and support strategies, (2) group support and family systems therapy, (3) psychoeducational and skills-based training approaches, (4) home-based environmental interventions, and (5) enhanced technology support systems. “REACH was
designed to examine the feasibility and outcomes of multiple different intervention approaches, . . .” (Schulz et al., 2003). A total of 1,222 participants were recruited with a strong emphasis on recruiting minority caregivers. For the purpose of this study, only data collected from the Miami and Palo Alto sites were examined.

**Hypotheses**

This study was a secondary analysis of a multi-site prospective randomized controlled trial in which data collected from the REACH project were used to examine predictors of attrition of Latino Alzheimer’s disease (AD) caregivers from research studies. Data used for this examination included (1) caregiver’s age, (2) caregiver’s level of education, (3) income, (4) depression, (5) social support, (6), caregiver health, and (7) attrition rate.

**The following six null hypotheses were tested in this study:**

- Ho1: There is no relationship between attrition drop-out status (attrition) and Latino caregivers’ age.
- Ho2: There is no relationship between drop-out status (attrition) and Latino caregivers’ achieved level of education.
- Ho3: There is no relationship between drop-out status (attrition) and Latino caregivers’ income level.
- Ho4: There is no relationship between drop-out status (attrition) and depression among Latino caregivers as measured by Center for Epidemiologic Studies Depression Scale (CES-D).
- Ho5: There is no relationship between drop-out status (attrition) and social support among Latino caregivers.
- Ho6: There is no relationship between drop-out status (attrition) and Latino caregivers’ health status as measured by the Caregiver Health and Health Behaviors Questionnaire from the REACH study.
Definition of Terms

**Alzheimer’s disease.** A progressive brain disorder that impairs a person’s intellectual functioning, that is, memory and the person’s ability to learn, reason, and communicate. It also impairs the person’s judgment, behaviors, and eventually, the ability to care for self (Alzheimer’s Association, 2006).

**Dementia.** An acquired set of symptoms that negatively affect a person’s intellectual functioning such as thinking, memory and judgment (Alzheimer’s Caregiver Support Online, 2006).

**Progressive memory disorders.** Refers to disorders of the brain, such as Alzheimer’s disease (AD), that cause worsening of a person’s intellectual abilities over time (Alzheimer’s Caregiver Support Online, 2006).

**Reach study.** A 5 year study conducted in six cities across the U.S to measure the effectiveness of different dementia caregiver interventions (Schulz et al., 2003).

**Silver tsunami.** A term used by many to describe the tidal wave of baby boomers that is about to have a significant societal impact (Fryling, 2006).

**Overview of the Remainder of Study**

The remainder of this study consists of four chapters. Chapter 2 provides a review of the related literature. Chapter 3 contains a description of the specific procedures for the study, including methodology, subjects, and research design. In Chapter 4, the results of the study are presented. Chapter 5 includes a discussion of the results, conclusions, implications, limitations, and recommendations for future research.
CHAPTER 2
REVIEW OF RELEVANT LITERATURE

The purpose of this chapter is to review the published literature pertinent to the proposed investigation. This chapter is organized into seven sections: (a) attrition rates and Latinos, (b) Latino caregivers’ age, (c) Latino caregivers’ level of education, (d) Latino caregivers’ income, (e) Latino caregivers’ depression, (f) Latino caregivers’ social support, (g) social support of Latino Alzheimer’s disease caregivers and (h) Latino caregivers’ health status.

As the U.S population grows older and more diverse, Latinos are becoming one the fastest growing segments of the population. According to the 2000 U.S. Census, (U.S. Census Bureau, 2001) the Latino population has increased dramatically over the last decade, becoming the largest minority group in the country. Census estimates indicate there are over 35 million Latinos living in the U.S. Of those, the U.S. Administration on Aging (2004) reports 4% are Latino elders 65 years of age and older and projects that by 2020 this percentage will increase to over 14%. By 2025, one in six elders living in the U.S. are expected to be Latinos (Horizon Project, 2000) and by the year 2050, Latinos 65 years of age and older will reach the 12.5 million mark (Gallagher-Thompson et al., 2003). Current estimates indicate that 44% of Latino elders seventy and older receive care at home by a family member or friend (Weiss, Gonzalez, Kabeto, & Landa, 2005).

The graying and diversification of the U.S. demographics are noteworthy due to high incidence of chronic conditions, such as Alzheimer’s disease, in this segment of the population (Weiss, Gonzalez, Kabeto, & Langa, 2005). The Alzheimer’s Association’s (2004) projects an increase from 200,000 Latinos with Alzheimer’s disease to over 13 million by 2050. There is a common misconception that most elders who require long-term care receive assistance from formal caregiving facilities, such as nursing homes; however, estimates indicate otherwise. Over
75% of long-term care for disabled adults takes place at the home of a family member or friend (Family Caregiving Alliance, 2001; Gallagher-Thompson et al., 2003). Currently, it is estimated that 44% of Latinos 70 years of age and older receive informal care at home (Weiss et al., 2005). As the Latino population continues to expand and grow older, so will the number of informal Latino caregivers.

Alzheimer’s disease is a devastating illness that adversely impacts the lives of patients and family caregivers alike. Alzheimer’s disease caregivers assume challenging responsibilities, for example, assisting the patient with activities of daily living such as grooming, toileting, and bathing. Often times, caregivers also engage in activities that involve role reversals such as managing the finances for a parent, preparing a meal for a wife, or driving a husband to medical appointments. In addition, caregiving responsibilities are time consuming. Thus, often caregivers will neglect their own needs (Miller & Mukherjee, 1999; Cox & Monk, 1996), health (Gallagher-Thompson, 2003; Pinquart & Sorensen, 2005), and social relationships (Cox & Monk, 1996). Curry and Jackson (2003) report that compared to White caregivers, Latino caregivers are more likely to care for a family member instead of caring for a friend. The implications of providing care for someone with a chronic condition are significant. Research findings suggest that compared to other racial groups, Latino caregivers provide more hours of informal caregiving (Weiss et al., 2005) and care for longer periods of time (Pinquart & Sorensen, 2005).

Consistent research findings suggest that Latino families have higher rates of caregiving at home for persons with Alzheimer’s disease than any other groups (Covinsky, Newcomer, Fox, Wood, Sands, Dane, & Yaffe, 2003; Markides, Rudkin, Angel, & Espino, 1997), despite higher levels of physical and psychological distress associated with the physical and cognitive
limitations of the patient. These numbers are significant because providing care for a person with Alzheimer’s disease has been associated with negative caregiver outcomes such as poor health, higher levels of depression, and decreased support (Gallagher-Thompson, 2003), in addition to increased mortality (Schulz, O’ Brien, Bookwala, & Fleissner, 1995; Schulz, Visintainer, & Williamson, 1990).

The existing literature on how Alzheimer’s disease impacts the lives of culturally diverse persons and their participation in research studies is scarce compared to the available literature on Whites. Inclusion of psychosocial and cultural variables such as age, socio-economic status, educational attainment, health-status, and social support are crucial to understand the impact of Alzheimer’s disease on the Latino population. When looking at these psychosocial and cultural variables, two important considerations need to be noted: first, differences among groups and second, degree of acculturation.

First, it is important to be cognizant of the differences among Latino groups in order to develop appropriate studies and interventions. Although these groups share many psychosocial characteristics, differences among groups and their needs have been documented (Briones, Ramirez, Guerrero, & Ledger, 2002; Gallagher-Thompson, Solano, Coon & Areán, 2003; Valle & Lee, 2002). Acculturation to mainstream society also has significant implications for families caring for relatives with progressive memory disorders (Gallagher-Thompson et al., 2003; Valle & Lee, 2002). While these differences warrant careful examination, well-designed research studies including Alzheimer’s disease patients and their families across these cultures will add to the knowledge base regarding the disease and its implications for Latino groups.

**Attrition Rates and Latinos**

It is well documented that members of diverse groups are underrepresented in research studies (Areán, Alvidrez, Rowena, Estes, & Linkins, 2003; Areán & Gallagher-Thompson, 1996;
Curry & Jackson, 2003; Gallagher-Thompson, Solano, Coon, & Areán, 2003). The significance of this issue was underscored in 1994 when the National Institutes of Health (NIH) issued guidelines for the inclusion of minority participants in clinical research trials (Curry & Jackson, 2003). Although there has been a boom in research studies on the impact of Alzheimer’s disease over the last decades, and efforts have expanded to include culturally diverse populations, there continues to be a gap in the literature on how this disease affects minority populations and their families. At the forefront of this issue is the failure to recruit and retain Latino caregivers into research studies. The inability to recruit and retain Latino caregivers in research studies has a detrimental effect on the ability of health care professionals to develop informed, culturally relevant programs to assist and alleviate the burden associated with caregiving. Furthermore, current findings that lack adequate numbers of ethnic participants cannot be generalized to the population without questioning the validity of the researchers’ conclusions (Levkoff & Sanchez, 2003). Few studies report successful implementation of recruitment and retention methods with older populations (Areán, Alvidrez, Rowena, Estes, & Linkins, 2003; Gallagher-Thompson, Solano, Coon, & Areán, 2003).

Areán and associates (Areán et al., 2003) examined recruitment and retention rates in two separate studies on older minority populations in order to compare the traditional recruitment and retention methods with a consumer-centered approach. They found that the mainstream older research participants tend to respond positively to traditional recruitment and retention methods that focus on eliminating practical barriers to research studies such as offering transportation to and from the research site as well as financial incentives. Ethnic older adults responded more favorably to the consumer-center recruitment model, which also resulted in greater retention rates. This model proposes that in order to successfully attract the participation of minority
elders into research studies, the following conditions must be met: securing the support and buy-in from local community leaders; enlisting research staff that either knows or belongs to the same ethnic group as the target population; anticipating and alleviating participants’ burden associated with the research study; and providing feedback to the community once the study is completed.

In a recent study by Gallagher-Thompson and colleagues (2004) aimed at comparing the effectiveness of three different recruitment methods among White and Latino female caregivers, results were consistent with the prior conclusions that favored consumer-centered methods over traditional approaches. The authors believe that the Latinos’ cultural values of trust (confianza) and close relationships (personalismo) demand the development and establishment of consumer-centered recruitment and retention methods derived from partnerships with local Latino-specific organizations.

Others such as Henderson, Gutierrez-Myka, Garcia, and Boyd (1993) have put forward similar efforts and developed a program to recruit minority caregivers to participate in existing support groups for Alzheimer’s caregivers who had no minority representation. This effort consisted of the following: training group leaders about culturally diverse populations; conducting purposeful advertisement and promotion using the media, presentations, and endorsement from community professionals and organizations; and using appropriate meeting locations. The authors indicated that 24 months later, attendance by African Americans and Hispanics rose dramatically. In addition, a meta-analysis on the effectiveness of interventions with caregivers has some significant revelations. According to Sorensen, Pinquart, and Duberstein (2002) the average drop-out rate across the 78 studies they reviewed was less than
20%, and most caregivers had at least a high school education, and were ethnic spouses or adult children.

Many explanations have been offered regarding the dismal participation of Latinos in research studies including mistrust of ethnic groups toward the scientific community, language barriers, and the burden placed on research participants (Areán et al., 2003; Gallagher-Thompson et al., 2003; Levkoff & Sanchez, 2003). However, caregiver-specific factors such as age, educational attainment, income level, depression, social support, and health status variables are also believed to influence the limited participation, more specifically the drop-out rate of Latinos in research studies. Currently, there is little information about how these psychosocial factors (i.e., caregiver age, achieved educational level, health status, level of depression, and social support) affect Latino caregivers’ participation in long-term research studies (Covinsky, Newcomer, Fox, Wood, Sands, Dane, & Yaffe, 2003). The results of studies with Latinos from different countries of origin need careful consideration due to the heterogeneity among Latino participants.

