FACTORS INFLUENCING LATINO/HISPANIC CAREGIVERS’ PERCEPTION OF THE EXPERIENCE OF CARING FOR A RELATIVE WITH ALZHEIMER’S DISEASE

A

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To my parents, Lyda Flechas de Arévalo and Luis Felipe Arévalo Valbuena, who always believed in me and gave me their unconditional love and support. Without you, this work would not have been possible.

La gaviota ha podido mirar lejos porque ustedes siempre la han ayudado a volar alto.

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Agustina Valbuena de Arévalo

y

Trina Ramírez de Flechas

All were cared for and died at home surrounded by the love and caring of their families.

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FACTORS INFLUENCING LATINO/HISPANIC CAREGIVERS’ PERCEPTION OF THE EXPERIENCE OF CARING FOR A RELATIVE WITH ALZHEIMER'S DISEASE

Publication No. _______________

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CONTEXT:
The role that culture and language has on a person’s perception of the caregiving experience has not been explored. Neither have appropriate instruments been developed to explore the concept of burden that are culturally sensitive and linguistically congruent. Furthermore, there is not a Spanish word that is equivalent to the English word burden.

AIMS:
1. To describe the perceptions of the caregiving experience of bilingual (Spanish-English) and monolingual (Spanish) Latino/Hispanic family caregivers of patients with Alzheimer’s disease (AD).
2. To describe the culturally and linguistically relevant expressions and terminology used by bilingual and monolingual Latino/Hispanic AD family caregivers to identify the consequences of caregiving on their lives.

METHODS:

Bilingual and monolingual (Spanish) Latino/Hispanic AD caregivers were recruited. An ethnographic approach as described by Spradley was used to interview the caregivers and analyze the data. Grand tour questions and probes were tested during preliminary work to ensure that the descriptive questions and domain analysis were complete. The domain analysis is followed by taxonomic and componential analyses of data generated with structural and contrast questions.

IMPLICATIONS:

Findings may enhance the understanding of the concept of burden within the context of the Latino/Hispanic culture. Ultimately, this can result in better interventions to improve the quality of life of Latino/Hispanic AD caregivers.
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I. INTRODUCTION

A. Background and Significance of the Problem

It is projected that by 2050 the composition of the U.S. older population will be 61% non-Latino white, 18% Latino, 12% Black, and 8% Asian (Federal Interagency Forum on Aging-Related Statistics, 2004). The Latino population is projected to grow the fastest, from approximately 2 million in 2003 to 15 million in 2050, and to be larger than the older Black population by 2028 (Federal Interagency Forum on Aging-Related Statistics). The Alzheimer’s Association (2008) estimates that there are now more than 5.2 million people living with Alzheimer’s disease (AD) in the United States. Of these, 5 million people with AD are over the age of 65, and individuals under age 65 experience early onset Alzheimer’s disease (Alzheimer’s Association). One out of 8 people age 65 and older has Alzheimer’s and nearly 1 out of 2 over age 85 has it.

The number of Latino/Hispanic elders affected by AD could increase more than sixfold, from fewer than 200,000 today to more than 1.3 million by 2050 (Alzheimer's Association, 2004). Because age is the single greatest risk factor for AD, Latinos/Hispanics are, and will continue to be, disproportionately represented in the older population groups. Regardless of race or ethnicity, the opportunity for a person with AD to live at home depends on the availability of support. Of those people with AD and other dementias, 70% live at home, being cared for by relatives and friends (Alzheimer’s Association, 2007). Despite the availability of home health services, community agencies, respite care, and formal settings, such as AD day cares, informal caregivers such as family and friends remain, by far, the primary providers of physical and emotional support. Approximately 10 million Americans
are caring for a person with AD or another dementia; one out of three of these caregivers is 60 years or older (Alzheimer’s Association, 2007).

AD involves impairments in memory, cognition, attention, and gradual intellectual and functional deterioration. Providing primary care for a relative with AD demands an extraordinary amount of energy, time, and resources. As the disease progresses, the AD caregiver is exposed chronically to a series of stressors that lead to physiological and psychological responses. The AD caregiver deals with stress that can have many causes, including the need to be constantly available to provide close supervision to the person with AD, the perceived lack of family and social support, the seeking and securing of resources, and the behavior and communication problems of the person with AD.

One of the effects of caregiving is the perception of burden. This multidimensional concept has been explored at length in the white population. The available burden instruments to date have been developed and normed with white caregivers, and used to evaluate the outcomes of interventions to reduce their stress. Few research studies have been focused on racial and ethnic minority caregivers. The existing studies have used these burden measures without establishing their cross-cultural validity.

Caregiver burden has been defined and studied extensively within the white culture. Still missing in the caregiver literature and research is the perspective of the Latino/Hispanic population. Therefore, a critical gap exists in the knowledge of this very important topic. Perception of the caregiving experience is shaped by language and by Latino/Hispanic cultural values of familismo, respeto, and marianismo, among others. Latino caregiving may not only be different, it might not be considered a burden. How culture can influence a person’s perception of the effects of caregiving has not been explored. In addition,
appropriate instruments to assess the effects of caregiving that are both culturally and linguistically congruent have not been developed.

The Spanish language does not have a word that translates to the exact meaning of the English word *burden*. Perhaps the closest Spanish word is *carga*, which translates to a physical load, but not an emotional one. From the Latino perspective, it could be honorable to carry a big load. However, if the word *carga* is accepted as an alternative to *burden*, then *agobio* (oppression, overwhelm), *zozobra* (anxiety, worry), *sobrecarga* (overload), and *peso* (as in weight) are just as adequate. Anthropological principles of linguistics dictate that language is culture and culture is language. If the word *burden* does not accurately translate, then one must question whether the concept of burden is perceived as such by Latinos/Hispanic caregivers. Exploring how the consequences of caregiving are perceived by Latino caregivers is of paramount importance.

By studying the Latino/Hispanic perception of caregiving and the language used to express that perception, we will be able to design caregiver intervention programs that are linguistically congruent and culturally sensitive. Culturally appropriate programs are needed to improve the quality of life of Latino/Hispanic AD caregivers.

B. Purpose

Researchers have warned that caution is needed when generalizing from the relatively few current studies available with Latino caregivers. Latino caregivers may not feel comfortable talking about their distress associated with caregiving duties. Additionally, acknowledging the caregiving experience as a burden would be equivalent to complaining about it, which is unacceptable in a culture in which family is placed before individual interests. In Latino/Hispanic caregivers who are not bilingual, the cultural incongruence is
perhaps clearer. The word burden has no literal translation to Spanish. The term carga, used in current translations of burden scales, is a physical attribute describing the load of a given thing, and not openly used to describe a person, especially a loved one.

Thus, the overall goal of this study is to uncover and explore the manner in which Latino AD caregivers perceive the caregiving experience. The concepts and terminology used by bilingual and monolingual Latinos to describe their perception of the impact of caregiving on their lives need to be uncovered. This in turn will facilitate the development of instruments using culturally relevant concepts and the design of effective interventions for Latino AD caregivers, a population already under distress, to help them improve their quality of life.

C. Specific Aims

The specific aims of this study are the following:

1. To describe the perceptions of the caregiving experience of bilingual (Spanish-English) and monolingual (Spanish) Latino/Hispanic family caregivers of patients with Alzheimer’s disease.

2. To describe the culturally and linguistically relevant expressions and terminology used by bilingual and monolingual Latino/Hispanic AD family caregivers to identify the effects of caregiving on their lives.

D. Research Questions

The specific aims will be met by conducting an ethnographic study collecting data from participant observations, semi-structured interviews, and demographic data forms from caregivers. Each aim will be addressed with its corresponding research question as follows:
1. What are the perceptions of the caregiving experience of bilingual (Spanish-English) and monolingual (Spanish) Latino/Hispanic family caregivers of patients with AD?

2. What are the culturally and linguistically relevant expressions and terminology used by bilingual and monolingual Latino/Hispanic AD family caregivers to identify the consequences of caregiving on their lives?

E. Conceptual Orientation

The concept of burden has been studied since the 1950s (Yin, Zhou, & Bashford, 2002) and is a central concept in family caregiving research. Between 1985 and 1990 most researchers conceptualized burden into two dimensions: subjective or objective (Chou, Chyun, & Chu, 2002; Montgomery, Gonyea, & Hooyman, 1985; Vitaliano, Russo, Young, Becker, & Maiuro, 1991). Gradually, burden has become a multidimensional construct defined as the psychological, social, and financial problems experienced by family members caring for impaired relatives (George & Gwyther, 1986). A simplistic definition offered by Molinari (2006) is that caregiver burden is the amount of difficulty a caregiver experiences in the day-to-day activities of caregiving.

As used in this study, caregiver burden will be defined as the degree to which an individual perceives an inability to deal with the stress of disruption of physical, social, environmental, financial, and personal life as responsibility for the well-being of another individual is assumed. In addition, this researcher believes that caregiver burden is one of the concepts that defines the construct of caregiving perception. Therefore, the focus of the study’s conceptual orientation is the emotional domain of the caregiving experience.
1. Possible conceptual explanation of caregiver burden.

As depicted in Figure 1, this researcher proposes to orient the concept of caregiver burden as one of the emotional consequences of caregiving realities. Regardless of racial or ethnic background, caregivers face these day-to-day situations that are the antecedents to caregiving coping and perceptions. A caregiver exposed to the realities of caregiving mobilizes coping mechanisms, both positive and negative. The resulting outcome is the perception that the caregiver has of the overall caregiving experience. Caregiver burden is one of those perceptions.

Caregiver expenditure, an antecedent to the caregiver coping response, is the degree to which one offers time, as well as physical, social, financial, environmental, and personal resources on behalf of another. The coping response can be defined as the degree to which one mobilizes personal, physical, financial, social, and environmental resources to increase one’s perceived ability to manage stressful events.

The outcome, which is caregiver perceptions, can include caregiver burden as well as caregiver satisfaction. Caregiver satisfaction can result from self-sacrifice of caregiving, which can be perceived as role fulfillment, especially among Latino/Hispanics. Culture and language moderate the relationship between the caregiver expenditures and the coping response, and the relationship between this response and the perception of burden.

2. Assumptions.

The following assumptions are extracted from principles of ethnography and psycholinguistics. Specifically, assumptions are made about culture, language, and meaning.
Figure 1

Conceptual Orientation of Caregiver Burden
1. Each culture provides people with a way of seeing the world (Spradley, 1979). This view of the world is transmitted from one generation to the next primarily through language.

2. Language is not only a means of communication, it also functions to create and express cultural reality (Spradley, 1979). People who speak different languages create and express different cultural realities. Ways of perceiving, categorizing, and thinking about one's world are the direct result of the language one speaks.

3. The linguistic (cognitive) categories that make up an individual's view of reality and with which actions are defined are meanings (Krauss, 2005). The role of meaning is of paramount importance to human life (Frank, 1963). Meaning making is one of those attributes that makes us human and allows us to make sense of our lives and experiences.
II. REVIEW OF THE LITERATURE

The review of the literature provides an overview of caregiver burden and interventions for caregivers. The review will point out the existing gaps in knowledge about Latino/Hispanic AD family caregivers. Caregiver burden is a central concept addressed in caregiving research. However, the concept of burden has not been considered from the perception of Latino/Hispanic caregivers taking into consideration their cultural values and language.

A. Caregiver Burden

Providing primary care for a relative with AD can become overly demanding, especially as the disease progresses. Caregiving stress can have many causes, particularly the need to provide constant supervision and dealing with communication and behavior problems. It has been reported by Grant (as cited in Lee & Cameron, 2005) that the primary sources of strain to caregivers of people with dementia are behavioral problems and incontinence. The stress of caregiving can increase due to a perceived lack of family and friends support, lack of supportive responses from local health and social services, and perceived criticism from family, among other things (Shaji, Smitha, Lal, & Prince, 2003). Ory, Yee, Tennstedt, and Schulz (as cited in Gallagher-Thompson, Solano, Coon, & Arean, 2003) found in their 2000 study that caregivers of dementia patients experience more role stress, psychological distress, emotional strain, family conflict, and interference with other activities than caregivers of frail elder relatives without dementia.

Burden – the emotion resulting from the perceived inability to deal with the stresses of caregiving – was developed as a construct by Zarit, Reever, and Bach-Peterson (1987)
with Black and white dementia caregivers. Since then, burden has been studied in diverse settings and samples and defined in several different ways. There is a general consensus that burden entails subjective and objective components (Chou et al., 2002; Robinson, 1983; Rymer et al., 2002; Teri et al., 1992; Vitaliano, Russo, Young, Becker, et al., 1991; Vitaliano, Young, & Russo, 1991; Zarit & Zarit, 1982).

In general, burden can be expressed by the equation:

\[
\text{Burden} = \text{Exposure to Stressors} + \frac{\text{Vulnerabilities}}{\text{Psychological and Social Resources}}
\]

(Vitaliano, Russo, Young, Becker, et al.; Vitaliano, Russo, Young, Teri, et al., 1991). Burden has been defined as the psychological, social, and financial problems experienced by family members caring for impaired older adults (George & Gwyther, 1986). In this study and based on pilot work, the definition of burden has been modified to include the environmental, physical, and personal life disruptions experienced by the caregiver (Arévalo & Lewis, 2005).

B. Interventions to Support Alzheimer’s Caregivers

Cochrane database systematic reviews have assessed the effectiveness of health and/or social interventions designed to support AD caregivers (Lee & Cameron, 2005; Thompson & Spilsbury, 2005). Lee and Cameron, for instance, found that the utilization of respite care has been very low in many studies. Some caregivers in the studies included for review had not used respite services at all. These researchers pointed out that it remains an imperative objective of research to evaluate why respite is not used and whether any harm is associated with provision of respite care for dementia caregivers. Likewise, it remains to be established that interventions such as information, support groups, educational programs, and
other social interventions are effective in the reduction of stress for AD caregivers (Thompson & Spilsbury).

The effectiveness of interventions to reduce dementia caregiver burden has been evaluated with meta-analytic techniques (Acton & Kang, 2001). Collectively, interventions have been shown to have no effect on caregiver burden. In some cases, the effect of the interventions on burden for the caregiver was negative. In other cases, the control group burden scores improved more than those of the treatment group (Acton & Kang).

Only multicomponent interventions (education, support group, counseling, respite, psychoeducation, and others) significantly reduced burden. Acton and Kang (2001) considered these results important because reports of burden are the most commonly used measurement of the effectiveness of caregiver interventions. Because there is no absolute clarity about the differences between objective and subjective burden, it is critical to identify other outcomes that demonstrate the effectiveness of caregiver interventions (Acton & Kang).

Multicomponent interventions were also reported by Pinquart and Sörensen (2006) as the only interventions that reduced the risk of institutionalization of the care-recipient. In their meta-analysis, Pinquart and Sörensen included 127 intervention studies with dementia caregivers that had been published between 1982 and 2005. In another review of the caregiver intervention literature, Schulz, Martire, and Klinger (2005) included 51 caregiver intervention studies published between 1999 and 2005. Of these studies, 41 focused on dementia caregivers. More than half of the dementia caregiving studies were not statistically powerful enough to detect the effects commonly observed with psychosocial interventions. Schulz et al. noted that many of the dementia caregiver intervention studies did not assess
outcomes for the patient. Schulz et al. suggested that in addition to measuring patient outcomes, instead of solely relying on information provided by the caregiver, it was important to shift the focus in caregiving from the physical and organizational challenges of caregiving to other less tangible sources of distress for the caregiver. The authors further pointed out that intervention strategies to date have been geared primarily to decrease burden, leaving unexamined other factors, such as the caregiver’s perceptions of patient suffering.

Acton and Kang (2001) suggested that burden may be an outcome too global to be affected consistently by intervention, and that better and more precise measurements are needed to evaluate the outcomes of interventions for caregivers. The recognition that burden may not be the best outcome to evaluate the effectiveness of the interventions is important because it implies that other types of measurements are needed. Perhaps focusing on the degree to which caregivers experience positive aspects of caregiving may be a better way to evaluate interventions. Murphy (2005) found strong evidence that Alzheimer's caregivers were able to describe positive motives, rewards, and coping strategies to deal with the stresses of caregiving. Murphy identified positive approaches such as maintaining a positive attitude, learning to seek out and ask for help, using respite services, and talking to family for support. The presence or absence of positive aspects of caregiving such as those identified by Murphy could provide a better indication of the effectiveness of interventions designed to reduce stress in the caregivers.

For Latino/Hispanic caregivers the use of burden scales to measure the outcomes of interventions is even more questionable. Considering that the English word burden does not accurately translate to a word in Spanish with the same contextual meaning and that cultural
differences have not been taken into consideration, the use of burden scales appears inappropriate with this population.

A few studies have included Latino/Hispanic caregivers, but none to the knowledge of this researcher has examined the cultural differences in the perception of burden. Until research is conducted clarifying how burden is perceived and expressed, researchers are limited in their ability to design interventions appropriate for a population known to underutilize available programs.

In summary, the effectiveness of interventions to reduce caregiver burden needs continued analysis. Research that corroborates or refutes the adequacy of burden as a measure of the outcomes of interventions with Latino/Hispanic caregivers is much needed.

C. Gender, Race, and Ethnicity

It has been reported that caregiving is more stressful for women – daughters and wives – than for males – sons and husbands (Pruchnno, Burant, & Peters, 1997; Schulz & Williamson, 1991). Delgado and Tennstedt (1997) studied Puerto Rican sons as primary caregivers of elderly parents. Contrary to findings reported by other authors (Dwyer & Coward, 1991; Mui, 1995), Delgado and Tennstedt (1997) reported that the sons might be at higher risk for experiencing caregiving stress. Gender, however, is not the only factor that influences burden. Ethnicity and race also have an impact on the level of burden experienced by caregivers.

In a 20-year review (1980-2000) of issues of race, ethnicity, and culture in caregiving, Dilworth-Anderson, Williams, and Gibson (2002) examined burden in 18 studies. White caregivers reported significantly higher burden than Blacks in five studies, while four studies found no difference in burden scores. Other studies not included in the 20-year
review have also shown that Black caregivers appraise caregiving as less stressful than do whites (Haley et al., 1996). Dilworth-Anderson et al. included in their review a variety of caregiver studies, not dementia caregivers only. Morycz (as cited in Dilworth-Anderson et al., 2002) and colleagues looked exclusively at dementia caregivers and found that white caregivers reported significantly higher levels of burden than African-Americans. This study supported the belief that dementia caregiving could create a differentiated risk for burden between African-American and white caregivers. In contrast, a qualitative study conducted with urban African-American dementia caregivers (Fox, Hinton, & Levkoff, 1999) presented caregiver stories that described burden, loss, emptiness, and alienation.

Research has suggested that ethnicity and culture may help to predict burden and psychological distress among ethnic groups (Montoro-Rodriguez, Small, & McCallum, 2006). There are, for instance, significant differences between Anglo-American and Mexican-American dementia caregivers in their reactivity to their caregiving role, with Latino caregivers feeling more bothered with the overall caregiving experience and with specific tasks (Valle, Cook-Gait, & Tazbaz, 1993). Compared with African-American caregivers, Latinos perceive their caregiving duties to be a greater burden (Cox & Monk, 1990, 1993). Empirical studies have suggested that Latino caregivers in comparison to Anglo-Americans are in poorer health; however, the evidence is unclear for differences in psychological distress (Aranda & Knight, 1997; Connell & Gibson, 1997; Coon et al., 2004; Knight & McCallum, 1998). It can be hypothesized that Latino/Hispanic caregivers experience at least similar and perhaps higher levels of burden and depression as their Anglo-American counterparts and higher levels of burden and distress as African-American caregivers (Montoro-Rodriguez et al.).
D. Latino/Hispanic AD Caregivers

The number of studies on Latino/Hispanic AD caregivers is relatively small. The paucity of information is primarily due to the historical lack of Latino/Hispanic and Latino/Hispanic subgroups identifiers in major data sets, including the census, mortality statistics, medical records, the National Health Interview Survey, and many other data sources (National Alliance for Hispanic Health, 2001). It was not until 1996 that all states had added Latino/Hispanic identifiers to mortality data, and not until 2000 that the U.S. Census Bureau included two minimum categories for ethnicity, Hispanic or Latino and Not Hispanic or Latino, and the acknowledgment that Hispanics could be of any race (National Alliance for Hispanic Health).

Latinos/Hispanics in the United States are a widely heterogeneous group made up of people migrating from different countries with unique cultural and historical traditions and people born on the mainland (Montoro-Rodriguez et al., 2006). Latinos/Hispanics are expected to contribute about 44% of the population growth on the mainland between 2000 and 2020, and about 62% from then to the middle of the century (U.S. Department of Commerce, as cited by Montoro-Rodriguez et al.). As of 2003, Hispanics were reported by the Census Bureau as the largest minority in the United States (U.S. Department of Commerce, 2007). Among Latinos/Hispanics, people of Mexican origin account for 64% (25.9 million), Puerto Ricans for 10% (3.9 million), and Central American for 7.2% (3.9 million) of the total. Of the 2.2 million people of South American origin, Colombians, with 686,000, were the largest group (U.S. Department of Commerce).

As the number of older adults in the United States grows in an unprecedented manner, the number of Latino/Hispanic older adults continues to escalate (U.S. Department...
of Health and Human Services, 2003). Latino/Hispanic older adults are estimated to increase to 2.9 million in 2010 and 13.8 million in 2050 from the 1.5 million in 2000 (Hayward & Zhang, 2001). The number of Latino/Hispanic elders affected by AD could increase more than sixfold, from fewer than 200,000 today to more than 1.3 million by 2050 (Alzheimer's Association, 2004). Currently in the United States, family members provide some type of care to at least 70% of persons with dementia who live at home (National Alliance for Caregiving and American Association of Retired Persons, 2004). More than 27% of Latino households provide informal caregiving to an impaired friend or family member (Talamantes, Trejo, Jimenez, & Gallagher-Thompson, 2006). Latino/Hispanic caregivers are mainly women around 40 years of age in the sandwich generation providing care for their children under 18 while also caring for older relatives (National Alliance for Caregiving and American Association of Retired Persons, 1997; U.S. Department of Health and Human Services, 2003).

Numerous studies pertinent to caregiving and caregiver burden found in the literature do not report specific data relevant to Latino/Hispanics. For instance, in a review and analysis of racial, ethnic, and cultural differences in dementia caregiving (Connell & Gibson, 1997), only two studies, Cox and Monk (1990) and Mintzer et al. (1992), included Latino/Hispanic subjects.

Few studies have attempted to capture cultural differences in caregivers. Mintzer et al. (1992) attempted to explore whether ethnicity made a difference among daughters’ caregiving for Latino/Hispanic and non-Latino/Hispanic Alzheimer patients. The comparison was made between 13 Cuban-American Latino/Hispanic and 15 white daughter primary caregivers. Almost two thirds of the caregivers reported symptoms of depression and one
third had depression scale scores associated with clinically significant levels of depression. There were no significant differences in the level of depression of Cuban American and white daughters. Of the care recipients, 75% lived with their daughters compared with 13% of the white care recipients. An interpretation was made that this was indicative of strong cultural beliefs of family responsibility. There were no other significant differences. Cox and Monk (1990) compared 31 Black and 19 Latino/Hispanic caregivers. Two thirds were dementia caregivers. The two groups were similar in burden scores and the acknowledgment of strong feelings of family obligation. Depression scores, however, were much higher in Latinos/Hispanics than Blacks. These findings were corroborated by Cox and Monk (1996) in a comparison of 76 African-American caregivers and 86 Latino/Hispanic caregivers of AD elders in New York and Baltimore. Latino/Hispanic caregivers reported significantly higher personal strain and role strain than African-Americans. Later, Aranda and Knight (1997) found that Latino/Hispanic caregivers reported a level of emotional burden or depression similar to or higher than that of white caregivers. Aranda and Knight also concluded that Latino/Hispanics were more likely than whites to feel bothered or upset by specific caregiving tasks such as instrumental support with activities of daily living and by care recipients’ problem behaviors.

Studies about Latino/Hispanic caregivers have increased in recent years (Baker, 2006). Most current research, however, has used nonprobability sampling methods and a large number of measures of psychological well-being that often cannot be compared (Aranda & Knight, 1997; Dilworth-Anderson et al., 2002; Talamantes & Aranda, 2004). Generalizability was lacking in the studies conducted with Latino/Hispanic caregivers prior to findings from the Resources for Enhancing Alzheimer’s Caregivers Health (REACH)
project. This project, which will be discussed in greater detail in the next section, initiated a new standard in studying dementia caregiving because it achieved probability sampling of separate subgroups of Hispanic subgroups such as Cuban Americans in Florida, Mexican-Americans in California, and others.