**Latino Caregivers’ Age**

It is estimated that, by the year 2050, the number of Latino elderly could reach twelve million persons, representing 15% of all Latinos living in the U.S. The age demographics of dementia caregivers seem to be in flux. A study by Schulz and Beach (1999) found that most caregivers are middle-aged adult children and spouses caring for a parent or spouse. In 2001, the Family Caregiver Alliance reported that the average age for caregivers of persons 50 years of age and older was 47 and the average age of caregivers of persons 65 and older was 63 years old. More recently, an Alzheimer’s Association (2004) publication about Alzheimer’s caregiving in the U.S indicates that the average age for an Alzheimer’s disease caregiver is 48 years old and that most caregivers provide care for an older relative.
A comprehensive inquiry into caregiving in the U.S. conducted by the National Caregiving Alliance and the American Association of Retired Persons (2005) estimates that over 44 million caregivers 18 years of age and older in the U.S. provide unpaid care to an adult family member or friend who is also 18 or older. Of these, 8% of all caregivers reported caring for someone with Alzheimer’s disease; 16% of caregivers are 50 years and older and an estimated 12% are Latinos.

A paucity of research studies look at the relationship between age and the Latino caregivers’ attrition rate from such studies. The limited available published studies show mixed results concerning the association between age and attrition rates in Latino research participants. Therefore, the present review of the literature examined the effects of age on attrition rates in other areas and other segments of the population. This approach identified several studies across racial and ethnic groups reporting an inverse relationship between age and drop-out rate (Honas, Early, Frederickson, & O’Brien, 2003; Warren-Findlow, Prohaska, & Freedman, 2003). A study on recruitment and retention of HIV participants found that younger Latino males were less likely to follow through with the research study (Villarruel, Jemmott, Jemmott, & Eakin, 2006). The investigators believed that conflict with job schedules and residency status mediated their results. Research studies in other areas consistently reported low participation of elder individuals in research studies, (Mirowsky & Reynolds, 2000; Murthy, Krumholz, & Gross, 2004; Cotter, Burke, Loeber, & Mutchka, 2005).

It appears that the ability of older caregivers to participate in research studies is influenced by factors such as knowledge about progressive memory disorders such as Alzheimer’s disease, health status, perceived burden associated with research involvement. Also influential are practical issues such as transportation, taking time off from work, and the
availability of another person to tend to the care recipient. These inferences are drawn from the existing literature on age and participation in research studies.

**Latino Caregivers’ Level of Education**

The U.S. Administration on Aging maintains that when compared to other groups, Latino adults have less formal education (2005). The study on Caregiving in the U.S. conducted by the National Caregiving Alliance and the American Association of Retired Persons (2005) shows that 29% of all caregivers have a high school education, 30% have some college education, and 35% are college graduates. A report by Schulz (2000) suggests that the median education of dementia caregivers is some college, the same as for the non-dementia caregivers. In 2004, the Alzheimer’s Association published a report indicating that almost 40% of dementia caregivers were college graduate; 25% had some college education, and 37% had a high school diploma or less schooling.

Due to the lack of studies aimed at measuring the relationship between educational level and Latino caregivers’ participation in research studies, some researchers infer that Latino caregivers have lower educational attainment when compared to other groups. The basis for this inference appears to be the poor understanding of Latinos about Alzheimer’s disease and other progressive memory disorders (Coon, Gallagher-Thompson, & Thompson, 2003; Schulz, 2000). However, making this assumption is problematic because the poor understanding may reflect their language differences and cultural beliefs about health and illness.

An examination of the literature on other ethnic caregivers found mixed results regarding recruitment and retention of African American into research studies. A study on recruitment and retention of underrepresented populations, specifically African Americans, into health promotion research, found that persons under 60 were less likely to enroll in their study (Warren-Findlow, Prohaska, & Freedman, 2003). The authors believed that the higher drop-out rate of younger
participants was related to lower educational levels, whereas other publications indicate that African Americans are highly suspicious of research due to a long history unethical medical and research protocols (Blakley & Harrington, 1997; Doty, 2007; Jonas, 1993; Ludmerer, 1999). Although this study did not include Latino participants, research findings like this may impact future researchers investigating the relationship between attrition rates and Latino caregivers.

**Latino Caregivers’ Income Level**

Lower educational level is typically associated with lower income. The Horizon Project (2000) reports that Latino elders are less well-educated than and more likely to live in poverty. The project estimates that 21% of Latino elders in the U.S. live at or below the federal poverty level compared to Whites. This study also reports that when compared to Whites, Latino elders are less likely to receive social security income. These findings are alarming considering the financial burden on caregivers who already struggle with a taxing financial situation.

The cost to government agencies for the care of patients who have Alzheimer's disease is substantial at present and it is rising rapidly (Prigerson, 2003). However, most of the cost is absorbed by the unpaid family caregiver. The unpaid portion accounts for a large proportion of the costs of treating the patient. Family caregivers spare the health care system billions of dollars annually, but depression, stress, and weakened physical health in these caregivers, if left untreated, come not only at a great personal cost to the caregivers and their families but potentially at a substantial financial cost to society. The negative impact on the health of dementia caregivers and the restricted ability to be away from the care recipient negatively impacts the caregiver’s limited resources as well as their earning potential. Specific to Latino elders, their lower educational accomplishments, English proficiency, and work experience negatively influence their financial attainment. Limited financial resources typically translate
into inability to pay for companionship services, professional assistance, and even transportation. These restrictions may in turn hinder the caregivers’ ability to participate in research studies.

**Depression in Latino Caregivers**

Depression in later life has been identified as one of the most common mental health problems affecting elders (Abu-Rayya, 2006; Blazer, 2003). Bourgeois, Schulz, and Burgios (1996) highlighted the risks associated with the negative consequences of depression in caregiver health when they reported that caregiver depression is correlated to decreased function and quality of life, and even death among caregivers. Majerovitz (2001) reports that caregivers who perceive the availability of social support report lower levels of depression associated with caregiving stress. Although research findings report mixed results about depression in Latino caregivers (Janevic & Connell, 2001), most research findings suggest that the prevalence of depression in Latino caregivers is equal or greater than found in other caregiver groups. (Aranda, 2001; Schulz, 2000).

The combination of poor health and limited financial resources also has been linked to higher rates of depression (Covinsky, Newcomer, Fox, Wood, Sands, Dane, & Yaffe, 2003). Since Latino caregivers tend to have lower financial resources and compromised health, it is not surprising that they are also believed to have higher rates of depression. Weiss, Gonzalez, Kabeto, and Langa (2005) found that older Latinos have a significant higher risk of depression than White or African American caregivers. Coon, Gallagher-Thompson, and Thompson (2003) maintain that the relationship between high levels of depression and adherence to traditional cultural norms is linked to the caregivers’ feelings of helplessness and difficulty managing problematic behaviors.

In an examination of patient and caregiver characteristics associated with caregiver depression, Covinsky and colleagues (2003) found that Latino caregivers reported significant
higher levels of depression when compared to Whites or Blacks. Despite higher levels of depression, this study found that Latinos were more reluctant to place their loved one in a facility compared to caregivers from other groups. Placement of a loved one with Alzheimer’s disease appears to be more consistent with White conventions rather than Latino values such as the importance of family and mutual assistance known as familismo despite the toll on family caregivers (Schulz, 2000).

A study measuring the relationship between racial or ethnic concordance between caregiver and researcher on caregivers’ attrition, depression, and burden found no significant difference in caregiver drop-out at the 12-month follow-up (McGinnis, Schilz, Stone, Klinger, & Mercurio, 2006) regardless of concordance of race or ethnicity. No additional studies examining the relationship between Latino caregivers, depression, and participation in research studies were available at the time of this review. However, due to the demands placed on research participants, it may be inferred that depressed caregivers are less likely to follow through with research protocols if they feel the involvement increases the amount of burden they already experience (Coon, Rubert, Solano, Mausbach, Kraemer, Arguelles, Haley, Thompson, & Gallagher-Thompson, 2003; Eisdorfer, Czaja, Loewenstein, Rubert, Arquelles, Mitrani, & Szapocznick, 2003; Miranda, Azocar, Organista, Muñoz, & Lieberman, 1996).

**Social Support and Latino Caregivers**

Responsibilities associated with caring for someone with a chronic illness may disrupt caregivers’ social networks. Caregivers usually obtain social support from two main sources, 1) informal networks such as family and friends and 2) formal services from community organizations. Both sources of social support may alleviate the strain associated with caregiving. While informal support is believed to lessen the negative consequences of caregiving (Miller, Townsend, Carpenter, Montgomery, Stull, & Young, 2001) there are mixed results on the
relationship between social support and levels of distress among caregivers. Cohen, Boyle, Coakley, and Lawlor (2002) found that lack of social support in conjunction with limited financial resources have a negative impact on caregivers. Caregivers from ethnic groups tend to have lower financial resources and health insurance coverage to meet their needs and thus seek formal supports such as day care centers and other programs. Keller, Gonzalez, and Fleuriet (2005) studied issues of recruitment and retention of ethnic women in an exercise program and found that participants who lacked social support did not follow through with the program.

The literature on Latino caregivers of persons with Alzheimer’s disease show that Latino caregivers may be reluctant to seek support for several reasons including limited knowledge about Alzheimer’s disease, the stigma associated with mental illness, feelings of shame, and the Latino cultural value of family pride and mutual assistance or familismo (Coon, Gallagher-Thompson, & Thompson, 2003; Schulz, 2000). Moreover, due to the strong sense of familial obligation in the Latino community, the responsibility of caring for a loved one with progressive memory problems rests primarily in the family, particularly on a female member (Coon et al., 2003). Reliance on help outside the extended family is typically viewed in a negative light. Other factors such as low educational attainment and employment may also contribute to Latino caregivers’ feelings of isolation and limited social support (Dilworth-Anderon & Gibson, 2002).

Informal social support is oftentimes possible because strong family connections are maintained by the close proximity in which Latinos tend to live in regards to their relatives. It is also possible due to their reliance on extended family connections which include members of the extended family, friends, neighbors, and members of their religious groups (Sue & Sue, 1990). Latinos’ strong emphasis on the extended family and their tendency to live in close proximity to relatives provide caregivers with the opportunity for to exchange aid. However, some studies
have found that the close connections typical in the Latino culture may also have negative effects. Lefley (1996) points out that the large social networks of Latinos may become a source of stress in the event of unmet expectations, poor advice, criticism, as well as the strong emphasis on protecting the family’s honor. Semple (1992) reports that interpersonal stress with social networks has negative effects on the well being of caregivers. Furthermore, in a study on the caregiving experience of Mexican-Americans, Phillips, Torres de Ardón, Komnenich, Killeen and Rusinak (2000) found that despite the availability of an extended family system, Latinos perceived that they had limited access to informal support and, therefore, used less support than Whites. The relationship between the availability of social support and Latino caregivers’ participation in research studies has not been documented. However, due to the cultural values of close relationships and privacy, it may be inferred that Latino caregivers with strong social support would not have high rates of participation in research studies.

**Latino Caregivers’ Health Status**

Not only has the drastic growth of the elderly population over the last few decades placed exceptional demands in caregivers and other family members but also on the whole healthcare system. Many researchers have discussed negative physical, mental, and emotional consequences of caregiving (Connell, Janevic, & Gallant, 2001). Others have addressed the impact of caregivers’ inability to cope and the feelings of distress on their overall health (Gallagher-Thompson et al., 2000). Pillemer and Suitor (2002) maintain that the negative outcomes associated with caregiving are heightened for caregivers of persons with Alzheimer’s disease and that poor social support exacerbates these problems. The health of caregivers is influenced by a myriad of factors including age, chronic conditions, physical problems, as well as psychological factors such as emotional well-being and stress. In a report by the U.S. Administration on Aging (2005), the leading disease-related causes of death in the Latino
community included heart disease, cardiovascular disease, and diabetes, among others, all believed to be risk factors for developing Alzheimer’s disease or other related dementias. A study by Corbeil, Quayhagen, and Quayhagen (1999) found that caregivers tend to have negative appraisals of their stress levels compared to non-caregivers. Other findings suggest that many caregivers report having poor health (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002) such as increased rates of high blood pressure and high insulin levels (Cannuscio, Jones, Kawachi, Colditz, Berkman, & Rimm, 2002) and high rates of cardiovascular disease (Lee, Colditz, Berkman, & Kawachi, 2003). The risk associated with chronic disease increases sharply with age (Manton, 1996).