The lack of validation of measures with Latino/Hispanic caregivers has resulted in the identification of cultural biases in certain instruments such as depression scales like the Center for Epidemiologic Studies Depression Scale (CES-D) used by Cox and Monk (1990). It is not surprising that excessively high or low scores may be given in different types of scales to a participant belonging to an ethnic group that is characterized as Spanish-speaking, socioeconomically disadvantaged, less educated, and medically underserved. Latino/Hispanic caregivers, compared with their white counterparts, are more likely to be poorer and in poorer health, and more likely to juggle multiple role responsibilities of family, work, and caregiving activities, which all contribute to greater psychological distress (Aranda & Knight, 1997). As possible explanations for the increased level of stress among Latino/Hispanic caregivers, Aranda and Knight discussed what many regard as a cultural advantage. According to these researchers, Latino/Hispanic caregivers’ great emphasis on valuing extended social support networks makes them more sensitive to crises. When Latinos/Hispanic caregivers experience a relative’s illness that disrupts the highly valued family system, requiring reorganization or relocation, the experience is perceived as distressing. Aranda and Knight added that Latino/Hispanic caregivers are less prone to talk about their situation or share their private feelings. Contrary to widespread beliefs about extensive Latino social support, studies have found that Latino caregivers have identified fewer networks for support (Phillips, Torres de Ardon, Komnenich, Killeen, & Rusinak,
2000), and that they report less social support compared with other cultural groups (Adams, Aranda, Kemp, & Takagi, 2002). In fact, many Latino elders believe that they will not have a caregiver available to them if they require care in the future (Talamantes, Cornell, Espino, Lichtenstein, & Hazuda, 1996).

E. Resources for Enhancing Alzheimer’s Caregiver Health (REACH)

The REACH project has contributed greatly to advancing our knowledge of the Latino/Hispanic AD caregiver. REACH is a unique multisite 5-year initiative investigating the effectiveness of innovative interventions to support AD family caregivers. Nine interventions and two control conditions were implemented at six sites throughout the country with 1,222 caregivers. The inclusion of sites such as Palo Alto, Miami, and Philadelphia ensured Latino/Hispanic participation. Latino/Hispanics could be fluent in either Spanish or English (Wisniewski et al., 2003). Analyses of REACH data have shown that Latino/Hispanic caregivers have higher levels of self-efficacy than white caregivers do. Higher levels of self-efficacy among Latino/Hispanics may relate to cultural values about caregiving and/or ethnic differences in appraisal (Depp et al., 2005). With data collected in the Palo Alto site, Gallagher-Thompson, Solano et al. (2003) compared 122 white and 91 Latino/Hispanic female caregivers. The caregivers were assigned either to a cognitive and behavioral skills learning group or to a support group. Both programs were adapted to be culturally sensitive to the concerns of white and Latino/Hispanic caregivers and delivered in either English or Spanish.

After 10 weeks the cognitive behavior group reported a significant reduction in depressive symptoms, increased use of coping strategies, and a decreased use of negative coping strategies when compared to the support groups. There were no effects for ethnicity
and no significant ethnicity by treatment interaction effects. These reports from the REACH study challenge previous assumptions about Latino/Hispanics, their levels of depression, and their low participation in research. The most valuable aspect of the Gallagher-Thompson, Solano et al. (2003) report is the demonstration that Latinos/Hispanics will participate and benefit from culturally sensitive research and programs designed to meet their unique needs. With larger samples, random assignment, and multisite data collection, the REACH project started a new phase in the study of Latino/Hispanic caregiving.

1. **REACH II.**

After the success of the initial REACH project, the principal investigators launched REACH II (Talamantes et al., 2006). The Coping with Caregiving (CWC), a skill-building, psychoeducational group intervention designed to reduce the stress experienced by caregivers, and part of REACH, was included in REACH II. The original CWC taught mood management skills in a small group format, with six to eight caregivers and one skilled leader. The group met weekly for 90 minutes over a period of 6-16 weeks. The full-length intervention had five components: behavioral management, cognitive reappraisal, communication skills, increasing everyday pleasant events, and planning for the future (Talamantes et al.).

REACH II incorporated many elements of the CWC intervention, but it was presented differently. This time the REACH intervention included 12 sessions (9 in-home sessions of 1.5 hours each and three telephone sessions of half hour each) and five structured telephone support group sessions (Belle et al., 2006). Preliminary data analyses indicated the success of this program on a number of caregiving distress indices. This study compared 212 Latino/Hispanic, 219 white or Caucasian, and 211 Black or African-American caregivers.
Latino/Hispanic and white caregivers in the intervention group experienced significantly greater improvement in quality of life than caregivers in the control group (Belle et al., 2006). The authors concluded that “a structured multicomponent intervention adapted to individual risk profiles can increase the quality of life of ethnically diverse dementia caregivers” (p. 727).

F. Cultural Congruency of the Concept of Caregiver Burden for Latinos/Hispanics

In all cultures there are certain unwritten rules that govern social interactions and that affect the manner in which individuals perceive events and situations. Cultural norms refer to a standard model or pattern regarded as typical for a specific cultural, racial, ethnic, religious, or social group. Cultural norms include thoughts, behaviors, patterns of communication, customs, beliefs, values, and institutions (Castellanos, 2000). In the Latino/Hispanic culture, in addition to the use of the Spanish language, there are central values that play a role in the perception of the caregiving experience. *Familismo, respeto, personalismo, dignidad,* and *marianismo* are values thought to have the greatest impact on the Latino/Hispanic perception of the caregiver role.

1. *Familismo.*

   This value refers to the strong identification and attachment that Latino/Hispanics have with their families (Sabogal, Marin, Otero-Sabogal, Marin, & Perez-Stable, 1987). *Familismo* includes strong feelings of loyalty, reciprocity, and solidarity among members of the same family (Sabogal et al.). Latino/Hispanic families traditionally emphasize interdependence over independence and cooperation over competition (National Alliance for Hispanic Health, 2001). For Latinos/Hispanics, family comes first, and it is at the center of
daily life. There is an emphasis on both the extended and the immediate family as a source of a sense of belonging, pride, purpose, and identity.

In most cultures, not just Latino/Hispanic, women play the role of primary caregivers, nurturers, and maintainers of the family unit. Among Latinos/Hispanics these roles are not played exclusively by mothers. Daughters, especially the oldest, comprise the majority of caregiver relatives with AD. The Latino/Hispanic culture values maintaining good relations with family members, caring for infirm relatives, and placing family needs above individual needs (National Center for Mental Health Promotion and Youth Violence Prevention, 2004).

_Familismo_ is seen as mediating the relationship between ethnicity and social support and burden (Talamantes et al., 2006). Latino/Hispanic caregivers who value familism highly are theoretically more willing to undertake caregiving responsibilities for a relative with dementia because they are more loyal and accepting of family duties (Talamantes et al.). _Familismo_ influences caregivers to report less perceived burden and fewer depressive symptoms (Robinson-Shurgot & Knight, 2004).

2. _Respeto_.

The interactions within the families and with close-knit family networks and Latino/Hispanic communities are mediated by _respeto_ (respect). _Respeto_ guides the deferential and appropriate behavior toward others based on sex, social position, and other factors. Older adults expect respect from those younger, adults from children, men from women, and so on (National Alliance for Hispanic Health, 2001). Traditionally _respeto_ generally applies to adults, especially to elders (National Center for Mental Health Promotion and Youth Violence Prevention, 2004). The formal style of addressing others in
Spanish (usted) conveys respeto. Qualities such as deference, obedience, and submissiveness are all ways of showing respeto (Castellanos, 2000).

3. Personalismo.

This value refers to the strong orientation that Latinos/Hispanics have toward close interpersonal relationships and friendship (Castellanos, 2000). Personalismo explains in part the fact that Latinos/Hispanics may turn first toward family and their communities for advice, rather than seeking professional opinions or utilizing American health care institutions. Despite the availability of formal care programs for persons with AD, these programs are underutilized by Latinos/Hispanics. Programs such as Alzheimer’s day cares can be seen by Latinos/Hispanics as having an impersonal, cold, unfriendly nature (National Center for Mental Health Promotion and Youth Violence Prevention, 2004).

An important part of living the value of personalismo is being simpático. No literal precise translation exists for this term. Being simpático or simpática suggests being charming, personable, easy going, agreeable, outgoing, and open (Castellanos, 2000). Personalismo also encompasses a sense of mutual trust (confianza) and the willingness to be servicial (to be of service, or to help others) (Castellanos).

4. Dignidad.

Castellanos (2000) defined dignidad (dignity) as the innate worth and integrity of all people. Latinos/Hispanics like to present themselves as dignified people, especially in public. Not preserving the dignity of parents, elders, and infirm relatives would be considered as a lack of respeto for them. Dignidad can be demonstrated to others through qualities such as being responsible, honest, hardworking, and respectful.
5. Marianismo.

Far from the polemic choice between Christ and Mary as worthy of devotion, *marianismo* refers to the admiration that most Latino/Hispanics (especially practicing Catholics) profess for the qualities of patience, sacrifice, and selfless devotion to a loved one. *Marianismo* is the stereotyped gender role of females in Latino/Hispanic societies. *Marianismo* can also be seen as the traditional sexual code of behavior for Latino/Hispanic women, specifying chastity before marriage, sexual passivity after marriage, and the subordination of women to men (Cofresi, 2002). It promotes a female spiritual superiority and teaches that women are semi-divine, morally superior to, and spiritually stronger than men (Stevens, 1994).

*Marianismo* refers especially to an excessive sense of self-sacrifice. The characterization of the ideal woman and mother includes traits and behaviors such as being pure of mind, body, and spirit, generous and giving, and ready to make the ultimate sacrifice for her family (Castellanos, 2000). It is not difficult to see how the ideal of *marianismo* sets Latino/Hispanic women up to attempt to achieve a revered status that is unattainable.

The opposite of *marianismo* is *machismo*, a traditional role that provides much more freedom for Latino/Hispanic males than females concerning sexual activity and public and social interaction. *Machismo* also refers to manly characteristics such as being virile, strong, courageous, and the family protector and provider.

A Latino/Hispanic caregiver’s perception of the experience of caregiving for a relative with AD is influenced by the values and norms described above. Latinos/Hispanics are likely to see caring for elder parents and relatives as a duty because, according to their culture, family comes first. In addition, caregiving is accepted as an interdependent function.
that takes precedence over being independent. Caregiving can be seen as the respectful manner to show responsibility and love, and, finally, valued as a visible sacrifice that can be rewarded by the admiration of others. With this in mind, it becomes clear that acknowledging the experience of caregiving as burdensome may not only take dignity away from the relative with Alzheimer’s disease, but also remove honor, respect, and the notion of self-sacrifice from the caregiver.

G. The Concept of Burden in Latino/Hispanic Caregiving Research

John and McMillian (1998) conducted focus group discussions with 17 participants to elicit Mexican-American caregivers’ interpretations of possible sources of burden during the caregiving experience. The purpose of their data collection was the cultural validation of an adapted and translated version of the Zarit et al. (1987) burden scale. The researchers reported qualitative themes. “The caregivers in the study saw caregiving as a responsibility to be accepted as both a pleasure and a privilege” (p. 107). Participants acknowledged that there were untoward emotional, physical, and interpersonal consequences to caregiving. When participants were questioned about experiencing burden, without exception they characterized their feelings as something other than burden. Descriptors of burden such as overwhelming, depression, worry, frustration, and carrying a heavy load were used. Participants did not characterize their feelings by the label of burden.

John and McMillian (1987) concluded that perhaps caregiver burden is an unfamiliar or unacceptable concept for Mexican-American caregivers or that they intentionally use language with a less negative connotation to preserve the honor, integrity, or reputation of the family. Cultural values appeared to limit the sense of burden experienced by these Mexican-American caregivers who were fulfilling a role with idealistic and unrealistic
expectations. These researchers concluded that the concept of burden was unpalatable to Mexican-American caregivers.

This key study supported this researcher’s aims of uncovering Latino/Hispanic perceptions of the consequences of caregiving and the terminology and expressions used by the caregivers to describe their experience. John and McMillian (1987) identified Latino/Hispanic traditions, filial duty, cultural aversion to nursing homes, and an over-idealization of the Latino/Hispanic family’s informal support group as possibly affecting the interpretation of burden.

Aranda and Knight (1997) discussed how minority caregivers in general may be reluctant to admit distress related to their caregiving duties when asked directly about it, either by professionals or by other family members. More recently, Talamantes et al. (2006) reported that Mexican-American caregivers participating in the Coping with Caregiving program, part of REACH, were “reluctant to admit to symptoms of burden” (Talamantes et al., p. 333). Admitting to an experience of burden implied that the caregivers did not accept their role and were not grateful for what the care receiver had done for them earlier in life (Talamantes et al.).

H. Language, Culture, and Perception

How culture can influence a person’s perception of burden has not been explored in Latinos/Hispanics. In their 20-year review of issues of race, ethnicity, and culture in caregiving research, Dilworth-Anderson et al. (2002) found that much of the research in this area lacked clear conceptualization and measures of culture. Most researchers included in the review found that cultural groups have values about reciprocity, filial obligation, and a sense of responsibility for providing care to older family members. However, more discussion was
needed on defining and measuring values and norms. In addition, although some well-known measures were used, most of them had not been tested for cultural relevance or sensitivity across groups (Dilworth-Anderson et al.).

Language has been identified as a major issue in minority AD outcomes research (Hazuda, 1997). In her study, Hazuda explained that the use of a 12-item personal strain measure showed substantially greater measurement error among Spanish-speaking Mexican-Americans. This undermined the validity of cross-cultural comparisons involving five ethnic-language subgroups. Three items had to be deleted from the measure to achieve consistent alpha coefficients across the groups. The items were:

1. How often do you feel embarrassed about your relative’s behavior?
2. How often do you feel that you will not be able to take care of your relative for much longer?
3. How often do you feel that you should be doing more for your relative?

These items appeared to have a distinctive meaning for Spanish-speaking Mexican-American elderly persons who were likely to have more traditional Mexican-American cultural orientation and to be of lower socioeconomic status than either English-speaking Mexican-Americans or Europeans. These distinctions, missed by the translators (Hazuda, 1997), have the underlying concept of burden as perceived by Euro-Americans. Items phrased in very similar words can be found in the most popular burden measures available to date. It can be seen then that quantitative studies can be strengthened by qualitative work that clarifies the concept of burden in Latinos/Hispanics. Qualitative inquiry with an ethnographic focus can provide the knowledge needed to develop measures using the appropriate language that respects the cultural values of Latinos/Hispanics.
Although in recent years there has been an effort to look into the cultural differences that affect the caregiver, no attention has been given to the role of language. No studies were found that attempted to compare the perception of burden in bilingual and monolingual caregivers. Even though both bilingual and monolingual caregivers may all belong to the same culture, the exposure of some to a second language influences the range of their verbal expressive ability. The lack of the word *burden* in Spanish may have had a tremendous impact on how investigators measured the outcomes of interventions geared to alleviate caregiver burden.

1. Cognition and emotion.

Linguists have understood for a long time that language and thought are closely related. Humans construct reality using thought processes, and these thoughts are expressed with language. Edward Sapir and his student Benjamin Lee Whorf brought attention to the relationship between culture, language, and thought. Neither of them wrote what has come to be known as the Sapir-Whorf hypothesis, but their writings about linguistics contained two main ideas. The first is linguistic determinism: the language people speak determines their thoughts. Therefore, language determines the interpretation of the world around us. Language and thought are identical. The second is linguistic relativism: an acknowledgment that differences among languages cause differences in the thoughts of individuals. Said differently, language influences our views about the real world. There are certain thoughts of an individual in one language that cannot be understood by those who live in another language. The way people think is strongly affected by their native languages.

Linguistic determinism had few supporters in the past. In recent years, however, more evidence has been found to support that it is very possible that terms exist in one
language that cannot be translated into another, and that the lack of such translation can preclude the speakers of one language from entertaining words encoded by the words or grammar of the other language (Gordon, 2004).

Distinctions made in English do not appear in other languages, and vice versa. For example, the English language has two different words for the colors blue and green, while other languages such as Tarahumara, an indigenous language of Mexico, instead uses a single color term that covers shades of both blue and green (The University of Chicago News Office, 2006). Kay and Kempton (1984) had shown that speakers of English and Tarahumara perceive colors differently. English speakers found blues and greens to be more distinct from each other than speakers of Tarahumara did, as if the English “green” / “blue” linguistic distinction sharpened the perceptual difference between the colors themselves. When shown chips of different blue and green shades, English speakers’ perceptions were distorted in the blue-green area, while speakers from Tarahumara, who lacked a blue-green distinction, showed no distortion.

The findings of the “Sally doll experiment” replicated by Peterson and Siegal (1995) also support linguistic determinism. In the Sally experiment, the investigator shows a child a doll called Sally placing a marble in a box and then Sally is taken out of the room. While she is gone, the investigator hides the marble in a basket. When Sally is brought back, the child is asked where Sally will look for her marble. Without explaining why, children know that Sally will look in the box rather than in the basket. This task does not appear to be related to intelligence. A cognitive process exists concerned with mental states but which itself is not mediated by mental state terms. This cognition is the ability to attribute mental states to others (to take their perspective and see things from their point of view in terms of desire,
intent, or belief). The presence of this cognition is what is tested with the “Sally doll” experiment. The only group previously known to have failed the experiment was autistic individuals. Peterson and Siegal conducted the Sally doll experiment with deaf children raised by deaf parents and compared them to deaf children raised by hearing parents. Even though they all belonged to the same culture, because sign language communicates concrete, rather than abstract concepts, hearing parents could not communicate to their deaf children about mental states, thoughts, or feelings. In contrast, deaf parents could communicate with their deaf children without the use of linguistic terms. Of 11 deaf children with hearing parents, only one answered correctly (Peterson & Siegal). Skoyles (2000) discussed this experiment at length and concluded that the results were direct evidence that language molds cognition.

In yet another study, Balinese people have been found to orient themselves differently from Westerners (Wassman & Dasen, 1998). In the Balinese language, the use of an absolute reference system based on geographic points on the island correlates to the significant cultural importance of these points to the people. The most recent and perhaps strongest evidence in support of linguistic determinism was reported by Gordon (2004). He examined the language used by the Piraha tribe in the Brazilian Amazonia. The language used by the Piraha contains only three counting words: “hoi” (in a falling tone) for roughly one or small, “hoi” (in a rising tone) for two, and “baagi” or “aibai” for many (Gordon). The Piraha have difficulty recounting numbers higher than three; there is simply a category for many. The Piraha’s impoverished counting system truly limits their ability to enumerate in excess of two or three items or draw. The presence of only three words to count precludes the translation of any precise number to Piraha language.
A life without number words cannot capture exact magnitudes (Gordon, 2004). When applied to the caregiving research area, this finding supports raising a question: Can cultural life without the word *burden* capture that experience? Both Sapir and Whorf agreed that it is our culture that determines our language, which in turn determines the way that we categorize our thoughts about the world and our experiences in it (Kay & Kempton, 1984; Ross, 1992). Likewise, what a person experiences in the context of one language may actually physically be the same as one occurring in another language or culture. Although both people are cognitively able to interpret the experience, their interpretation and value of what is occurring can be completely different. These differences in interpretation are guided by cultural values and the use of the language specific to that culture. Even among members of the same culture, the use and interpretation of certain words may be different.

2. **Code-switching.**

The findings available about the Latino/Hispanic caregiver have been obtained in studies with mostly bilingual participants, who, because of their bilingualism, can be considered much more acculturated than monolingual Latinos/Hispanics. When bilingual participants are asked in one language about a phenomenon that has a precise word in another language, researchers must be prepared to control for the phenomenon known as code-switching. Events that are recounted in the process of an interview, for instance, are emotion-related. Bilingualism is widely accepted as an advantage to gain access to services, and, in general, to improve the daily functioning of a person across cultures. Bilingual caregivers have a choice as to which language to use, and, therefore, have the ability to select the words that most clearly capture the idea that they are trying to convey.
Bilinguals, however, can also use their second language to distance themselves from troubling events (Altarriba, 2002). Caregiver burden researchers have not considered that their bilingual participants may be using code-switching to distance themselves from emotions that could be considered shameful. When Latino/Hispanic cultural values of filial responsibility (duty to parents and elders) are taken into consideration, researchers need to realize that their bilingual participants talk about burden in English, but if asked to speak Spanish, they may deny the existence of the experience of burden altogether (Arévalo & Lewis, 2005, 2006a, 2006b).

I. Burden Scales used by Latino/Hispanic Caregiving Researchers

Numerous instruments have been designed to measure caregiver burden. These instruments have been developed and normed with white subjects. Scales such as the Burden Interview (Zarit et al., 1980), the Caregiver Strain Index (Robinson, 1983), the Subjective and Objective Burden Scale (Montgomery et al., 1985), the Caregiver Burden Inventory (Novak & Guest, 1989), the Relatives’ Stress Scale (Greene, Smith, Gardiner, & Timbury, 1982), the Rabins, Mace, and Lucas’ Structured Interview (Rabins, Mace, & Lucas, 1982), the Caregiver Hassles Scale (Kinney & Stephens, 1989), and the Screen for Caregiver Burden (SCB) (Vitaliano, Russo, Young, Becker et al., 1991), among many others, lack validation across languages and across cultures. The REACH study has used the Revised Memory and Behavior Problem Checklist (RMBPC) (Gallagher-Thompson, Coon et al., 2003; Roth et al., 2003; Teri et al., 1992).

Vitaliano, Russo, Young, Becker et al. (1991) conducted a review of 10 measures used among caregivers. The content validity, conceptualization, and psychometric properties, such as reliability and construct validity, were compared. Overall it was noted that the
content validity of burden measures had not been addressed, and that burden measures for caregivers of individuals with a certain diagnosis, may not be appropriate for caregivers of individuals with dementia. All burden measures with the exception of Vitaliano, Russo, Young, Becker et al. had targeted diverse groups of caregivers. Caregiver specificity was identified as an important subsequent step in burden research. In terms of the conceptualization of burden, the results yielded several referents of the construct. Only five measures considered a distinction between objective and subjective burden. Distinguishing these aspects of burden allows for the measurement of the frequency of experiences as well as for the level of distress, both aspects that when clearly differentiated can allow for distinct interventions. In terms of the psychometric properties, most of the examined burden measures had not been systematically and rigorously tested. Criterion validity and sensitivity to change were present in only one of the studies reviewed (Vitaliano, Russo, Young, Becker et al.). None of the instruments included by Vitaliano, Young et al. (1991) in their review were analyzed for applicability across cultures.

More recently, the Revised Memory and Behavior Problem Checklist (RMBPC) was used in the multisite REACH initiative designed to develop interventions for family caregivers of individuals with moderate levels of cognitive impairment (Roth et al., 2003). Although the RMBPC was translated to Spanish, the cultural relevancy of its items was not found in this review of the literature.

It is clear then that despite a few studies about caregiver burden with Latino/Hispanic participants none of the measures has really been evaluated for cultural relevancy and linguist congruency. Qualitative research can provide the exploration needed to ascertain that
measures used over the past 50 years truly capture the concept of burden in Latino/Hispanic caregivers.

Although a few of the scales (SCB and the RMBPC) have been translated to Spanish, there is no published information on their cultural validation. In addition to the lack of cultural validation, it is particularly interesting that the vast majority of scales are not caregiver-centered, but rather focused on the behaviors of the person with AD. Despite this, the scales have been used in the few available studies on Latino/Hispanic caregivers. These scales will continue to be used until new research confirms or refutes Latino/Hispanics caregivers’ perceptions of caregiving. Scales that are predominantly caregiver-centered and sensitive to Latino/Hispanic attitudes and beliefs remain to be created.

1. Burden or carga?

The fact that there is not a Spanish word that exactly translates the concept of burden raises concern when it is measured in Hispanics. Perhaps the closest Spanish word is carga, which in fact translates to load (a descriptor of a physical rather than emotional nature). However, if the word carga is accepted as an alternative to burden, then agobio (oppression, overwhelm), zozobra (anxiety, worry), sobrecarga (overload), and peso (as in weight), are just as adequate.

Burden, however, is not the only concept in the caregiving area that presents this problem. Stress has several different recognized equivalent words, among them, tensión (as in mental stress), sobrecarga (overload, as in stress fracture), esfuerzo (as in stress test), and even énfasis (emphasis). Cope, as well, can be approximately translated to manejar (manage), lidiar (to deal with, to combat, to contend), tener fuerza para (to have the strength for), arreglándose (to fix by one self), and poder con (deal with). The term cuidador, the
translation of caregiver, is a word that traditionally had been used as an adjective, and that was rather considered antiquated Spanish. Currently, the Royal Academy of The Spanish Language (2001) acknowledges its use as a substantive. This use may have been prompted by the inclusion of the word in Spanish psychology, nursing, and psychiatry journals dealing with caregiving issues.