Researchers such as Fox, Newcomer, Yordi, and Arnsberger (2000) maintain that the caregiving responsibilities for a person with Alzheimer’s disease can contribute to the decline of the caregivers’ health. In addition, Schulz and Beach (1999) believe that the negative impact of the combined chronic stress, sense of loss, physical demands, and the biological vulnerability of older caregivers put them at a higher risk of death.

Hinton’s (2002) emphasis on the cultural nature of the caregiving experience stressed that cultural factors impact the caregivers’ perception of the illness, burden of care, ability to cope with caregiving stress, and ability to care properly for themselves. Caregiver burden includes physical, mental, emotional, and financial costs of providing care and close supervision to someone and is accompanied by a negative appraisal of one’s health.

Several factors contribute to the poor health status of Latino caregivers such as the higher prevalence of diabetes (U. S. Department of Health & Human Services, 2005) and cardiovascular disease (Urizar & Sears, 2006). Moreover, the lower socioeconomic status of Latinos has been correlated with poor health. Dilworth-Anderson and Gibson (1999) maintain that the Latinos’
disadvantaged socioeconomic status places them at higher risks for health conditions such as cardiovascular disease and diabetes, which in turn are risk factors for developing cardiovascular dementia, perhaps in combination with Alzheimer’s disease. Weiss, Gonzalez, Kabeto, and Langa (2005) found that older Latinos have a high burden of some diseases and poor self-perceived health and that they are at a higher risk for poor health outcomes due to higher rates of poverty and lower rates of health insurance coverage. When compared to the white population, Latinos are believed to suffer higher rates of morbidity and mortality. Compounding these health disparities are the cultural and linguistic barriers that racial/ethnic minorities encounter when seeking health care. Lack of communication and ease can occur between patient and provider when cultural differences in perceptions of illness, disease, and medical roles are not recognized and addressed, thereby adversely affecting health outcomes. Other barriers include immigration status, discrimination, lack of access to high quality educational opportunities, unavailability of transportation and childcare, and inconvenient and insufficient hours of operation at health facilities. In addition to the existing unfavorable health status in the Latino community, caregiving responsibilities often introduce adverse consequences to caregivers’ health.

**Summary and Conclusions**

Little information exists in the literature about how the person-based variables of age, educational level, income, level of depression, amount of social support, and health status influence the participation and drop-out rates from research studies of Latino caregivers of persons with Alzheimer’s disease. Available literature on drop-out rates for members of diverse groups, more specifically Latino research participants, is scare and suggests mixed results. It appears that due to the changing demographics, many caregivers are adult children caring for a parent. The existing demands from work and nuclear families on adult children caregivers may
prevent them from participating in research studies. Moreover, the relationship between health status and Latino caregivers’ participation in research studies does not appear to have been examined. However, it appears that depressed caregivers might not participate or complete their participation in research studies if they feel that doing so exacerbates their burden. Finally, since Latinos are believed to rely on support from within their networks, it is reasonable to assume that those caregivers with adequate social support will be less likely to participate in studies and, thus, keep their personal affairs within the family unit.

Due to the numerous unanswered questions regarding barriers to research participation in the Latino community, studies examining these barriers are warranted. The existing body of knowledge on predictors of attrition for Latinos occurs mostly in the areas of substance abuse and health promotion research, leaving a sea of opportunities for researchers.
This study was an archival analysis of the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) project; a multi-site prospective randomized controlled trial. The purpose of this investigation was to examine variables identified in the published literature as relevant to the prediction of drop-out status (i.e., attrition) in a sample of Latino Alzheimer’s disease caregivers.

**Resources for Enhancing Alzheimer’s Caregiver Health**

REACH participants were recruited from memory disorder clinics, primary care clinics, community organizations and physicians’ offices. In order to recruit caregivers from diverse populations, REACH investigators used local community media to target these groups. Criteria for inclusion required potential participants to be over the age of 21 and living with and providing care for a relative with Alzheimer’s disease or other memory progressive disorder for at least four hours a day and for a minimum of six months. A total of 1,222 participants were recruited and randomly assigned to an intervention condition. This study only examined the Latino caregivers in the Miami and Palo Alto sites. Assessment instruments, as described by Wisniewski, Belle, Marcus, Burgio, Coon, Ory, Burns, & Schulz (2003) were translated into Spanish for these two samples.

The Miami site (as described by Wisniewski et al., 2003) examined the effectiveness of family-based structural multisystem in-home intervention (FSMII) and a family-based structural multisystem in-home intervention plus a computer telephone integration system (FSMII + CTIS). The FSMII was based on a family systems approach, aimed at improving communication between caregivers and other members of the family by identifying problems in communication.
and facilitating interactions. The FSMII + CTIS was an enhanced version of the FSMII with the additional use of screen phones as a tool to increase interactions among family members.

The Palo Alto site (as described by Wisniewski et al., 2003) examined the effectiveness of the coping with a caregiving class (CWC) and an enhanced support group (ESG). The CWC was a psychoeducational class based on cognitive behavioral theories that demonstrated the consequences of negative thoughts and behaviors in caregivers’ mood. The ESG was a professionally led support group in which caregivers were encouraged to attend regular meetings and commit to participate for one year. Participants in this site were randomized into the intervention group based on language preference and availability.

In addition to two active treatments, each site also included a control condition. Both control conditions consisted of a minimal support condition in which the participants regularly received written educational material and check-in phone calls (Wisniewski et al., 2003). The remainder of this chapter addresses the following topics: 1) sample description and characteristics, 2) variables, 3) null hypotheses, 4) research procedures, and 5) data analysis, and 6) methodological limitations.

**Sample Characteristics**

The sample for this investigation consisted of $N = 223$ Latino Alzheimer’s disease caregivers in the United States. The sample was obtained from the Latino caregivers who participated in two of the six sites in the REACH study: Miami, FL and Palo Alto, CA. The Miami site consisted of $n = 113$ Latino caregivers whereas the Palo Alto site was comprised of $n = 110$ Latino caregivers. Participants were randomly assigned to either the treatment group or control measure.

**Palo Alto Sample.** All 110 participants in the Palo Alto sample were females with a mean age of 51.14 years ($SD = 12.91$). Annual income was measured categorically and ranged from a low
of less than $5,000 to a high of $70,000 or more; the modal income was $15,000 to 19,999. The average level of education achieved was 10.49 years ($SD = 3.99$). Caregivers in this sample had a mean of 35.62 years ($SD = 17.27$) living in the U.S. and a mean of 17.44 years ($SD = 18.28$) living with the care recipient. The mean depression CES-D score was 17.60 points ($SD = 12.60$).

**Miami Sample.** In the Miami sample ($n = 113$), 86 (76%) participants were females and 27 (24%) were males. The mean age for this sample was 66.58 years ($SD = 10.54$). Caregiver annual income measured categorically, ranged from a low of less than $5,000 to a high of $70,000 or more; the modal income was $5,000 to $9,999. The average level of achieved education was 11.67 years ($SD = 3.79$). The mean number of years that caregivers had lived in the U.S. was 31.36 years ($SD = 8.83$) and the mean number of years caregivers had lived with a care recipient was 35.0 years ($SD = 19.76$). Caregivers in the Miami site had a mean CES-D score of 20.12 points ($SD = 11.09$) which falls above the “at risk for depression” cutoff score of 16.

**Variables of Interest and Operational Definitions**

The predictor variables in the study were: age, educational achievement, income, degree of depressive symptomatology, social support, and health status. The criterion variable was drop out status (i.e., attrition). In the sections that follow, each construct is described along with its operational definition (i.e., measure) according to the REACH study.

**Age.** Refers to the time elapsed from date of birth to the time of the REACH study. This measure was acquired from the Caregiver Sociodemographic Form from the REACH project that was used to obtain descriptive information about the caregivers. Age was measured in years. This study set out to elucidate the relationship between the age of caregivers and attrition.

**Depressive symptoms.** This variable was operationally defined as the affective state of the caregiver at the time of measurement with the Center for Epidemiological Studies Depression
Scale (CES-D). The CES-D has 20 items to measure depression and is used widely to identify individuals who are prone to depression (Radloff, 1977). The CES-D scores range from 0-60 points. Higher scores indicate greater depressive symptoms and a threshold of 16 or higher often indicates a risk for clinical depression (Wisniewski et al., 2003). Cronbach’s alpha was .90 (α = .90). This study set out to measure the relationship between caregiver depressive symptoms and attrition from the REACH project.

**Drop-out status (attrition).** This variable was operationally defined as the loss of research participants (i.e., caregivers) through withdrawal or mortality during the course of the REACH study. For this research, participants’ drop-out status (i.e., drop-out or treatment completer) was assigned according to their status at the completion of the REACH trial.

**Educational achievement.** This variable refers to the number of years of formal education completed by caregivers. This measure was acquired from the Caregiver Sociodemographic form used to obtain descriptive information about the caregivers. Educational level was measured by a range, from a low of 1 indicating an educational level of less than high school to 17 indicating a graduate degree. This study set out to measure the relationship between the educational level achieved by caregivers and attrition from the REACH project.

**Health status.** This variable was operationally defined as the physical health status of the caregiver as measured by the Caregiver Health and Health Behaviors questionnaire from the REACH study. This measured was modified by the original REACH investigators from its initial conception by combining items from existing measures including the Short Form Health Survey (SF-36), the Asset and Health Dynamics Among the Oldest Old, and the Nutrition Screening Initiative (NSI) (Switzer, Wisniewski, Belle, Dew, & Schulz, 1999). This research examined the relationship between health status and attrition from the REACH project.
**Income.** Refers to the total amount (from all sources) of money earned on an annual basis by an individual. This measure was acquired from the Caregiver Sociodemographic form used to obtain descriptive information about the caregivers. The form used ten categories to measure income level, from a low of less than $5,000 per year to a high of $70,000 or more per year. This study set out to measure the relationship between caregivers’ annual total income and attrition from the REACH project.

**Social support.** This variable refers to the amount of support that the caregivers received from friends, neighbors, and other members of the family as measured by the Social Support form. This measured was also modified from its initial conception by the original REACH investigators. They changed the response scale and/or eliminated or added items to the scale (Wisniewski et al., 2003). This study attempted to measure the relationship between social support and attrition from the REACH project.

**Null Hypotheses**

The following six null hypotheses were tested in this study:

- Ho1: There is no relationship between attrition drop-out status (attrition) and Latino caregivers’ age.
- Ho2: There is no relationship between drop-out status (attrition) and Latino caregivers’ achieved level of education.
- Ho3: There is no relationship between drop-out status (attrition) and Latino caregivers’ income.
- Ho4: There is no relationship between drop-out status (attrition) and depression among Latino caregivers as measured by Center for Epidemiologic Studies Depression Scale (CES-D).
- Ho5: There is no relationship between drop-out status (attrition) and social support among Latino caregiver’s.
- Ho6: There is no relationship between drop-out status (attrition) and Latino caregivers’ health status as measured by the Caregiver Health and Health Behaviors Questionnaire from the REACH study.
Research Procedures

The REACH investigators provided permission for use of the data from the Miami and Palo Alto sites for purposes of this study. The data were obtained from the Inter-university Consortium for Political and Social Research (ICPSR), at the University of Michigan. ICPSR maintains and provides access to a vast archive of social science data for research. Finally, an application to the Institutional Review Board (IRB) for an Exempt Status was filed and granted since this study involved a collection of existing data that is available for public use and has de-identified information, recorded so that participants cannot be identified.