It is common for healthcare journals to adopt English terminology for the lack of better words in Spanish. For instance, to speak of *síndrome de “burnout”* is generally understood, even though the word *burnout* is not Spanish. The monolingual, lay Spanish speaker, however, could be puzzled by such an expression. It becomes apparent then that different words and expressions may be needed if we are to obtain data that accurately reflects the meaning of the experience of caregiver burden.

Gallagher-Thompson, Solano et al. (2003) warned that caution is needed in generalizing from the relatively few current studies available with Hispanics compared to the large body of literature available on the impact of caregiving on white/Anglos. Among six major barriers identified affecting recruitment of Hispanics into research studies were cohort differences. Older Hispanic caregivers may not feel comfortable talking about their distress associated with caregiving duties. “Terminology that is used to describe caregiver stress may also discourage participation” (Gallagher-Thompson, Solano et al., p. 47). The term *burden* is not acceptable to many Mexican-American caregivers (John & McMillian, 1998). The strong value of *familismo*, in which duty to family takes prominence, is seen in the powerful feeling of obligation to care for aging parents at home. Acknowledging the experience of burden is equivalent to complaining about being a caregiver, which is not culturally appropriate (Gallagher-Thompson, Solano et al.). The word *burden* itself has been found to
be “unpalatable” to many Hispanics. While Hispanic caregivers might use descriptors of burden, such as feeling socially isolated, resentful, or frustrated; the concept of burden is not acceptable (Calderon-Rosado & Tennstedt, 1998; John & McMillian, 1998).

Likewise, Roth et al. (2003), in their study that expanded the Revised Memory and Behavior Problems Checklist (RMBPC) to simple occurrences and caregiver ratings of perceived burden, found that older Hispanics in particular were not comfortable admitting any distress associated with family caregiving. In this study, all measures were translated to Spanish to ensure the inclusion of Spanish-speaking participants. The use of the words *bother* or *upset*, however, as they relate to the caregiving experience, may have been of limited use. Cultural values could have influenced the extent to which the caregivers used these words to report behaviors and the degree of reactivity to them, which was measuring perceived burden (Roth et al.).

Along the same lines, an analysis of change in indices of distress among Latino/Hispanic and Anglo caregivers of elderly relatives with dementia, also part of the REACH study, used the RMPBC (Gallagher-Thompson, Coon et al., 2003). The cultural sensitivity of this study was heightened by the use of bilingual-bicultural staff. In addition, the translation methodology focused on conceptual translation to maximize meaning, intent, and understanding across Spanish speakers representing different age cohorts, education levels, national origins, and levels of acculturation languages. However, the use of the words *bother* and *upset* remained in the instrument.

Other instruments, like the Screen for Caregiver Burden (SCB) (Vitaliano, Russo, Young, Becker et al., 1991; Vitaliano, Young, & Russo, 1991), have also been translated. The title given in Spanish to the SCB is *Escala Subjetiva de Carga Familiar* (Family Load
Subjective Scale). The use of the word *carga*, meaning “load,” was not well received by bilingual Latino/Hispanic caregivers interviewed in a pilot study exploring the concept of burden (Arévalo & Lewis, 2005, 2006a, 2006b).

Language used in a study has been identified as a barrier to participation and retention of Hispanics in research by Gallagher-Thompson, Solano et al., (2003). Language may determine if a participant is willing to enter and remain in a research study. After all, Spanish is the preferred language for many Latino/Hispanic caregivers (Gallagher-Thompson, Talamantes, Ramirez, & Valverde, 1996)

**J. Summary**

The previous sections have discussed the major points about current knowledge in the caregiving research area, caregiver burden (measures and interventions), Latino/Hispanic caregivers, and the relationships of culture, language, and emotion. When all these elements are brought together, there is a clear area of intersection where much remains to be explored about the Latino/Hispanic AD caregiver.

Despite more than 50 years of research, the concept of caregiver burden remains too broad to be the best outcome indicator of the effectiveness of caregiver interventions (Acton, 2001). As the Latino/Hispanic culture component overlaps with the areas of burden conceptualization, burden measures, and caregiver interventions, other limitations become apparent. The majority of the studies employed measures that were not designed for or normed with Latino/Hispanic caregivers. For the most part, research in the area of Latino/Hispanic caregiver burden has been neither culturally competent nor linguistically congruent.
The absence of certain words in Spanish such as \textit{burden} and \textit{coping} has not been adequately considered in the existing research; consequently, the use of a concept such as \textit{burden} that is culturally and linguistically nonexistent is questionable for measuring the effectiveness of interventions with Latino/Hispanic caregivers. This researcher suggests that the best measures of the impact of caregiving duties and of the interventions that minimize the negative effects of caregiving lie, not in the imposition on Latinos/Hispanics of the Euro-American concept of burden, but in other concepts that more positively express the impact of caregiving. Therefore, there is a tremendous need for further research that can either add clarity to the conceptualization of burden in the Latino/Hispanic Alzheimer’s caregivers or identify the appropriate terminology and expressions that describe the caregiving experience and its consequences. Qualitative inquiry can best assist this population to cope more effectively with the challenges of caregiving.
III. METHODS

Ethnography as a form of qualitative inquiry guided the exploration of Latino/Hispanic AD caregivers’ experience of caregiving. The purpose of this ethnographic study was to describe the perceptions of the caregiving experience of bilingual (Spanish-English) and monolingual (Spanish) Latino/Hispanic family caregivers of patients with Alzheimer’s disease.

Language is more than a way of communication about reality; it is a tool for constructing reality (Spradley, 1979). By using ethnographic interviews, participant observations, field notes, artifacts, and a reflective journal, the researcher explored the culturally and linguistically relevant expressions and terminology used by bilingual and monolingual Latino/Hispanic AD family caregivers to describe the effects of the realities of caregiving on their lives. The researcher described the realities of caregiving as narrated by the caregivers in the language they speak.

A. Ethnography

Ethnography is a qualitative research design in which the investigator describes and interprets the shared and learned patterns of values, behaviors, beliefs, and language of a culture-sharing group (Creswell, 2007). Ethnography is focused on discovery rather than verification, and its product is made up of narrative interpretations of cultural phenomena and language. Ethnography is both a process and an outcome of research (Agar, 1980). It is a way of studying a culture-sharing group, as well as a final extensive written work (Creswell). The culture-sharing group object of this investigation is bilingual and monolingual Latino/Hispanic AD caregivers.
Anthropologists such as Boas, Malinowski, Radcliffe-Brown, and Mead gave ethnography its beginning in the early 20th century (Creswell, 2007). These researchers took the natural sciences as a model for research. Atkinson and Hammersley (1994) collected firsthand data concerning existing primitive cultures. More recently, scientific approaches to ethnography have expanded to include subtypes of ethnography with different theoretical orientations and aims (Creswell).

Ethnography is the work of describing a culture (Spradley, 1979). It has its roots in the fields of sociology and anthropology. The goal of ethnography is to capture the native’s point of view. Field work to learn this point of view is the hallmark of cultural anthropology (Spradley).

In ethnography the ethnographer is the primary research instrument (Munhall, 2001). The researcher uses data collection methods such as participant observation, ethnographic interviews, field notes, and a reflective journal to discover the way of life, and, most importantly for this study, the meaning of the events and relationships to the people from their point of view (emic).

1. Assumptions and general principles.

The following assumptions, synthesized by this researcher from Spradley’s (1979) classic work on ethnographic interviews, provided the justification of the ethnographic approach given to this study:

1. Knowledge of all cultures is valuable.
2. Language is the primary means for transmitting culture from one generation to the next.
3. Much of any culture is encoded in linguistic form.
4. People everywhere learn their culture by observing other people, listening to them, and then making inferences.

5. A large part of any culture consists of tacit knowledge. We all know things that we cannot talk about or express in direct ways.

6. Cultural inferences can be made from three sources: (a) from what people say, (b) from the way people act, and (c) from the artifacts people use.

7. Language is more than a means of communication about reality; it is a tool for constructing reality.

8. Different languages create and express different realities. They categorize experience in different ways.

2. Participant observation.

All ethnography encompasses participant observation, even though not all research that uses participant observation has as its final product an ethnography (Munhall, 2001). Participant observation refers to the immersion of the researcher in the cultural data of the field to observe behaviors directly (Munhall). These observations are made in such manner that the researcher induces as little change as possible.

Data collected during participant observation are recorded as specifically as possible and with great detail. If notes cannot be taken at the time of the observation, they are recorded as soon as possible and as close to verbatim as possible (Munhall, 2001). The researcher can be a complete observer, an observer who participates, or a participant who observes. In this study, the researcher was a complete observer of Latino/Hispanic caregivers interacting with other caregivers at gatherings at a local agency that supports dementia caregivers, during two 4-hour sessions of a Spanish support program for Alzheimer’s
caregivers, and during three 2-hour Alzheimer's caregiver support group sessions held by a Colombian agency supporting AD caregivers. The local support agency, located in South Texas, is a facility dedicated to provide resources for Alzheimer’s caregivers and their families. The Spanish support program for Spanish-speaking Alzheimer's caregivers was implemented by a Colombian bilingual geriatrician and a bilingual Mexican-American gerontologist. These two settings provided the researcher with the opportunity to observe bilingual Latino/Hispanic Alzheimer’s caregivers. In contrast, the researcher was able to complete participant observations during Alzheimer support group session in Colombia. These support groups were sponsored by nonprofit associations dedicated to teach and support Alzheimer’s disease caregivers in Colombia. The researcher had the opportunity to observe the caregivers interacting and speaking Spanish only.

3. Field notes.

The researcher kept notes of the observed behaviors, language used, artifacts, and any other event that could provide meaning to the experience under study. These field notes were used to gain an understanding of the participant’s beliefs, costumes, and culture in their natural setting (Lincoln & Guba, 1985). These notes were collected and transcribed to Microsoft Word documents. These notes did not include interpretation of events or behaviors but rather reflected in the most accurate way possible what had transpired.

4. Reflective field work journal.

A journal of all field work was also kept by the researcher. Unlike the field notes, the journal is characterized by the expression of the perspective of the researcher. The journal included a record of feelings, biases, reactions, fears, and problems faced in the field (Munhall, 2001). The journal can also include theoretical insights, ethical issues, and in
general the researcher’s response to the data collection experience (Munhall). This journal included entries made after the meetings with Dr. Sara Gill, who was a crucial part of the audit trail in this study. Likewise, insight was documented in the journal after peer debriefing meetings with psychology and counseling doctoral students, staff members of the program to support Alzheimer’s caregivers.

5. Ethnographic interview.

The ethnographic interview can be structured, semi-structured, or unstructured interviews of individual participants or groups (Munhall, 2001). The goal of the ethnographic interview is to uncover the cultural meaning of the participant’s behaviors. This study followed Spradley’s (1979) guidelines of ethnographic interviewing and research. The types of questions and how and when they were formulated are explained under the data collection section.

B. Research Design

An adaptation of Spradley’s (1979) developmental research sequence (DRS) guided this investigation. The ideal sequence of the DRS includes twelve steps. In practice, many scientists deviate from this pattern or modify it to fit the needs of the investigation. This study followed the DRS sequence.