Measures

The original REACH study used several scales and modified others to measure the variables and meet the needs of the original study. For the present study, original data were used, however, two measures, social support and health status, were modified. Demographic information for this study was obtained and used as reported by the REACH investigators. These data were collected through the “Caregiver Sociodemographic Questionnaire” (Appendix A). The data for the demographic variables of interest (i.e., age, educational level, and income) were included in this study.

Caregivers’ depressive symptoms were measured with the Center for Epidemiological Studies Depression Scale (CES-D). The CES-D scores were obtained from the original data (Appendix B). A score of 16 points indicated the cut-off point for the presence of depression. The higher the score, the higher the number of depressive symptoms reported by the caregivers.

In order to measure the contributions of the independent variable social support, a social support index was obtained from one of the three original questionnaires used by the REACH investigators; the “perceived social support questionnaire” (Appendix C). This subscale included
nine questions regarding the caregivers’ perception about support available to them from friends and family, and was rated using with a Likert-type scale. The lower the number, the less perceived support the caregivers reported. The score for this subscale ranged from 9 to 32 points.

Similarly, in order to measure the contributions of the independent variable health, two independent indices were created from the original data acquired from the REACH project (Appendix D). Questions from the two subscales, 1) perceived health, and 2) self-reported health problem, were included. The first subscale, the perceived health questionnaire included a total of three questions. This scale was rated on a Likert-type scale and measured the caregivers’ subjective assessment of their health. The scores ranged between 1 and 4.67 points. The higher the score, the healthier the caregivers’ perceived their health. The second subscale, the self-reported health problems questionnaire, included a total of seven questions regarding the presence or absence of medical conditions such as high blood pressure, heart condition, and cancer. The scores ranged between a low of 0 and a high of 5. Higher scores reflect a higher number of reported perceived and/or established health problems.

**Data Analysis**

To test the hypotheses for this study, a hierarchical logistic regression analysis procedure was performed by the statistical program Statistical Package for the Social Sciences (SPSS). Based on existing literature, the following sets of predictors were identified and used in the hierarchical logistic regression model: demographic variables (age, level of educational achievement, level of income) and person-based factors (depression, health status index, and social support index) as defined in previously published REACH studies. Alpha (α) will be set at 0.05.
In order to examine the unique contribution of the independent variables to the prediction of attrition, the demographic variables age and educational level were entered first into the initial block. For the Miami sample, the variable gender was also included in the first model. Income was entered into the logistic regression next, followed by depression score (CES-D), and social support. In the last model, the indices used to measure health status, perceived health status and reported health problems were entered in the last block. The order of entry for the variables was determined by two factors. First, demographic variables were entered into the model. The order of entry for the remaining three variables (i.e., depression, social support, and health status) was determined based on the review of the literature.

**Methodological Limitations**

There are limitations associated with archival analyses. First, as a secondary analysis it does not lend itself for purposeful collection of data. Therefore, the data in this study are limited to the original REACH investigators’ research questions and data collection. Second, there is an inability to control for levels of acculturation in this sample of Latinos, which may influence caregivers’ belief, attitudes, and willingness to participate and complete research studies. Moreover, there are inherent limitations associated with self-report measures including differences in comprehension levels or interpretation, memory deficiencies such as forgetfulness, and using the forced-choice response categories which may simplify answers or distort the information obtained along particular response (or choice) sets (Hilton, Harry, & Rice, 2003). In addition, there is a danger associated with self-report assessment of physical and emotional ailments, which is influenced by the culture of ethnic groups. Furthermore, there is an absence of a control or comparison group. There are also limitations associated with the data analysis procedures of hierarchical logistic regressions such as the less than optimal control of covariate
variables and their correlational nature; thus, caution must be employed when inferring a causal link (Huck, 2004).
CHAPTER 4
RESULTS

The present study entailed a secondary analysis of the multi-site Resources for Enhancing Alzheimer’s Caregiver Health (REACH) study. The purpose of this investigation was to examine predictors of attrition from the REACH trial. Specifically, the importance of age, educational achievement, income, self-reported levels of depressive symptoms, perceived social support, and health status on the drop-out rates for Latino caregivers of persons with Alzheimer’s disease from the REACH trial.

This chapter presents the results of the analyses completed for this study. The information in this chapter is organized as follows. First, data on the subjects who participated in this study are presented with a comparison of the subjects by research site and drop-out status (i.e., completion vs. non-completion). Then the hypotheses and the analyses are presented to address the hypotheses. A summary concludes this chapter.

Preliminary Analyses

A total of 219 participants from the two research sites, Palo Alto and Miami, were included in this study. These participants were from Palo Alto (n =107, 48.8%) and Miami (n =112, 52.1%). Subjects with missing data and those with extreme scores on the variables of interest for this study were deleted from the dataset. There were a total of 59 dropouts (26.9%) and 160 completers (82.1%). The mean age of the total group was 58.90 years, ranging from 25 to 90 years (SD = 14.08) and the mean years of completed education for the total group was 11.12 years, ranging from 2 to 17 years (SD = 3.86). The median and mode annual total income for the participants was $15,000 to $19,999. Table 4-1 illustrates the data for all of the variables for the
total group as well as by location and Table 4-2 shows the data for all of the variables by completion status.

It was also of interest to this study to determine whether there were significant differences between sample sites (Palo Alto and Miami) and between drop-out status (completer and drop-out). In order to compare the mean values for the variables of interest between groups, analysis of variance was used to compare respondents between location site and drop-out status for the continuous variables (age, years of education, CES-D score, perceived social support, perceived health status and reported health status). Chi Square was used to test for differences in categorical data (income). The mode income for Palo Alto was between $15,000 to $19,999 and the mode for Miami was $5,000 to $9,999. Participants from Miami had a lower income level than did Palo Alto participants. Median income in Palo Alto was between two ranges, $15,000 to $19,999 and $20,000 to $29,999 while the median income for Miami was between the two ranges of $10,000 to $14,000 and $15,000 to $19,999. The Chi Square for location was significant for income ($X^2 (9) = 22.249, p = .008$); however, there were six cells with counts less than five and the test may not be valid.

The mode income for completers was $15,000 to $19,999 and the mode income for dropouts was $5,000 to $9,999. It is interesting to note that income was noticeably less for dropouts. The Chi Square test for dropouts versus completers by income found no significant differences ($X^2 (9) = 16.514, p = .057$), however this may not have been an appropriate test as there were four cells with counts less than five bringing into question the validity of this test. Table 4-3 shows the income breakdown by location and drop-out status.

To further test the differences between sites and drop-out status, ANOVA tests were conducted. Table 4-4 shows the results of the ANOVA test between research sites. The
ANOVA test indicates there are significant differences between participants in the Palo Alto site and the Miami site for age, years of education, CES-D score, social support, perceived health, and reported health status. Inspection of the ANOVA findings for dropouts and completers found no statistically significant differences between dropouts and completers for age, years of education, CES-D score, perceived social support, perceived health, and reported health status. Table 4-5 shows the results of the ANOVA test between drop-outs and treatment completers. Dropouts and completers were remarkably similar; however, there were noticeable differences between locations. A Spearman Rho Correlation was used to test for correlations between the predictor variables and the criterion (i.e., drop-out status) in this study. These correlations are discussed next.

**Palo Alto Correlations**

A Spearman Rho Correlation was calculated between the predictor variables and criterion variable (i.e., drop-out status) in this study. The variable of primary interest was how the independent variables (age, years of education, income, CES-D score, received support, perceived health status, and health problems) were correlated with the dependent variable drop-out status. Age was significantly correlated with drop-out status \( r = .212, p = .028 \) although it was a weak correlation. Years of education was inversely correlated with age \( r = -.232, p = .016 \). Income was strongly correlated with years of education \( r = .252, p = .009 \). The most powerful correlation in this study occurred between health problems and age \( r = .393, p = <.001 \). The CES-D (depression) score had a low correlation with health problems \( r = .288, p = .005 \) and with perceived health problems \( r = .312, p = .003 \). All of the other correlations were not strong correlations nor were they statistically significant. Table 4-6 shows the correlation matrix for the Palo Alto sample.
Miami Correlations

A Spearman Rho Correlation was used to test for correlations between the variables used in this study. The variable of primary interest was how the independent variables (age, years of education, gender, income, CES-D score, received support, perceived health status, and health problems) were correlated with the dependent variable of dropping out or staying in the REACH program. There was a significant though low correlation between drop-out status and years of education ($r = .198, p = .037$) for the Miami participants. There was a strong correlation between years of education and income ($r = .537, p = <.001$). The correlation between years of education and gender was significant but weak ($r = .211, p = .025$). The correlation between age and health problem score was weak but statistically significant ($r = .232, p = .015$). Age was inversely correlated with income ($r = -.424, p = <.001$), moderately correlated with gender ($r = -.347, p < .001$). There was a low moderate positive correlation between CES-D score and health status ($r = .314, p = .002$) and between CES-D and health problems ($r = .215, p = .041$). There was a low but significant correlation between gender and income ($r = .188, p = .050$) and between gender and CES-D score ($r = .273, p = .008$). The correlation between received support and health status was inverse and low but statistically significant ($r = -.209, p = .032$). Table 4-7 shows the correlation matrix for the Miami sample.

Hypothesis Testing

This study sought to address the following hypotheses:

- Ho1: There is no relationship between attrition drop-out status (attrition) and Latino caregivers’ age.

- Ho2: There is no relationship between drop-out status (attrition) and Latino caregivers’ achieved level of education.

- Ho3: There is no relationship between drop-out status (attrition) and Latino caregivers’ income.
• Ho4: There is no relationship between drop-out status (attrition) and depression among Latino caregivers as measured by Center for Epidemiologic Studies Depression Scale (CES-D).

• Ho5: There is no relationship between drop-out status (attrition) and social support among Latino caregiver’s.

• Ho6: There is no relationship between drop-out status (attrition) and Latino caregivers’ health status as measured by the Caregiver Health and Health Behaviors Questionnaire from the REACH study.

**Data Analysis**

Logistic regression was conducted on research questions concerning the relative importance of each block (set) of independent variables: demographics (age, gender, years of education, income), CES-D score (CES-D), social support perceived (SSPerc), health status perceived (HSPercd), and actual health problem (HProb) served as statistically significant predictors of dropping out of the REACH study. Tabachnick and Fidell (1996) maintain that logistic regression does not require the adherence to any assumptions about the distribution of the variables. Study data were checked for collinearity and found to be within an acceptable range for tolerance and the variance inflation factor (Mertler & Vannatta, 2001). The data for the two sites (Palo Alto and Miami) were also checked for outliers prior to commencing data analysis. The Mahalobis $X^2$, a test for outliers, identified four outliers with scores in excess of the test statistic. Three cases were deleted from the Palo Alto dataset and one case was deleted from the Miami dataset. This resulted in Miami having an $n = 112$ and Palo Alto having an $n = 107$. Missing data were treated as missing and no substitutions were made for missing data. Since the participants from Palo Alto and Miami were statistically different on a number of the independent variables as presented previously, each location was treated as a separate entity for purposes of the logistic regression analysis.
Logistic regression using the enter method (simultaneous entry of predictors) was conducted to determine which of the set of independent predictor variables would predict whether the participant completed or dropped out of the REACH treatment program for each location. Independent variables were entered in blocks to measure the effect of adding a particular variable or set of variables into the model.

**Palo Alto Sample**

The first block used age and years of education as predictors of completing or dropping out of the REACH program in the model. The [-2 Log likelihood (72.644) and $\chi^2 (2) = 4.123, p = .127$] for this model indicated the model was not statistically significant. However, the model using age and years of education correctly identified 83.9% of the participants. Wald statistics, as shown in Table 4-8 indicated none of the variables served as a significant predictor of drop-out status for the Palo Alto group of participants. The odds ratios for these variables suggest there is little change in the likelihood of dropping out or completing the program when the predictors variables (i.e., age and years of education) increased by 1. Table 4-8 shows the results of the first model for the Palo Alto logistic regression analysis.

The second model added income to the model to determine the effects of income on the model. The model was not statistically significant [-2 Log likelihood (71.679), $\chi^2 (3) = 5.088, p = .165$] and the model fit indices were fairly large indicating model fit was questionable. The age, years of education, and income model did correctly identify 83.9% of the participants. The Wald statistics presented in Table 4-9 indicated that none of the variables (i.e., age, years of education, and income) served as a significant predictor of dropping out or completion for the Palo Alto group of participants. The odds ratios for these variables found little change in the likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-9 shows the results of the second model of the Palo Alto logistic regression analysis.
The third model added the score on the Center for Epidemiologic Studies Depression Scale (CES-D) as a predictor along with age, years of education and income. The model was not statistically significant [-2 Log likelihood (71.674), \( \chi^2 (4) = 5.094, p = .278 \)] and the model fit indices were fairly large indicating model fit was questionable. The age, years of education, income, and CES-D model did correctly identify 83.9% of the participants. The Wald statistics presented in Table 4-10 indicated none of the variables (i.e., age, years of education, income, CES-D score) served as a significant predictor of dropping out or completion for the Palo Alto group of participants. The odds ratios for these variables found little change in the likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-10 shows the results of the third model of the Palo Alto logistic regression analysis.

The fourth model added the variable perceived social support (SSPerc) into the model with age, years of education, income, and CES-D score. The model was not statistically significant [-2 Log likelihood (71.666), \( \chi^2 (5) = 5.101, p = .404 \)] and the model fit indices were fairly large indicating model fit was questionable. The model with age, years of education, income, CES-D score, and received social support correctly identified 83.9% of the participants. The Wald statistics presented in Table 4-11 indicated none of the variables (i.e., age, years of education, income, CES-D score, and perceived social support) served as a significant predictor of dropping out or completion for the Palo Alto group of participants. The odds ratios for these variables found little change in the likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-11 shows the results of the fourth model of the Palo Alto logistic regression analysis.

The fifth model added the variable perceived health status (HSPercd) and reported health status (HSProb) into the model predicting dropping out or completing the REACH program. The
model was not statistically significant \([-2 \text{ Log Likelihood } (69.3056) \chi^2 (6) = 7.462, p = .382]\). The model fit indices were fairly large indicating model fit was questionable and the Chi Square statistic was not significant. The model correctly classified 82.8\% of the cases. Regression coefficients are presented in Table 4-12. Wald statistics indicated none of the variables (i.e., age, years of education, income, CES-D score, received social support, perceived health status and reported health status) served as a significant predictor of dropping out or completion for the Palo Alto sample. The odds ratios for these variables indicate there is little change in the likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-12 shows the results of the fifth model of the Palo Alto logistic regression analysis.

**Miami Sample**

The first block used age, years of education, and gender as predictors of staying or dropping out of the REACH program in the model. This model was not statistically significant as indicated by \([-2 \text{ Log likelihood } (107.284) \chi^2 (3) = 2.407, p = .492]\). However, the age and years of education model did correctly identify 62.7\% of the participants. Wald statistics indicated none of the variables (age and years of education) served as a significant predictor of dropping out or completion for the Miami sample. The odds ratios for these variables indicate there is little change in the likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-13 shows the results of the first model of the Miami logistic regression analysis.

The second model added income to the model to determine the effects of income on the model. The model was not statistically significant \([-2 \text{ Log likelihood } (107.260), \chi^2 (4) = 2.431, p = .657]\] and the model fit indices were fairly large indicating model fit was questionable. The age, years of education, gender, and income model did correctly identify 62.7\% of the participants. The Wald statistics presented in Table 4-14 indicated none of the variables (age,
years of education, and income) served as a significant predictor of dropping out or completion for the Miami group of participants. The odds ratios for these variables found there was little change in the likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-14 shows the results of the second model of the Miami logistic regression analysis.

The third model added the depression score, as reported by the Center for Epidemiologic Studies Depression Scale (CES-D), as a predictor along with age, years of education and income. The model was not statistically significant [-2 Log likelihood (106.773, $X^2(5) = 2.918, p = .713$] and the model fit indices were fairly large indicating model fit was questionable. The age, years of education, income, and CES-D score model did correctly identify 60.2% of the participants. The Wald statistics presented in Table 4-15 indicated none of the variables (age, years of education, gender, income, and CES-D) served as a significant predictor of dropping out or completion for the Miami sample. The odds ratios for these variables found little change in the likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-15 shows the results of the third model of the Miami logistic regression analysis.

The fourth model added Social Support Received (SSPerc) into the model with age, years of education, income, and CSED. The model was not statistically significant [-2 Log likelihood (106.708, $X^2(6) = 2.983, p = .811$] and the model fit indices were fairly large indicating model fit was questionable. The age, years of education, income, CES-D score, and perceived social support model did correctly identify 62.7% of the participants. The Wald statistics presented in Table 4-16 indicated none of the variables (age, years of education, income, CES-D score, and perceived social support) served as a significant predictor of dropping out or completion for the Miami group of participants. The odds ratios for these variables found little change in the
likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-16 shows the results of the fourth model of the Miami logistic regression analysis.

The fifth model added the health variables, perceived health status (HSPercd) and reported health status (HSProb) into the model predicting dropping out or completing the REACH program. The model was not statistically significant $[-2 \text{ Log Likelihood} (105.783; \chi^2(8) = 3.908, p = .865]$. The model fit indices were fairly large indicating model fit was questionable and the Chi Square statistic was not significant. The model correctly classified 61.4% of the cases. Regression coefficients are presented in Table 4-17. Wald statistics indicated none of the variables (age, years of education, income, CES-D, perceived social support, and perceived health status and reported health status served as a significant predictor of dropping out or completion for the Miami research site. The odds ratios for these variables indicate there is little change in the likelihood of dropping out or completing the program when the predictors increased by 1. Table 4-17 shows the results of the fifth model of the Miami logistic regression analysis.

**Summary of Results**

The outcomes of the study were not significant. None of the predictor variables contributed significantly to the understanding of caregiver drop-out status (the criterion) from the REACH trial. There were no significant differences between drop-out status though income between the two samples groups varied significantly. In addition, there were significant differences between the Palo Alto and Miami samples for age, years of education, CES-D score, perceived social support, perceived health, and reported health status. There were no statistically significant differences between dropouts and completers for age, years of education, CES-D score, social support, perceived health, and reported health status.
Table 4-1. Variable means for total group and by location (Palo Alto and Miami)

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Total</th>
<th>Total</th>
<th>Miami</th>
<th>Miami</th>
<th>Miami</th>
<th>Palo</th>
<th>Palo</th>
<th>Palo</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
<td>N</td>
<td>Mean</td>
<td>SD</td>
<td>N</td>
</tr>
<tr>
<td>Age</td>
<td>219</td>
<td>58.90</td>
<td>14.08</td>
<td>66.51</td>
<td>10.55</td>
<td>112</td>
<td>50.94</td>
<td>12.89</td>
<td>107</td>
</tr>
<tr>
<td>YrEduc</td>
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<td>11.11</td>
<td>3.86</td>
<td>11.63</td>
<td>3.78</td>
<td>112</td>
<td>10.57</td>
<td>3.89</td>
<td>107</td>
</tr>
<tr>
<td>CES-D</td>
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<td>11.96</td>
<td>19.98</td>
<td>11.06</td>
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<td>17.39</td>
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<td>SSPerc</td>
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<td>7.85</td>
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<td>HSPercd</td>
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<td>.69</td>
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<td>.70</td>
<td>111</td>
<td>2.65</td>
<td>.67</td>
<td>107</td>
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<tr>
<td>HSProb</td>
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<td>1.11</td>
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<td>1.13</td>
<td>110</td>
<td>.88</td>
<td>1.03</td>
<td>104</td>
</tr>
</tbody>
</table>

Note: YrEduc = Years of Education; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support; HSPercd = Perceived Health Status; HSProb = Self-reported Health
Table 4-2. Variable means for total group and dropouts and completers

<table>
<thead>
<tr>
<th></th>
<th>Total N</th>
<th>Total Mean</th>
<th>Total SD</th>
<th>Drop Mean</th>
<th>Drop SD</th>
<th>Drop N</th>
<th>Compl Mean</th>
<th>Compl SD</th>
<th>Compl N</th>
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</thead>
<tbody>
<tr>
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<td>11.20</td>
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<td>CES-D</td>
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<tr>
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<td>.75</td>
<td>58</td>
<td>2.67</td>
<td>.66</td>
<td>160</td>
</tr>
<tr>
<td>HS Prob</td>
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<td>1.11</td>
<td>1.05</td>
<td>1.02</td>
<td>59</td>
<td>1.16</td>
<td>1.14</td>
<td>155</td>
</tr>
</tbody>
</table>

Note: YrEduc = Years of Education; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support; HSPercd = Perceived Health Status; HSProb = Self-reported Health; Drop = Drop-outs; Compl = Completers
Table 4-3. Income level group for completion status and location

<table>
<thead>
<tr>
<th>Income</th>
<th>Drop N</th>
<th>Comp N</th>
<th>Miami N</th>
<th>Palo Alto N</th>
<th>Total N</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(%)</td>
<td>(%)</td>
<td>(%)</td>
<td>(%)</td>
<td>(%)</td>
</tr>
<tr>
<td>&lt;$5,000</td>
<td>5 (8.6)</td>
<td>7 (4.4)</td>
<td>6 (5.5)</td>
<td>6 (5.6)</td>
<td>12 (5.6)</td>
</tr>
<tr>
<td>$5–9,999</td>
<td>11 (19.0)</td>
<td>21 (13.3)</td>
<td>23 (21.1)</td>
<td>9 (8.4)</td>
<td>32 (14.8)</td>
</tr>
<tr>
<td>$10–14,999</td>
<td>15 (25.9)</td>
<td>20 (12.7)</td>
<td>21 (19.3)</td>
<td>14 (13.1)</td>
<td>35 (16.2)</td>
</tr>
<tr>
<td>$15–19,999</td>
<td>6 (10.3)</td>
<td>31 (19.6)</td>
<td>17 (15.6)</td>
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<td>37 (17.1)</td>
</tr>
<tr>
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<td>9 (15.5)</td>
<td>19 (12.0)</td>
<td>16 (14.7)</td>
<td>12 (11.2)</td>
<td>28 (13.0)</td>
</tr>
<tr>
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<td>3 (5.2)</td>
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<td>10 (9.2)</td>
<td>17 (15.9)</td>
<td>27 (12.5)</td>
</tr>
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<td>8 (5.1)</td>
<td>4 (3.7)</td>
<td>5 (4.7)</td>
<td>9 (4.2)</td>
</tr>
<tr>
<td>$60–69,999</td>
<td>3 (5.2)</td>
<td>4 (2.5)</td>
<td>5 (4.6)</td>
<td>2 (1.9)</td>
<td>7 (3.2)</td>
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<tr>
<td>$70,000 &gt;</td>
<td>2 (3.4)</td>
<td>6 (3.8)</td>
<td>4 (3.7)</td>
<td>4 (3.7)</td>
<td>8 (3.7)</td>
</tr>
<tr>
<td>Total</td>
<td>58 (100)</td>
<td>158(100)</td>
<td>109(100)</td>
<td>107 (100)</td>
<td>216 (100)</td>
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</table>

Income reported in dollars
Table 4-4. ANOVA test between sites (Palo Alto and Miami)

<table>
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<td>CES-D</td>
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<td>HSProb</td>
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<td>.001</td>
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Note: YrEduc = Years of Education; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support; HSPercd = Perceived Health Status; HSProb = Self-reported Health.

p < .05.
Table 4-5. ANOVA test between treatment dropouts and treatment completers

<table>
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<td>.493</td>
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Note: YrEduc = Years of Education; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support; HSPercd = Perceived Health Status; HSProb = Self-reported Health.