1. DRS steps for data collection and analysis.

The sequence of steps is as follows:

a. 1. Locating informants. Informants are native speakers engaged by the researcher to speak in their own language (Spradley, 1979). Informants provide a model for the researcher to imitate, thus becoming teachers for the researcher (Spradley). A description
of what was considered a key informant for this study is provided in the sample criteria section.

b. 2. Interviewing the informants. The ethnographic interview is carried out more like a series of friendly conversations than a formal interrogation (Spradley, 1979). The most important aspects of the interview are to have an explicit purpose, ethnographic explanations, and ethnographic questions (Spradley). During each interview, the researcher and the informant must realize that the talking has a purpose and direction. The explanations offered during an interview refer to what the project is about, reasons for tape recording or note taking, use of native language, the type of interview, and type of questions. The questions asked to the caregivers were initially descriptive in nature. Later structural and contrast questions are included in the interview. Formal semi-structured interviews were conducted with 20 caregivers. Informal interviews were conducted with caregivers during several of the participant observations, and family gatherings.

c. 3. Making an ethnographic record. The ethnographic record consists of field notes, tape recordings, artifacts, pictures, and any other element that can contribute to the understanding of the culture under study (Spradley, 1979). The record is a reflection of the actual field situation and, therefore, it must be a verbatim record of what people say (Spradley). The ethnographic record in this study included the verbatim transcription of the semi-structured interviews in the source language, audio tapes of these interviews, the transcription of the researcher’s field notes and reflective field work journal, and artifacts. The artifacts included in the ethnographic record were: the manuscript ¡Mi mamacita tiene Alzheimer’s! (My beloved mother has Alzheimer’s!), brochures from the Asociación
Colombiana de Alzheimer, newspaper clips submitted by a caregiver, and an article from a Colombian magazine on familial Alzheimer’s disease in that country.

d. 4. Asking descriptive questions. These questions are asked to elicit a large sample of answers in the participant’s native language (Spradley, 1979). In this study, the descriptive questions were framed to obtain a rich narrative of what is like to be a caregiver to a relative with Alzheimer’s Disease. An example of a descriptive question used was: Can you tell me what being a caregiver is like for you?

e. 5. Analyzing ethnographic interviews. This analysis enables the researcher to discover the questions to ask in future interviews (Spradley, 1979). During this analysis, terms and semantic relationships emerge to make up symbolic categories or domains. Domains are the first and most important unit of analysis in ethnographic research. The focus of this step is to look for domains that are “names for things” (Spradley, p. 100). The first five semi-structured interviews were analyzed to identify emerging domains. The interviews were also analyzed separately by Dr. Sara Gill to ensure that emerging domains identified by the researcher were supported by the data when analyzed by a different person.

f. 6. Making a domain analysis. Domain analysis is a more systematic procedure that leads to finding other kinds of domains. Through the selection of semantic relationships and informant statements, the researcher looks for possible terms that appropriately fit the semantic relationship. Structural questions were formulated for each domain as needed to gain clarification and were used in later interviews (Spradley, 1979). The domain analysis is further described in the data analysis section.
g. 7. Asking structural questions. The purpose of these questions is to verify the domains and elicit folk terminology included in the domains (Spradley, 1979). These questions are adapted to each individual informant, meshed with other kinds of questions, and repeated over and over again (Spradley). Structural questions were asked concurrently with descriptive questions and were designed to complement rather than replace descriptive questions. From this point on, structural questions were part of every interview (Spradley). Examples of structural questions used in this study were: What effect does being a caregiver have on you? and How have you been most affected by being a caregiver?

h. 8. Making a taxonomic analysis. This analysis limits the scope of the ethnography by focusing on the internal structure of the domains. The goal is to formulate a tentative taxonomy and generate more structural questions to verify the taxonomy and elicit new terms. During this step, the researcher looked at the domains that had been identified and generated a taxonomy of terms used by the caregivers. From this analysis, structural questions were also generated. These questions were aimed at discovering new terms.

i. 9. Asking contrast questions. The goal of this analysis is to discover the meaning of the taxonomies of cultural domains. The meaning of a symbol can be discovered by finding out how it relates to all other symbols by asking how it is used rather than asking what it means, by finding out how it is similar to other symbols, and, most important for this analysis, by finding out how it is different from other symbols. Contrast questions are asked to verify differences, to point out a folk term, and to ask if any other terms contrast on that characteristic (Spradley, 1979). Examples of contrast questions asked in this study were: Are there positive or negative aspects of caring for _________?, and Is burden the same thing as carga?
j. 10. Making a componential analysis. The differences that emerge from contrast questions and from the review of field notes give rise to componential analysis (Spradley, 1979). This analysis enables the researcher to take all the contrasts that have been discovered and organize them in a systematic fashion, identify missing contrasts, and represent the components of meaning for any contrast set (Spradley).

k. 11. Discovering cultural themes. In this step, the nature of the cultural themes that have emerged is examined to give the researcher a holistic view of the cultural scene (Spradley). Spradley defined a cultural theme as any cognitive principle, tacit or explicit, recurrent in a number of domains and serving as a relationship among subsets of cultural meaning. Three major cultural themes emerged from the data in this study.

l. 12. Writing ethnography. In this step the discovered meaning of one culture is translated and communicated to the members of another culture (Spradley, 1979). In addition, the researcher may present recommendations for what else could be studied in this cultural scene (Spradley). Discussion of the findings is presented in Chapter V and includes recommendations for future research.

2. Sample size and sample size justification.

Qualitative studies generally use small non-random samples (Polit & Beck, 2004). Sample size in qualitative research is a function of the purpose of the inquiry, the quality of the informants, and the type of sampling strategy used (Polit & Beck). In general, the principle of data saturation guides qualitative sampling; that is, no further participant sampling is needed because no new information is being obtained (Morse, 2000).

In the ethnography tradition, investigators may converse with many people, usually between 25 and 50, but rely heavily on a smaller number of key informants (Morse, 2000).
These key informants are participants that the investigators consider knowledgeable of the culture and chosen purposively guided by the investigators’ theoretically informed judgments (Morse).

The sample size planned for this study consisted of 20 bilingual (Spanish/English) and 20 monolingual (Spanish) Latino/Hispanic caregivers caring for a relative with Alzheimer’s disease. Based on the data obtained during the preliminary study (Appendix A), it was anticipated that data saturation would be reached prior to completing interviews with 20 participants. If participants were good informants who were able to reflect on their own experiences and communicated them effectively to the investigators, data saturation could be achieved with a relatively small sample (Morse, 2000). The sample of key informants for this study consisted of six bilingual caregivers and 14 monolingual caregivers. The researcher did not find it necessary to include more bilingual participants because saturation of the data was reached with the six participants. In addition, data were available on the eight bilingual participants included in the preliminary study. In addition to the 20 key informants, nine different caregivers were informally interviewed, and 27 caregivers were part of the participant observations. A total of 56 caregivers were part of the overall sample. Table 1 summarizes the recruiting sources, the numbers of caregivers recruited from each source, and the specific role of the caregivers in this study in terms of their contribution to the data.

1. **Data saturation.** The term saturation refers to the point at which all levels of codes are complete (Munhall, 2001). This point can be determined when no new information, domains, concepts, or ideas emerge indicating the need to create or expand domains.
Table 1

Recruiting Sources and Participant Roles

<table>
<thead>
<tr>
<th>Recruitment Source</th>
<th>Key Informants</th>
<th>Informal Interviews</th>
<th>Participant Observations</th>
<th>Total per Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>English program for AD caregivers</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Spanish program for AD caregivers</td>
<td>0</td>
<td>2</td>
<td>18</td>
<td>20</td>
</tr>
<tr>
<td>Community center for dementia caregivers</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Personal referrals</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Colombian agency for support of AD caregivers</td>
<td>14</td>
<td>3</td>
<td>6</td>
<td>23</td>
</tr>
<tr>
<td>Total of Caregivers</td>
<td>20</td>
<td>9</td>
<td>27</td>
<td>56</td>
</tr>
</tbody>
</table>
Munhall stated that although new descriptive data can be added, the information will not be useful unless the theoretical codes need to be altered. In the case of ethnography, these codes are the domains identified by the researcher. When all data fit into these domains, the cultural themes emerge. The researcher achieves a sense of closure by repeatedly checking and asking questions of the data (Munhall). Data saturation is reached when new data yield redundant information (Polit & Beck, 2004). Data saturation can be reached with a relatively small number of participants, provided they are good informants. As explained in the previous section, the researcher found that data saturation had been reached with six bilingual and 14 monolingual caregivers.

b. Good informants. Key to qualitative inquiry is the richness of the information that can be obtained from the participants. Purposive sampling allows careful selection of the cases that will most benefit the study (Polit & Beck, 2004). This selection is based on the participants’ particular knowledge of the phenomenon of interest (Sandelowski, 1995). Using the guidelines provided by Spradley (1979) and inclusion and exclusion criteria to select the participants, a wide variety of participants were selected for the study. Three caregivers, who had participated in a National Institute of Health (NIH) program for English-speaking caregivers, had been described as articulate by members of the research team in that study. The other three bilingual caregivers were recruited by word of mouth and selected based on their demographic characteristics and an initial brief screening telephone interview. Monolingual caregivers were selected with the assistance of the president of a Colombian agency that supports AD caregivers, who was very familiar with the caregivers and their personal situations. Caregivers included in the study were able to provide a rich description of their caregiving experience.
The first step in Spradley’s (1979) DRS sequence is the location of the informants (participants). A good informant according to Spradley must meet five requirements: (a) thorough enculturation, (b) current involvement, (c) an unfamiliar culture scene, (d) adequate time, and (e) be nonanalytic.

(1) **Enculturation.** As the natural process of learning a particular culture (Spradley, 1979), the informants needed to be enculturated to the Latino/Hispanic culture and the Alzheimer’s caregiving culture. To be considered thoroughly enculturated into the Alzheimer’s caregiving culture in accordance with Spradley’s guidelines, a good informant was considered to be one that had at least a year of involvement in the cultural scene. In addition, in terms of cultural ethnicity, the bilingual informants needed to self-identify as Latino/Hispanic and speak Spanish. To be considered part of the bilingual group, the informants needed to speak both English and Spanish. It was not necessary to be able to read or write Spanish. The participants recruited in Colombia by definition were Latino/Hispanic according to the definition used in the United States.

(2) **Current involvement.** The participants must be currently carrying out their caregiving duties. Those participants whose relative had already died of Alzheimer’s were interviewed because of their Latino/Hispanic background and the data they could provide, but were not considered key informants. This was the case of Martha, the current president of the Colombian agency supporting AD caregivers. When people are currently involved in a cultural scene, they use their knowledge of the culture to guide their actions (Spradley, 1979).

(3) **Unfamiliar culture scene.** To avoid taking things for granted, the informants should not be members of the researcher’s cultural group. Ideally, an investigator
should study unfamiliar cultures (Spradley, 1979). Although the investigator was bilingual and bicultural and had lived in the United States for 22 years, she had not had the experience of being a caregiver for a relative with Alzheimer’s disease. Similarly, the investigator was born and raised in Colombia and through frequent visits remained familiar with the culture. However, she had not care for anyone with Alzheimer’s disease.

(4) Adequate time. AD caregivers are taxed with an incredible number of duties that can make it difficult to be available for interviews. To meet Spradley’s (1979) requirement that a good informant must have adequate time, the investigator conducted the interviews at a time and place convenient to the participants. It was the participants’ choice if they wanted to be interviewed in the home setting or, if they preferred a different setting, such as a soundproof room available at a local hospital. It was anticipated that, given the high degree of disruption that the relative with AD could cause in the home setting, the majority of the interviews would be conducted in the soundproof biofeedback room at a local hospital. This was the case for all bilingual caregivers in South Texas. Caregivers in Colombia preferred to be interviewed at home at a time convenient for them. Interviews conducted in Colombia were longer than interviews conducted in the United States. Nine of the caregivers interviewed in Colombia invited the researcher to stay longer after the interview. This extended time in the caregivers’ homes allowed the researcher to observe these key informants in their natural setting and informally interview other relatives of the care-receivers.

(5) Non-analytic informants. This requirement was met by excluding participants who were sophisticated in the social sciences and psychology. These participants could draw from their education and analyze their own behavior in an attempt to
help the investigator (Spradley, 1979). During the preliminary study, an AD caregiver who was a retired geriatric nurse practitioner was the only caregiver used the word *burden* to describe the difficulties of the caregiving experience. This caregiver was unable to describe events and actions from the perspective of an insider. In the current study, two of the bilingual participants had nursing background. One had a vocational technical degree and the other was a registered nurse.

c. Sample criteria. In addition to meeting Spradley’s (1979) five criteria to be a good informant, the following inclusion and exclusion criteria were utilized.

(1) Inclusion criteria. The following were inclusion criteria for participation in this study:

1. AD caregivers needed to self-identify as Latino/Hispanic of any race. (By definition all Colombian monolingual caregivers met this criterion.)

2. Participants had to have been in the role of primary caregiver for at least a year.

3. Participants could be either monolingual (Spanish) or bilingual (Spanish/English).

4. Participants had to be family caregivers.

5. Participants had to be caregivers for a family member with AD or related dementia.

6. Participants had to be providing care for at least eight hours a day, five days a week.
(2) Exclusion criteria. The following were exclusion criteria for participation in the study:

1. Caregivers caring for a family member with Parkinson’s disease and dementia.
2. Caregivers who had not provided care for more than a year at the time of the interview.

C. Sampling Technique

This study used maximum variation sampling. This purposive sampling strategy (Patton, 2002) encompasses the selection of cases with a wide range of variation on dimensions of interest (Polit & Beck, 2004). Maximum variation sampling allows for the selection of participants with diverse backgrounds (e.g., age, race, nationality, gender, relationship to the relative with AD, educational level, and socioeconomic background among others).

Initial participant recruiting took place by direct approach of the investigator. The potential participants were purposively selected from the pool of AD caregivers taking part in the NIH program for AD caregivers in English. Two caregivers were selected from the participants in the Spanish program for AD caregivers. These two caregivers were informally interviewed. The researcher had informally met AD caregivers participating in these two programs. Once a potential participant was identified, he or she was contacted and provided a brief explanation of the purpose of the study. If the participant met all criteria for inclusion, the investigator obtained informed consent from the participant. The consent forms were available in English and Spanish. If the participant agreed to be a part of the study, an interview was scheduled at a time and place convenient to the caregiver.
In addition to the caregivers who may have participated in the two aforementioned programs, the investigator sought key informants from a geriatric medicine clinic and from the local community agency that offered support for dementia caregivers. The inclusion of participants who had not been part of the English or Spanish programs for AD caregivers fostered maximum variation of the sample. In ethnography, sampling is done of events, activities, informants, documents, and other data sources (Munhall, 2001). Therefore, the sampling was not based on the number of interviews, artifacts, or participants, but rather on the richness of the data. Recruiting Spanish monolingual caregivers who could be considered key informants and would add to the richness of the data became difficult in South Texas. On two different occasions, caregivers who were thought to be monolingual did speak English. Although their command of the English language was limited, the researcher could not consider them monolingual Spanish speakers. The researcher contacted the president of a Colombian agency that provides support for AD caregivers and recruitment of monolingual caregivers was initiated in Colombia.

D. Setting

The study took place in two major settings. The settings of the study were a city in South Texas and a city in Colombia, South America. Formal and informal interviews, as well as participant observations took place in a variety of settings in these two cities.

1. South Texas City.

This metropolitan city was located in South Texas, approximately three hours from the United States-Mexico border. The Latino/Hispanic population of the city is 61.3% (U.S. Census, Bureau, 2006). In 2003, the estimated total population of the city was reported as
1,214,725 people (U.S. Census Bureau, 2007). There was an increase of 5.5% in the total population between 2000 (1,144,646 people) and 2003.

The breakdown of the 61.3% Latino/Hispanic population of the South Texas city is as follows: 41.4% Mexican, 0.7% Puerto Rican, 0.1% Cuban, and 16.5% other Latino/Hispanic nationalities (U.S. Census Bureau, 2003). It was anticipated that the sample obtained in this city would reflect a majority of caregivers of Mexican descent.

A strong Spanish influence is felt in this South Texas city. The primary reason for this influence is the Mexican culture heritage preserved in the language, customs, architecture, and many other aspects of life. The presence of great numbers of people of Mexican descent in South Texas is explained by history. Prior to 1824, Texas was a Spanish possession and it was part of independent Mexico until 1836. After being an independent republic for nine years, in 1845, Texas was annexed by treaty to the United States.

Although English is the official language, many people in this city are bilingual in Spanish. The vast majority of bilinguals have received their formal education in English, and Spanish is an informal language that they speak but do not read or write well. In addition, a mix of English and Spanish known as Tex-Mex is spoken by many Mexican-Americans. Of the city’s population, 11.7% are foreign born, and 46.7% of the population speak a language other than English at home (U.S. Census Bureau, 2007).

a. Biofeedback Room. Bilingual caregivers participating in the study were interviewed in a soundproof room located on the fourth floor of a hospital in the South Texas city. The biofeedback room is part of the facilities used by the NIH Caregivers Program study staff. In this room, caregivers undergo biofeedback testing. Bilingual caregivers were
invited to the hospital. The researcher conducted the interviews in this room where there were no interruptions and the caregivers could sit comfortably.

b. Participant observations in South Texas. Participant observations were also conducted in a city in South Texas. Caregivers were observed interacting during two 4-hour sessions of the program AD caregivers in Spanish. This program was conducted in a small auditorium in a hospital located in the city’s downtown. Although the program was advertised by the investigators as conducted in Spanish, the presentations and discussions were bilingual. Caregivers were also observed at a community center for caregivers located in the northeast area of the city. These caregivers were at the community center to learn about services available to them. Participant observations also took place at informal family gatherings to which the researcher was invited.

2. Colombia.

Monolingual caregivers were interviewed in Spanish in a major city in Colombia. This city had a metropolitan area with a population of 6,840,116 people (DANE, 2008). Like México, Colombia was a Spanish possession. Colombia won its independence from the Spanish crown in 1810. Spanish is the official language in Colombia. Of the 2.2 million people of South American origin living in the United States, Colombians are the largest group (U.S. Census Bureau, 2007).

a. Caregiver's homes. All the monolingual interviews were conducted by the researcher in the caregivers' homes. The location, size, and upkeep of the houses were a direct reflection of the caregivers’ socioeconomic status. Property taxes and utilities are charged in the city according to strata assigned by the appraisal district. There are six strata,
with Estrato 1 being the poorest and Estrato 6 the wealthiest. There was at least one caregiver from each estrato among the caregivers interviewed in this major Colombian city.

E. Data Collection

The data collected during this investigation included participant observations, demographic data, English version (Appendix B), demographic data, Spanish version (Appendix C), taped-recorded semi-structured ethnographic interviews, field notes, and a reflective field work journal. In addition, during the course of the study several documents and artifacts became part of the data. These artifacts include the manuscript ¡Mi mamacita tiene Alzheimer’s! currently in press and with a planned publication date in the summer of 2008, a Colombian magazine with an article on familial Alzheimer’s disease in this country, a Colombian newspaper clip on caregiving, and brochures about caregiving from the Asociación Colombiana de Alzheimer and Fundación Acción Familiar Alzheimer Colombia (AFACOL).

The ethnographic interview guide (Appendix D, English; Appendix E, Spanish) was developed and tested during preliminary work (Appendix A) (Arévalo & Lewis, 2005, 2006a, 2006b). The main sources of data for analysis were the semi-structured interviews. The demographic information was collected orally as the final part of the interview. No data regarding immigration status were collected. The interviews were transcribed verbatim in the source language. Three different types of questions were included in the interviews: descriptive, structural, and contrast. The first interviews included only descriptive questions as shown in Appendixes D and E. From these questions and initial analysis, structural and contrast questions emerged.
1. Descriptive questions.

Initially, descriptive questions were asked to elicit a large sample of answers in the participant’s native language (Spradley, 1979). The descriptive questions in the study were designed to encourage the AD caregivers to talk about the caregiving experience in the context of Latino/Hispanic culture and in their preferred language. An example of a descriptive question is: Can you tell me what being a caregiver is like for you? This question was followed by other questions such as: Tell me about caring for your ________ with Alzheimer's, what is a typical day for you like? Descriptive questions were included in every interview.

2. Structural questions.

Structural questions were aimed at discovering folk terms and domains of cultural knowledge (Spradley, 1979). Structural questions were adapted to each individual informant, and were asked to complement rather than replace descriptive questions (Spradley). Structural questions were included in every interview once the domain analysis had been completed. Examples of structural questions asked to the caregivers were:

1. Can you tell me what made you decide to become a caregiver for your ________?
2. How did you learn to be a caregiver?
3. What are some of the things that have made caregiving difficult?
4. Has caregiving affected other members of the family?
3. Contrast questions.

Contrast questions had as a main purpose to determine what a participant meant by folk terms used in his or her native language (Spradley, 1979). For instance, caregivers were asked if duty was the same thing as obligation. Caregivers were asked how a given expression was used, or how it was similar to or different from other expressions. Contrast questions were also generated after the domain analysis of the data had taken place. Once the contrast questions were formulated, they were included in each new interview. Contrast questions can be formulated in several ways. Spradley discussed at least seven different kinds: verification, directed contrast, dyadic, triadic, sorting, question game, and rating questions. Examples of contrast questions used in this study were:

1. Are there negative or positive aspects of caring for_________?
2. Is sacrificing for ________ something positive or negative?
3. What other words can we use to describe the difficulties of caregiving?
4. Sometimes caregivers say that caring for their relatives is a burden. Is that something that you have experienced?
5. Burden was not on the list of words you gave me earlier to describe what caregiving is like for you. Can you tell me what burden means for you?
6. Is burden the same as carga?

In general, contrast questions required contextual information, often required an explanation, were asked concurrently with descriptive questions, and were phrased in cultural as well as terms used by the caregivers.
F. Data Management

Once interviews and field notes were completed, a bilingual bicultural transcriptionist transcribed them. The interviews were transcribed in the language in which they occurred (source language). The transcripts were then converted to Microsoft Word text data. The researcher reviewed all transcripts for accuracy against the audio tape-recorded interviews. Text data from the transcribed interviews and field notes were managed by with Microsoft Microsoft Office 2007 Word and One Note computer software.

G. Data Analysis

In qualitative research, interpretation and analysis of the data occur almost simultaneously (Spradley, 1979). As the data are being categorized and interpreted, themes begin to emerge for integration to a whole that provides the meaning. In this study, data analysis and collection occurred simultaneously (Spradley).

1. Domain search.

The analysis of the data followed Spradley’s (1979) sequence of ethnographic data analysis. A domain search was conducted after the first five interviews were completed. This search included selecting a sample of verbatim interview notes, looking for names for things, identifying possible cover terms and included terms from the sample, and searching through additional interviews for other included terms. The domain search served as the basis to formulate structural questions that expanded the domain analysis. Examples of the domains that were first identified were: duty, responsibility, family, respect, sacrifice, and satisfaction.
2. Domain analysis.

The domain analysis included examining the transcripts for semantic relationships and uncovering terms that fit the relationships. For each of the identified domains, structural questions were generated. A list of hypothesized domains was formulated. The domain analysis has as an objective to isolate the fundamental units of cultural knowledge (domains) into which the participants organized what they know (Spradley, 1979). The structural questions, as discussed in the previous section, were generated from the domain analysis. These questions had the purpose of verifying the domains and eliciting folk terminology included in the domains. For instance, verification was needed that distribution of duties among siblings was a domain and that the impact of caregiving as described by the caregivers was organized by three domains: physical, emotional, and financial.

3. Taxonomic analysis.

Taxonomic analysis followed to find the relationship among all the folk terms in a domain (Spradley, 1979), looking at the internal structure of each identified cultural domain. The researcher selects a domain for taxonomic analysis, usually one for which the most data have been collected. The semantic relationship is established and a substitution frame formulated. The substitution frame has the format “________ (is a kind of) _______.” Once the substitution frame is identified, the researcher searches for possible subsets among the terms in the taxonomy. The researcher formulated more structural questions to verify the taxonomic relationships that had been identified. For instance, stress, isolation, sadness, and loneliness were identified as kinds of emotional consequences. To move beyond the identification of cultural domains and formulation of a taxonomy, the researcher created contrast questions. These questions facilitated the discovery of meaning. An example of a
contrast question asked to the caregivers was: Are there positive or negative aspects of caregiving? This question sought to clarify under what theme the domains sacrifice, duty, and satisfaction needed to be assigned.

4. Componential analysis.

A componential analysis of the interviews was completed using contrast sets. This analysis encompasses a search for the attributes that signal differences among symbols in a cultural domain (Spradley, 1979). More contrast questions were created to fill any gaps that appeared in the data. An example of an additional contrast question asked to the caregivers was: Are duty and obligation the same?

From the aforementioned types of questions and analyses, the investigator discovers cultural themes. This analysis entails the search for the relationships among domains and how they relate to the whole (Spradley, 1979). It was anticipated that emic descriptions of the caregiving experience for Latinos/Hispanics would emerge from this thematic analysis. From this analysis, the researcher identified three major cultural themes for Latino/Hispanics caring for a relative with Alzheimer’s disease: caregiving has consequences, caregiving is my duty, and caregiving is satisfying.

H. Ensuring Trustworthiness of the Study

Qualitative research departs from the quantitative research criteria of validity and reliability to establish the quality of the study. The degree of confidence that the researcher can have in the data, the evaluation, and interpretation is assessed using the criteria proposed by Lincoln and Guba (1985). Scientific adequacy of the study, or trustworthiness, is established through four operational techniques: (a) credibility, (b) transferability,
(c) dependability, and (d) confirmability (Lincoln & Guba). These dimensions and how the study fulfilled them are explained in the following sections.