*p < .05.*
<table>
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<th>Income</th>
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<th>SSPerc</th>
<th>HSPercd</th>
<th>HSProb</th>
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<td>.127</td>
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<tr>
<td><strong>p</strong></td>
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<td>.079</td>
<td>.740</td>
<td>.439</td>
<td>.733</td>
<td>.199</td>
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<td><strong>Note:</strong></td>
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Table 4-6. Palo Alto correlations

Note: Age = Years of Life; YrEduc = Years of Education; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support; HSPercd = Perceived Health Status; HSProb = Self-reported Health

*p < .05.*
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<tr>
<td>HSPercd</td>
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<tr>
<td>HSProb</td>
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Note: Age = years of Life; YrEduc = Years of Education; Gender = Male or Female; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support; HSPercd = Perceived Health Status; HSProb = Self-reported Health

*p < .05.*
Table 4-8 Palo Alto logistic regression, model one

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<th>Odds/Ratio</th>
<th>CI</th>
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</thead>
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<td>.028</td>
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Note: YrEduc = Years of Education

$p < .05$. 
Table 4-9 Palo Alto logistic regression, model two

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<td>.105</td>
<td>1.043</td>
<td>991, 1.097</td>
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<td>YrEduc</td>
<td>.047</td>
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<td>.598</td>
<td>0.00954</td>
<td>.800, 1.137</td>
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<tr>
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<td>.334</td>
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<td>.866, 1.525</td>
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<tr>
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<td>.039</td>
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<td>.843</td>
<td>.703</td>
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Note: YrEduc = Years of Education
p < .05.
Table 4-10. Palo Alto logistic regression, model three

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<td>.990, 1.098</td>
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<td>.799, 1.137</td>
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<td>.334</td>
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<td>.866, 1.525</td>
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<td>.998</td>
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Note: YrEduc = Years of Education; CES-D = Center for Epidemiologic Studies – Depression Score
p < .05.
Table 4-11. Palo Alto logistic regression, model four

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<td>.598</td>
<td>.954</td>
<td>.799, 1.138</td>
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<td>.335</td>
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<td>.866, 1.525</td>
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<tr>
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<td>.004</td>
<td>1</td>
<td>.950</td>
<td>.998</td>
<td>.950, 1.050</td>
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Note: YrEduc = Years of Education; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support
p < .05.
Table 4-12. Palo Alto logistic regression, model five

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<td>.963</td>
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<td>.842</td>
<td>.994</td>
<td>.939, 1.053</td>
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<td>.739, 5.102</td>
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<td>.538</td>
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Note: YrEduc = Years of Education; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support; HSPercd = Perceived Health Status; HSProb = Self-reported Health

\( p < .05 \).
Table 4-13. Miami logistic regression, model one

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<td>.953, 1.050</td>
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Note: YrEduc = Years of Education; Gender = Male or Female

\( p < .05 \).
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Note: YrEduc = Years of Education; Gender = Male or Female

*p < .05.*
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<th>p</th>
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<tr>
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Note: YrEduc = Years of Education; Gender = Male or Female; CES-D = Center for Epidemiologic Studies – Depression Score

*p < .05.*
### Table 4-16. Miami logistic regression, model four

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<td>.954, 1.263</td>
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Note: YrEduc = Years of Education; Gender = Male or Female; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support

\( p < .05 \).
Table 4-17. Miami logistic regression, model five

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<td>.193</td>
<td>1.099</td>
<td>.954, 1.267</td>
</tr>
<tr>
<td>Gender</td>
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<td>.033</td>
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<td>.855</td>
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<td>.321; 3.939</td>
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<td>.988</td>
<td>.763, 1.279</td>
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<td>.987</td>
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<td>.124</td>
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<td>.725</td>
<td>.990</td>
<td>.937, 1.046</td>
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<td>.477</td>
<td>.772</td>
<td>.378, 1.576</td>
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<td>.526</td>
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<td>.468</td>
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<td>.762, 1.806</td>
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</table>

Note: YrEduc = Years of Education; Gender = Male or Female; CES-D = Center for Epidemiologic Studies – Depression Score; SSPerc = Perceived Social Support; HSPercd = Perceived Health Status; HSProb = Self-reported Health

\(p < .05\).
CHAPTER 5
CONCLUSION

This chapter includes a discussion of the findings for each hypothesis as well as additional conclusions and interpretations resulting from the analyses of data. The implications and limitations of the study are also presented. Recommendations for future research conclude the chapter.

In order to address current concerns in the literature about the low participation and retention of Latino caregivers of persons with Alzheimer’s disease in research studies, the goal of this research was to examine six variables believed to be relevant to the attrition rate of Latino caregivers of persons with Alzheimer’s disease from research studies. Specifically, this study set out to examine the extent to which the variables caregiver age, caregiver attained educational level, caregiver income, caregiver depression score (CES-D), caregiver perceived social support, and caregiver health status help explained caregivers’ drop-out status from two sites in the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) trial; Miami and Palo Alto. The Miami site (as described by Wisniewski et al., 2003) examined the effectiveness of family-based structural multisystem in-home intervention (FSMII) and a family-based structural multisystem in-home intervention plus a computer telephone integration system (FSMII + CTIS). The Palo Alto site (as described by Wisniewski et al., 2003) examined the effectiveness of the coping with a caregiving class (CWC) and an enhanced support group (ESG).

Conclusions

The outcomes of the study were not significant. None of the predictors help to significantly explain caregiver drop-out status. While other studies have suggested that these variables may help explain why dementia caregivers drop-out prematurely from research studies,
this set of variables did not help predict attrition in these two samples of Latino caregivers of persons with Alzheimer’s disease. Although the outcomes of this study did not produce significant results, these findings contribute to the existing literature on Latino caregivers of persons with Alzheimer’s disease and serve to inform future research studies by underscoring the importance of an adequate sample size, purposeful instrumentation, and cultural considerations. Thus, this study should be considered a pilot study that tested the feasibility of this investigation.

**Palo Alto**

No significance was found between caregivers’ age and the likelihood of dropping out of the REACH clinical trial (hypothesis 1). No significance was found between caregivers’ level of education and the likelihood of caregivers dropping out of the REACH trial (hypothesis 2). No significance was found between caregivers’ income level and the likelihood of caregivers dropping out of the REACH trial (hypothesis 3). No significance was found between caregivers’ CES-D score (i.e., depressive symptoms) and the likelihood of caregivers dropping out from the REACH trial (hypothesis 4). Similarly, no significance was found in caregiver perceived social support and the likelihood of caregivers dropping out of the REACH trial (hypothesis 5). Finally, no significance was found in caregivers’ health status and the likelihood of caregivers dropping out of the REACH trial (hypothesis 6).

**Miami**

No significance was found in caregivers’ age and the likelihood of caregivers dropping out of the REACH trial (hypothesis 1). No significance was found in caregivers’ level of education and the likelihood of caregivers dropping out of the REACH trial (hypothesis 2). In addition, no significance was found in caregivers’ income level and the likelihood of caregivers dropping out of the REACH trial (hypothesis 3). No significance was found in caregivers’ CES-D score (i.e.,
depressive symptoms) and the likelihood of caregivers dropping out of the REACH trial (hypothesis 4). No significance was found in caregivers’ perceived social support and the likelihood of caregivers dropping out of the REACH trial (hypothesis 5). Finally, no significance was found in caregivers’ health status and the likelihood of caregivers dropping out of the REACH trial (hypothesis 6).

**Implications**

The predictor variables in this investigation (i.e., caregiver’s age, achieved educational level, income level, CES-D score, health status, and perceived social support) did not achieve statistical significance for the criterion of drop-out status. However, for the Palo Alto sample, it appears that there may be significance for the variables, caregivers’ age, income, and perceived health, if the sample size were larger or if the instruments were sufficiently powered to test these specific variables. Similarly, in the Miami sample, the predictor variable of caregivers’ achieved educational level also indicates it may achieve significance with a larger sample size or better instrumentation.

These findings are consistent with the existing mixed results in the current literature regarding the participation of Latinos in research studies. A few studies have been successful recruiting and retaining Latino participants (Gallagher-Thompson et al., 2004; Schulz, 2003). However, many others have documented the challenges in recruiting and retaining Latino participants in research studies (Bank, Arguelles, Rubert, Eisdorfer, & Czaja, 2006; Levkoff & Sanchez, 2003; Morano, & Bravo, 2002; Aranda, 2001; Fitten, Ortiz, & Pontón, 2001; Williams, Tappen, Buscemi, Rivera, & Lezcano, 2001). These mixed results may continue to be related to the under-representation of Latinos in research studies. Although the participants in these two samples were Latinos, these two sample sizes are considered small sample sizes for this type of
analysis. The samples were also different regarding the country of origin; while the Miami sample was mostly Cuban-American, the Palo Alto sample was mostly Mexican-American. In addition, these findings are inconsistent with other research findings that suggest the variables included in this study help explain why Latino caregivers drop-out prematurely from research studies. For example, Gallagher-Thompson, Solano, Coon, and Areán (2003) underscore the need to examine the influence of physical health and mental well-being (i.e., depression) in Latino caregivers in future research studies. Schulz et al. (2003) and Haley, Levine, Brown, & Bartolucci, (1987) emphasize the role of social support. Consequently, recruitment and retention of culturally diverse individuals have been areas of major concern for researchers. Schulz et al. (2003) report that “one of the disappointments in the caregiving intervention research literature has been the relative lack of success in achieving clinically meaningful outcomes” (p. 519). Thus, it is critical to continue the efforts to advance the knowledge base about the impact of these and other variables in the retention of Latino caregivers in research studies.

The aging of the population in combination with the rapid growth of the Latino population and the increasing incidence of Alzheimer’s disease warrant the continuation of efforts to advance knowledge about the impact of Alzheimer’s disease. Over one million Latinos are expected to suffer from this devastating illness (Alzheimer’s Association, 2004). Thus, these numbers underscore the need to include culturally diverse groups in investigations in order to develop effective methods to meet their needs. Although numerous studies have been conducted to advance the knowledge about the impact of Alzheimer’s disease, only a handful have included ethnic minority participants, particularly Latinos (Bank et al., 2006). The debilitating and progressive nature of Alzheimer’s disease demands careful consideration of and developing
strategies and resources to address the needs of caregivers, especially ethnic minorities, since the
generalizability of most studies cannot be extended to these groups.

Continued inquiry regarding the impact of these person-based variables (i.e., age,
education level, depressive symptoms, physical health, and social support), the impact of burden
associated with the caregiver role, and reasons for participation in research studies are crucial.
Moreover, inclusion and examination of other variables such as culture-specific variables (i.e.,
acculturation level, language proficiency, perception about the etiology of Alzheimer’s disease,
and the perception about research studies), care recipient characteristics (i.e., physical limitations
and degree of cognitive impairment), as well as different research delivery methods (i.e., use of
technology) may prove beneficial. The need for including cultural variables when examining
ethnic minorities has been well-documented in the literature (Mahoney, Cloutterbuck, Neary, &
Zhan, 2005; Moreno-John et al., 2004; Areán, Alvidrez, Nery, Estes, & Linkins, 2003; Levkoff
& Sanchez, 2003; Curry & Jackson, 2003; Aranda, 2001). Another area of inquiry that is
attracting much attention is the development of alternative service and research delivery options.
For example, as the baby boomers age, an increasing number of potential participants will
probably have had significant experience with telecommunication technology such as the
telephone and the internet, which may be excellent vehicles for gathering data (Bank, Arguelles,
Rubert, Eisdorfer, & Czaja, 2006).

Limitations

Due to the archival nature of this inquiry, this study did not lend itself for purposeful
collection of data nor allow for adding more research participants. The hypotheses in this study
were not powered to test the relationships of the variables of inquiry. The data in this study are
limited to the original REACH investigators’ research questions and data collection which may
have negatively impacted this study’s predictive variables. The sample size for this study was also near the minimum for logistic regression analysis (Hsieh, Bloch, & Larsen, 1998). Furthermore, there was no control or comparison group in the REACH trial.

Perhaps the most relevant limitation associated with this study was that it did not consider cultural variables. This study did not examine the specific influence of culture in the retention of the study’s participants which may contribute to their motivation and investment in the research outcome. In addition, there is a danger associated with self-report assessment of physical and emotional ailments, which are subjective and are influenced by the culture of ethnic groups. This study was limited in its inability to control for levels of acculturation in the two samples of Latinos, which may influence caregivers’ belief, attitudes, and willingness to participate and complete research studies. The study was also limited in its scope, in that no measures considered important environmentally based variables, such as community resources and transportation issues, were examined.

Another limitation of this study was that participants were recruited from physicians’ offices, Memory Disorder Clinics, and other clinical settings; recruitment did not include other types of community-based caregivers. Additionally, the small number of males and caregivers older than 65 years of age limited the power and applications of the findings. Thus, results should only be generalized to younger female Latinas.

In addition, it is important to consider that the variables examined in this study may not have been effective predictors of drop-out status (the criterion) because the participants may have been more motivated, younger, and in better health than older caregivers. Typically, older caregivers are at higher risk for potentially significant health problems associated with older age, length of time caring for someone with progressive dementia (i.e., Alzheimer’s disease), and less
social support, which may influence their ability and willingness to participate in research studies.

**Recommendations**

It is recommended that future research studies strengthen efforts to include Latino caregivers of persons with Alzheimer’s disease in their studies. It is important to note that the understanding of the variables examined in this study are embedded in the cultural context. However, as mentioned earlier, this study did not measure any cultural variables. Thus, it is recommended that future inquiries into Latino caregivers of persons with Alzheimer’s disease are designed in a manner that allows for the measurement of cultural considerations such as level of acculturation, language proficiency, and participants’ perceptions about research, as well as their perception about the variables of interest. In addition, because of the close-knit nature of Latino families, it is recommended that future research examines the caregiving experience from a family or systemic context. It is imperative that clinicians understand the obstacles hindering Latinos’ access to services (i.e., transportation issues, immigration status, awareness of community services, etc). Religion is also a significant factor in the Latino community. Religious belief may influence Latinos’ belief and understanding about an illness or may be a valuable source of support and endurance. The role of religion in the Latino population and its influence on the caregiving experience warrants closer examination.

Many researchers have brought attention to the issue of language and language proficiency (Aranda, 2001; Gallagher-Thompson et al., 2003; Levkoff & Sanchez, 2003; Gallagher-Thompson, 1996). Therefore, conducting the study in Spanish when appropriate and having interviewers who can speak the language fluently and accurately reflect the sample population are crucial and may help foster trust. Latinos may drop-out prematurely from research studies if
they feel inadequate due to language limitations or if they do not feel at ease with the researcher. Thus, conducting consumer-center recruitment and retention practices that are informed by the culture of the target population, as proposed by Areán et al., (2003), is necessary to reach out effectively to this group. These culturally-appropriate practices may prove beneficial in alleviating the potential for stigma associated with participation in the research study and the stress associated with speaking in another language.

Gallagher-Thompson, Solano, Coon, and Areán (2003) report that one aspect of their success in recruiting and retaining Latino caregivers was taking into account the practical barriers to participation in research studies. Research protocols should be designed to reduce the burden of participation and to cover some of the cost such as travel and sitter services (Areán, Alvidrez, Nery, Estes, & Linkins, 2003; Areán & Gallagher-Thompson, 1996). It is also imperative that researchers are mindful of the time requirements. They must consider conducting shorter interviews, and, if necessary, breaking down longer assessments into smaller components. Researchers should also consider bringing the research to the Latino caregivers instead of expecting them to come to the research site. This may be accomplished by partnering with religious organizations or local businesses to conduct interviews in a neutral yet familiar environment. This notion is supported by the work of Levkoff and Sanches (2003). Consequently, attending to the barriers associated with the group of interest may prove beneficial in minimizing any issues of mistrust regarding researchers.

In addition, research questions should also have practical value for the research participants. It is important that Latino caregivers understand the value of participating in research protocols, and, if possible, that they obtain services they normally would not access. For example, many caregivers report poor health as a consequence of their role as caregiver.
Future research studies may benefit from addressing the impact of caregiving on the physical health of caregivers. This notion is supported in the literature by the work of Gallagher-Thompson et al., (2003) and Cox and Monk (1993), among others. It also important that the research team provides feedback to the community once the study is completed (Areán et al., 2003). Sharing the research findings and assisting professionals in the community to translate the findings into practice serves to inform consumers, professionals, and to foment an atmosphere of trust and collaboration.

Alternatively, future investigators should consider conducting an examination on the influence of these variables through different data analysis methods. The relationships among the variables age, income, health, and attrition warrant future investigation. The large scale nature of research like the REACH study allows the best probability of examining the strength of association between variables of interest. The REACH data are available for research from the Inter-university Consortium for Political and Social Research (ICPSR) at the University of Michigan. Future research is needed in order to develop better models using predictors of drop-out status, including attitudes and beliefs, and to explore alternative ways to identify predictors of attrition and recruitment and retention strategies for Latino caregivers of persons with Alzheimer’s disease.

As the scientific community continues to strengthen efforts to increase the recruitment and retention of Latinos in research studies, health professionals need to keep up with new findings. While more information is needed to inform future research and practice, current health professionals should translate these recommendations into practice. Thus, ensuring that Latino caregivers of persons with Alzheimer’s disease are receiving adequate and culturally-relevant services. It is necessary that health professionals, such as counselors, working with
Latino families understand and incorporate into their practice the values of this cultural group. These include: the close-knit and extended nature of the Latino family, degree of acculturation into mainstream society, and language proficiency, role of religion, perceptions about Alzheimer’s disease and research studies, among others. However, it is also critical to consider differences within Latino groups. As several investigators (Mohoney, Clutterbuck, Neary, & Zhan 2005; Gallagher-Thompson et al., 2003) have pointed out, members of the Latino population have the most geographically diverse origins. Moreover, it is important to keep in mind the generational differences within a single family unit which may manifest as different language preferences and degree of acculturation to mainstream society. Given the paucity of evidenced-based research findings, clinicians must take responsibility to ensure they are well-prepared to provide Latino families with the best available services. In order to gain culturally-appropriate skills, clinicians may participate in diversity trainings or incorporate Latino consultants in the advisory boards. If these were not available, the clinician should find a more appropriate referral source to work with this population.

The implications regarding the expected increase in cases of Alzheimer's disease in the Latino community are overwhelming. Therefore, in order to keep up with the increasing numbers of Latino families dealing with Alzheimer's disease, investigators must strengthen their efforts to design appropriate research, to translate cultural sensitivity into culturally competent recruitment and retention endeavors to enlist Latino participants into research studies. As the cost of caring for persons suffering from Alzheimer's disease and related dementias continues to soar, it is imperative to advance the knowledge base about how caregivers carry out the demands associated with caregiving over the long-term. It is only through the acquisition and application of this knowledge that society will effectively and sensitively manage this looming health crisis.
APPENDIX A
CAREGIVER SOCIODEMOGRAPHIC INFORMATION

Caregiver Sociodemographic Information Questionnaire.

1. During which visit is this interview taking place?
   1 ( ) Baseline
   2 ( ) 6 month follow-up visit
   3 ( ) 12 month follow-up visit
   4 ( ) 18 month follow-up visit
   5 ( ) Other
   1.1 Specify ______________________________________

2. Date of interview: __ __/ __ __/ __ __
   Month/day/year

Now I would like to obtain some general information about you.

4. What is your marital status?
   Never married (0)
   Married or living as married (1)
   Widowed, not currently married (2)
   Divorced, not currently married (3)
   Separated (4)
   Unknown (-3)
   Refused (-4)

4.1. What is the primary occupation your spouse has had most of his/her working life? Since many people have more than one job at a given time, we would like to know about the job that is/was your spouse's primary source of income.

_____________________________________________________________________

4.1.1 Job Code __ __ __
5. How many years of formal education did you complete?
No formal education (0)
Grade 1 (1)
Grade 2 (2)
Grade 3 (3)
Grade 4 (4)
Grade 5 (5)
Grade 6 (6)
Grade 7 (7)
Grade 8 (8)
Grade 9 (9)
Grade 10 (10)
Grade 11 (11)
Grade 12/ High school diploma/ GED (General Education Diploma) (12)
Vocational/ training school after high school (13)
Some college/ associate degree (14)
College graduate (4 or 5 year program) (15)
Master's degree (or other post-graduate training) (16)
Doctoral degree (PhD, MD, Ed.D., D.V.M., DDS., JD, etc.) (17)
Unknown (-3)
Refused (-4)

6. What country did you reside in during the last year of formal education?
United States (1)
Canada (2)
Cuba (3)
Mexico (4)
Other (5)

6.1. Specify ____________________________________________
Unknown (-3)
Refused (-4)

7. How would you describe your primary racial or ethnic group?
White, Caucasian (1)
Black, African-American (2)
Native American, Eskimo, Aleut (3)
Asian or Pacific Islander (4)
Hispanic, Latino (5)

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7.1. Would you describe yourself as
Mexican, Mexican American, Chicano (1)
Cuban or Cuban American (2)
Puerto Rican (3)
Dominican (4)
Other (5)
Unknown (-3)
Refused (-4)

7.1.1. Specify: ________________________________________
No primary group (6)

7.2. Specify: ______________________
Other (7)

7.3. Specify: ______________________
Unknown (-3)
Refused (-4)

8. In which country were you born?
United States (1)
Canada (2)
Cuba (3)
Mexico (4)
Other (5)

8.1 Specify: _________________________________________
Unknown (-3)
Refused (-4)

9. How many years have you lived in the United States? __ __ Years

10. What is the primary occupation you have had most of your working life? Since many people
have more than one job at a given time, we would like to know about the job that is/was your
primary source of income.

____________________________________________________

10.1 Job Code __ __ __
11. What is your current employment status?
Employed at a job for pay, full-time (1)
Employed at a job for pay, part time (2)
Homemaker, not currently working for pay (3)
Not currently employed, retired (4)
Not currently employed, not retired (5)
Unknown (-3)
Refused (-4)

11.1. Are you employed outside of the home?
No (0) Yes (1) Unknown (-3) Refused (-4)

11.2. How many hours per week do you work at your paid job?
__ __ : __ __
Hours:minutes

11.3. Have you had to reduce the number of hours that you work in an average week in order to provide care to (CR)?
No (0) Yes (1) Unknown (-3) Refused (-4)

11.3.1. How many hours have you had to reduce per week?
__ __ : __ __
Hours:minutes

11.4. Did you stop working because of (CR)’s need for care?
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

11.4.1. Why?
You anticipated having to care for (CR) (1)
To provide additional care for (CR) (2)
Other (3)

11.4.1.1. Specify _____________________________

Next, I would like to ask you about your household income. Some people may not be comfortable answering this question, but I want to assure you that your responses will be kept strictly confidential. This information is very important to the project because it helps us understand how caregiving affects people with different incomes.
12. Which category on this card [give respondent card] best describes your yearly household income before taxes? Do not give me the dollar amount, just give me the category. Include all income received from employment, social security, support from children or other family, welfare, Aid to Families with Dependent Children (AFDC), bank interest, retirement accounts, rental property, investments, etc.

Less than $5000 (0)
$5000 - $9,999 (1)
$10,000 - $14,999 (2)
$15,000 - $19,999 (3)
$20,000 - $29,999 (4)
$30,000 - $39,999 (5)
$40,000 - $49,999 (6)
$50,000 - $59,999 (7)
$60,000 - $69,999 (8)
$70,000 or more (9)
Unknown (-3)
Refused (-4)

13. How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Would you say it is:

Not difficult at all (1)
Not very difficult (2)
Somewhat difficult (3)
Very difficult (4)
Unknown (-3)
Refused (-4)

14. How many people are living with you in your home excluding yourself?
___ ___ persons

15. How long have you lived with (CR)? ___ ___ years

16. Did you and (CR) start living together so that you could take care of him/her?
No (0)
Yes (1)
Unknown (-3)
Refused (-4)
APPENDIX B
CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (CES-D)

CES-D Questionnaire.

1. During which visit is this interview taking place?
   1 ( ) Baseline
   2 ( ) 6 month follow-up visit
   3 ( ) 12 month follow-up visit
   4 ( ) 18 month follow-up visit
   5 ( ) Other
   1.1 Specify ______________________________________

2. Date of interview: __ ___/ __ ___/ __ ___
   Month/day/year

This section deals with statements people might make about how they feel. Let me give you a card with possible responses. [Give respondent card.] For each of the statements, please indicate how often you felt that way during the past week.

4.1. I was bothered by things that usually don't bother me.
   Rarely or none of the time [< 1 day] (0)
   Some or a little of the time [1-2 days] (1)
   Occasionally or a moderate amount of time [3-4 days] (2)
   Most or almost all of the time [5-7 days] (3)
   Unknown (-3)
   Refused (-4)

4.2. I did not feel like eating; appetite was poor.
   Rarely or none of the time [< 1 day] (0)
   Some or a little of the time [1-2 days] (1)
   Occasionally or a moderate amount of time [3-4 days] (2)
   Most or almost all of the time [5-7 days] (3)
   Unknown (-3)
   Refused (-4)

4.3. I felt that I could not shake off the blues, even with help from my family and friends.
   Rarely or none of the time [< 1 day] (0)
   Some or a little of the time [1-2 days] (1)
   Occasionally or a moderate amount of time [3-4 days] (2)
   Most or almost all of the time [5-7 days] (3)
   Unknown (-3)
   Refused (-4)
4.4. I felt that I was just as good as other people.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.5. I had trouble keeping my mind on what I was doing.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.6. I felt depressed.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.7. I felt that everything that I did was an effort.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.8. I felt hopeful about the future.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)
4.9. I thought my life had been a failure.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.10. I felt fearful.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.11. My sleep was restless.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.12. I was happy.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.13. I talked less than usual.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.15. People were unfriendly.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.16. I enjoyed life.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.17. I had crying spells.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.18. I felt sad.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)
4.19. I felt that people disliked me.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

4.20. I could not get going.
Rarely or none of the time [< 1 day] (0)
Some or a little of the time [1-2 days] (1)
Occasionally or a moderate amount of time [3-4 days] (2)
Most or almost all of the time [5-7 days] (3)
Unknown (-3)
Refused (-4)

5. CES-D Score ___ ___

6. Is the CES-D score greater than or equal to 28?
No ( )
Yes ( )

6.1 Has the Principal Investigator or appropriate site personnel been notified?
No ( )
Yes ( )

Please notify the Principal Investigator or appropriate site personnel.
Social Support (SS) Questionnaire.

1. During which visit is this interview taking place?
   Baseline (1)
   6 month follow-up visit (2)
   12 month follow-up visit (3)
   18 month follow-up visit (4)
   Other (5)
   
   1.1 Specify ________________________________

2. Date of interview: __ __/ __ __/ __ __
   Month/day/year

Social Networks
Now I would like to ask you some questions about your friends and family.

4.0. Overall, how satisfied have you been in the last month with the help you have
received from friends, neighbors, or family members?
   Not at all (0)
   A little (1)
   Moderately (2)
   Very (3)
   Unknown (-3)
   Refused (-4)

4.1. How many relatives other than (CR) do you see or hear from at least once a
month?
   None (0)
   One (1)
   Two ( )
   Three or four (3)
   Five to eight (4)
   Nine or more (5)
   Unknown (-3)
   Refused (-4)
4.2. Think about the relative other than (CR) with whom you have the most contact. How often do you see or hear from that person?
Less than monthly (0)
Monthly (1)
A few times a month (2)
Weekly (3)
A few times a week (4)
Daily (5)
Unknown (-3)
Refused (-4)

4.3. How many relatives other than (CR) do you feel close to? That is, how many do you feel at ease with, can talk to about private matters, or can call on for help?
None (0)
One (1)
Two (2)
Three or four (3)
Five to eight (4)
Nine or more (5)
Unknown (-3)
Refused (-4)

4.4. How many friends do you feel close to? That is, how many friends (not including relatives) do you feel at ease with, can talk to about private matters, or can call on for help?
None (0)
One (1)
Two (2)
Three or four (3)
Five to eight (4)
Nine or more (5)
Unknown (-3)
Refused (-4)

4.5. How many of these friends do you see or hear from at least once a month? (not including relatives)
None (0)
One (1)
Two (2)
Three or four (3)
Five to eight (4)
Nine or more (5)
Unknown (-3)
Refused (-4)
4.6. Think about the friend (not including relatives) with whom you have the most contact. How often do you see or hear from that person?
Less than monthly (0)
Monthly (1)
A few times a month (2)
Weekly (3)
A few times a week (4)
Daily (5)
Unknown (-3)
Refused (-4)

4.7. When you have an important decision to make, do you have someone other than (CR) you can talk to about it?
Never (0)
Seldom (1)
Sometimes (2)
Often (3)
Very often (4)
Always (5)
Unknown (-3)
Refused (-4)

4.8. When other people you know have an important decision to make, do they talk to you about it?
Never (0)
Seldom (1)
Sometimes (2)
Often (3)
Very often (4)
Always (5)
Unknown (-3)
Refused (-4)

Received Support and Satisfaction

5.1. In the past month, how often has someone, such as a friend, neighbor, or family member other than (CR), provided transportation for you?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)
5.2. In the past month, how often has someone, such as a friend, neighbor, or family member other than (CR), pitched in to help you do something that needed to get done, like household chores or yardwork?
   Never (0)
   Once in awhile (1)
   Fairly often (2)
   Very often (3)
   Unknown (-3)
   Refused (-4)

5.3. In the past month, how often has someone helped you with shopping?
   Never (0)
   Once in awhile (1)
   Fairly often (2)
   Very often (3)
   Unknown (-3)
   Refused (-4)

5.4. Overall, how satisfied have you been in the last month with the help you have received with transportation, housework and yardwork, and shopping?
   Not at all (0)
   A little (1)
   Moderately (2)
   Very (3)
   Unknown (-3)
   Refused (-4)

5.5. In the past month, how often was someone right there with you (physically) in a stressful situation?
   Never (0)
   Once in awhile (1)
   Fairly often (2)
   Very often (3)
   Unknown (-3)
   Refused (-4)

5.6. In the past month, how often has someone provided comfort to you?
   Never (0)
   Once in awhile (1)
   Fairly often (2)
   Very often (3)
   Unknown (-3)
   Refused (-4)
5.7. In the past month, how often has someone listened to you talk about your private feelings?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)

5.8. In the past month how often has someone expressed interest and concern in your well-being?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)

5.9. In the past month, how satisfied have you been with the support received during difficult times, comforting from others, how others have listened, and interest and concern from others?
Not at all (0)
A little (1)
Moderately (2)
Very (3)
Unknown (-3)
Refused (-4)

5.10. In the past month, how often has someone suggested some action you should take in dealing with a problem you were having?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)

5.11. In the past month, how often has someone made a difficult situation clearer and easier to understand?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)
5.12. In the past month, how often has someone helped you understand why you did not do something well?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)

5.13. In the past month, how often has someone told you what they did in a situation that was similar to one you were experiencing?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)

5.14. Overall, how satisfied in the last month have you been with the suggestions, clarifications, and sharing of similar experiences you have received from others?
Not at all (0)
A little (1)
Moderately (2)
Very (3)
Unknown (-3)
Refused (-4)

I’d like to ask you a few more questions about your relationship with others. Remember, when the term “others” is used, it includes friends, neighbors, or family members other than (CR).

Negative Interaction

6.1. In the past month, how often have others made too many demands on you?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)
6.2. In the past month, how often have others been critical of you?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)

6.3 In the past month, how often have others pried into your affairs?
Never (0)
Once in awhile (1)
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)

6.4 In the past month, how often have others taken advantage of you?
Never ( )
Once in awhile ( )
Fairly often (2)
Very often (3)
Unknown (-3)
Refused (-4)

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Caregiver Health and Health Behaviors Questionnaire.

1. During which visit is this interview taking place?
   Baseline (1)
   6 month follow-up visit (2)
   12 month follow-up visit (3)
   18 month follow-up visit (4)
   Other (5)
   1.1 Specify ________________________________

2. Date of interview: __ __/ __ __/ __ __
   Month/day/year

Now I would like to ask a few questions about your health.

In general, would you say your health is:
   Poor (1)
   Fair (2)
   Good (3)
   Very good (4)
   Excellent (5)
   Unknown (-3)
   Refused (-4)

How true or false are each of the following statements for you? Please refer to the responses listed on this card.

5.1 I seem to get sick a little easier than other people.
   Definitely false (1)
   Mostly false (2)
   Neither false nor true (3)
   Mostly true (4)
   Definitely true (5)
   Unknown (-3)
   Refused (-4)
5.2. I am as healthy as anybody I know.
Definitely false (1)
Mostly false (2)
Neither false nor true (3)
Mostly true (4)
Definitely true (5)
Unknown (-3)
Refused (-4)

5.3. I expect my health to get worse.
Definitely false (1)
Mostly false (2)
Neither false nor true (3)
Mostly true (4)
Definitely true (5)
Unknown (-3)
Refused (-4)

Do you currently have, or has a doctor told you that you have, any of the following health problems?
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

6.1. Arthritis
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

6.2. High Blood Pressure
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

6.3. Heart Condition (specifically heart disease, heart attack, chest pain due to your heart, congestive heart failure, angina, MI).
No (0)
Yes (1)
Unknown (-3)
Refused (-4)
6.4. Chronic Lung Disease such as chronic bronchitis or emphysema (not asthma).
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

6.5. Diabetes
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

6.6. Cancer
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

6.7. Have you ever had or been told by a doctor that you had a stroke?
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

During the past two weeks, to what extent have you experienced the following symptoms.

7.1 Dizziness
Not at all (0)
A little (1)
A lot (2)
Unknown (-3)
Refused (-4)

7.2. Headaches
Not at all (0)
A little (1)
A lot (2)
Unknown (-3)
Refused (-4)
7.3. Stomach or bowel problems
Not at all (0)
A little (1)
A lot (2)
Unknown (-3)
Refused (-4)

The following questions ask about your daily routine.

8.1. Do you typically eat fewer than 2 meals per day?
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

8.2. Do you have 3 or more drinks of beer, liquor or wine almost every day?
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

8.3. Without wanting to, have you gained or lost 10 lbs or more in the last 6 months?
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

8.4. Do you do vigorous exercises for 15-30 minutes or more at least 3 times a week? (Examples include running, sports, swimming, brisk walking, job that involves physical labor.)
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

8.5. Do you smoke cigarettes now?
No (0)
Yes (1)
Unknown (-3)
Refused (-4)

8.5.1 About how many cigarettes do you usually smoke in a day now?
cigarettes/day: ____ ____
REFERENCE LIST


BIOGRAPHICAL SKETCH

Magaly Freytes was born and raised in Puerto Rico. She moved to Gainesville, Florida, in 1992 to attend the University of Florida where she earned a B.A. in sociology in 1996. After working for a year, she decided to pursue a graduate education. In 1999 she earned a master’s and a specialist in education degrees (M.Ed/Ed.S) in mental health counseling from the Department of Counselor Education from the same institution. After gaining clinical experience working as a counselor in a community mental health facility for several years, she returned to graduate school to earn a Ph.D. in Counselor Education in May 2007.

Since 2002 Ms. Freytes has been working for the Center for Telehealth & Healthcare Communications in the College of Public Health & Health Professions at the University of Florida. She is the Coordinator for the Alzheimer’s Caregiver Support Online project, where she develops and delivers information, education, and support for informal and formal dementia caregivers in English and Spanish. In addition, she has been a volunteer at the Alachua County Crisis Center for over 10 years and has collaborated in a handful of projects geared toward the investigation of diverse populations. Ms. Freytes has been a presenter numerous times at local, state, and national conferences for academic, professional, and general public audiences.