1. Credibility.

Lincoln and Guba (1985) considered credibility to be the main goal of qualitative inquiry. Credibility refers to confidence in the truth of the data and their interpretations (Polit & Beck, 2004). Credibility of this study was achieved with the following activities:

a. The researcher used prolonged engagement by spending sufficient time during participant observations and interviews. This prolonged engagement allowed for an in-depth understanding of the culture, language, and views of the participants. The researcher had spent time with Alzheimer's caregivers and had conducted preliminary work. These two activities had facilitated the orientation of the researcher to the Alzheimer’s caregiving culture.

b. Persistent observation of the participants. The researcher focused on the salient characteristics of the data. Persistent observation provides depth to the study (Lincoln & Guba, 1985). Caregivers were observed in varied settings and situations. In addition, artifacts were made available to the researcher to enrich the descriptions of the culture.

c. Triangulation of the data. The researcher used multiple sources of data. The triangulation had a space dimension (Polit & Beck, 2004) because data were collected about the same phenomenon in different settings. The use of a maximum variation sample allowed for person triangulation. The Alzheimer's caregiving experience was analyzed from the perspective of a variety of caregivers.

d. Peer debriefing. Through this activity the researcher sought to find external validation of the method, the culture under study, and the interpretation of data. The
researcher used the experience of Drs. Sharon Lewis and Gayle Acton with Alzheimer's caregivers, Dr. Sara Gill with qualitative methodology and Latino/Hispanic culture, Dr. Martha Medrano with cultural competence, and Dr. Carrie Braden with nursing theory and methodology to explore aspects of the inquiry that may not have been analyzed or explored by the researcher.

In addition, two bilingual bicultural doctoral students with a background in psychology and counseling were available to provide feedback in the interpretation of data collected. One of the doctoral students was bicultural and bilingual and familiar with Alzheimer’s disease caregivers. Both doctoral students were members of the research team working with an NIH program for AD caregivers.

e. Member checking. Lincoln and Guba (1985) considered this activity the most important technique to establish credibility of the data. The researcher provided feedback to the participants in reference to the emergence and interpretation of the data. The reactions and statements of the participants provided validation to the researcher that her interpretation of the caregivers’ realities was accurate and reflected their views. Member checking took place in both South Texas and Colombia.

2. Transferability.

This criterion refers to the generalizability of the data to other settings or groups (Lincoln & Guba, 1985). In order to provide the research consumer with data and findings that are transferable to other contexts, maximum variation sampling was used. In addition, the researcher provided thick descriptions of the sample, setting, and general context in which the transactions took place (Polit & Beck, 2004).
3. Dependability.

Lincoln and Guba (1985) have concluded that without dependability there cannot be credibility. This study achieved dependability by conducting an inquiry audit. The qualitative research expertise offered by Dr. Sara Gill made her an ideal investigator to conduct this audit. The purpose of the audit was to scrutinize the data and supporting documentation to verify that they supported the findings and interpretations. Numerous meetings with Dr. Gill were held to ensure that data were being analyzed following ethnographic methodology, that identified domains were supported by the data, and that the cultural themes were inclusive of the domains and logically formulated.


To ensure the objectivity and neutrality of the data, an audit trail was developed. The audit was conducted by an independent auditor, in this case Dr. Sara Gill. The materials from this study available to an auditor were: (a) Field notes reflecting participant observations and notes taken during interviews, (b) demographic data sheets, (c) audio tapes and transcripts of the interviews, (d) reflexive journal notes, (e) results from preliminary work, (f) any artifacts collected in the process of the study, and (g) notes from the researcher’s meetings with Dr. Gill.

I. Protection of Human Subjects

Potential study participants were contacted by the researcher. The prospective informants were informed of the study and invited to take part in it. Before any data were collected, informed consent was obtained. The consent was approved by the University of Texas Health Science Center Institutional Review Board in English and Spanish (Appendices F and G). The consent was presented to and signed by each participant prior to
the interview appointment. In addition to the consent, the participants received a Health Insurance Portability and Accountability Act (HIPAA) authorization in either English or Spanish. After the consent and HIPAA forms were completed, the participants were assigned a number and a pseudonym.

Only self-identified Latino/Hispanic participants were included. No minor children took part in the study. Both male and female caregivers were recruited.

1. Safeguarding of data.

After obtaining signatures from the participant on the HIPAA and consent forms, these forms were filed separately from the rest of the data and stored in a locked cabinet in the researcher’s office. Once a number and pseudonym were assigned to the participant, all forms of data collection and documentation reflected these two study identifiers. A log containing the name of the participant, contact information, number, and pseudonym was kept under lock and key in the researcher’s office, separate from the consent and HIPAA forms, and the participant’s data files. The electronic version of the log was secured by using a password known only to the researcher.

The participants’ data files, identified only by number and pseudonym, contained audio tapes, field notes, demographic data sheets, transcripts of interviews, and electronic copies of notes and transcripts. These files were kept under lock and key and separate from all other identifying information.

2. Benefits of the study.

The main benefit to be obtained from this ethnographic study was gaining knowledge about the Latino/Hispanic family Alzheimer's caregiver. Secondarily, during the preliminary study the researcher learned that most of the participants enjoyed the opportunity to interact
with a person different from their relative with AD, welcomed the opportunity for a short respite period, and manifested gratitude for the opportunity to talk about their experience. The participants in this study were compensated financially with $20.00 in the form of a gift card from either WalMart store or HEB grocery store. Colombian participants received a $50,000 Colombian pesos (equivalent to US $20.00) gift card for EXITO stores. The gift card was given to the participant at the conclusion of the initial interview and completion of the demographic data sheet. If the participant was identified as a key informant who needed to be subsequently interviewed, he or she would receive a second gift card for $20.00.

3. Potential risks for the participant.

The potential risk of the study for the informants was that during the interviews or participant observations they could experience strong emotional reactions. During the preliminary study, caregivers experienced anger and sadness. Several caregivers cried as they narrated their experiences and frustrations. This was also the case for all but one participant in this study. Two doctoral students (counseling and psychology) who are part of Dr. Sharon Lewis research team were available for prompt interventions in the event of emotional distress experienced by the participants. These doctoral students would make referrals to health care professionals and community agencies as appropriate. In Colombia, the researcher was supported by a social worker who volunteered at the Asociación Colombiana de Alzheimer and who was available telephonically. No referrals were needed in either South Texas or Colombia.
IV. RESULTS

The specific aims of this study were to describe the perceptions of the caregiving experience of bilingual (Spanish-English) and monolingual (Spanish) Latino/Hispanic family caregivers of patients with Alzheimer’s disease and the culturally and linguistically relevant expressions and terminology used by these caregivers to describe the consequences of caring for a family member with Alzheimer’s disease. This chapter presents the answers to the research questions formulated in Chapter I.

A. Sample

Twenty caregivers participated in formal semi-structured tape-recorded interviews. In addition, nine informal interviews were conducted, and approximately 65 hours of participant observations were completed with 27 additional caregivers. Caregivers were recruited from five main sources. The first recruitment site was a pool of participants available from NIH-funded study to support Alzheimer’s disease caregivers. The second site was a community center in South Texas. The third source was a pool of Latino/Hispanic AD caregivers who attended a program for Spanish-speaking caregivers in South Texas. The fourth source was a Colombian agency supporting AD caregivers. The fifth source of caregivers was personal referrals made by other researchers. Table 2 summarizes the wide range of characteristics of the 20 caregivers who were the key informants in this study. Table 3 summarizes the general demographic information on each of these key informants. Caregivers were assigned pseudonyms to ensure confidentiality.
Table 2

Variation Range in Key Informant Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Variation in Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver’s gender</td>
<td>Male and Female</td>
</tr>
<tr>
<td>Caregiver’s age</td>
<td>26 to 75 years old</td>
</tr>
<tr>
<td>Relationship to care-receiver</td>
<td>Wives, sons, daughters, granddaughter</td>
</tr>
<tr>
<td>Living arrangements</td>
<td>Live-in, Not live-in same city, Long-distance</td>
</tr>
<tr>
<td>Institutionalization</td>
<td>Non institutionalized, Institutionalized</td>
</tr>
<tr>
<td>Respite services</td>
<td>None, adult day care, paid in-home help</td>
</tr>
<tr>
<td>Education level of caregiver</td>
<td>High school, vocational school, some college, college graduate, graduate degree</td>
</tr>
<tr>
<td>Country of origin</td>
<td>México, United States, Colombia</td>
</tr>
<tr>
<td>Language spoken</td>
<td>Spanish, English, bilingual</td>
</tr>
<tr>
<td>Care-receiver’s age</td>
<td>55 to 88 years old</td>
</tr>
<tr>
<td>Number of years since diagnosis</td>
<td>2 to 18 years since diagnosis; therefore, at different stages of Alzheimer’s disease</td>
</tr>
<tr>
<td>Number of care-receiver’s children</td>
<td>0 to 9</td>
</tr>
<tr>
<td>Bilingual caregivers’ number of years in the United States</td>
<td>30 years, all their lives</td>
</tr>
</tbody>
</table>
Table 3

General Demographic Information

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Age</th>
<th>Gender</th>
<th>Relationship To C-R</th>
<th>Living Arrangements</th>
<th>C-R Age</th>
<th>C-R Gender</th>
<th>Number of C-R Children</th>
<th>Level of Education</th>
<th>Diagnosis</th>
<th>Location of Interview</th>
<th>Country of Origin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rosie</td>
<td>70</td>
<td>F</td>
<td>Only daughter</td>
<td>Live-in</td>
<td>88</td>
<td>F</td>
<td>2</td>
<td>College Graduate</td>
<td>1987</td>
<td>Texas</td>
<td>USA</td>
</tr>
<tr>
<td>Rosita</td>
<td>69</td>
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<td>Wife</td>
<td>Not live-in</td>
<td>70</td>
<td>M</td>
<td>2</td>
<td>Vocational School</td>
<td>1997</td>
<td>Texas</td>
<td>USA</td>
</tr>
<tr>
<td>Virginia</td>
<td>59</td>
<td>F</td>
<td>Daughter</td>
<td>Not live-in</td>
<td>85</td>
<td>M</td>
<td>6</td>
<td>High School</td>
<td>2003</td>
<td>Texas</td>
<td>USA</td>
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<td>Maria</td>
<td>75</td>
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<td>Live-in</td>
<td>80</td>
<td>M</td>
<td>4</td>
<td>College Graduate</td>
<td>2005</td>
<td>Texas Mexico</td>
<td></td>
</tr>
<tr>
<td>Brandi</td>
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<td>F</td>
<td>Daughter</td>
<td>Not live-in</td>
<td>55</td>
<td>M</td>
<td>4</td>
<td>Some College</td>
<td>2004</td>
<td>Texas USA</td>
<td></td>
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<tr>
<td>Teresa</td>
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<td>F</td>
<td>Daughter</td>
<td>Not live-in</td>
<td>89</td>
<td>F</td>
<td>9; 1 died</td>
<td>College Graduate</td>
<td>1996</td>
<td>Texas USA</td>
<td></td>
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<td>Live-in</td>
<td>76</td>
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<td>Aida</td>
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<td>Wife</td>
<td>Live-in</td>
<td>75</td>
<td>M</td>
<td>4</td>
<td>College Graduate</td>
<td>2006</td>
<td>Colombia Colombia</td>
<td></td>
</tr>
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<td>F</td>
<td>Daughter</td>
<td>Live-in</td>
<td>75</td>
<td>M</td>
<td>4</td>
<td>College Graduate</td>
<td>2006</td>
<td>Colombia Colombia</td>
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<tr>
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<td>Daughter</td>
<td>Live-in</td>
<td>85</td>
<td>M</td>
<td>4; 1 died</td>
<td>College Graduate</td>
<td>2001</td>
<td>Colombia Colombia</td>
<td></td>
</tr>
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<td>Live-in</td>
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<td>F</td>
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<td>Vocational School</td>
<td>1998</td>
<td>Colombia Colombia</td>
<td></td>
</tr>
<tr>
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<td>Granddaughter</td>
<td>Live-in</td>
<td>89</td>
<td>F</td>
<td>3</td>
<td>Some College</td>
<td>1998</td>
<td>Colombia Colombia</td>
<td></td>
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<tr>
<td>Julio</td>
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<td>M</td>
<td>Son</td>
<td>Live-in</td>
<td>80</td>
<td>F</td>
<td>5</td>
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<td>1999</td>
<td>Colombia Colombia</td>
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<td>Wife</td>
<td>Live-in</td>
<td>79</td>
<td>M</td>
<td>4</td>
<td>High School</td>
<td>2006</td>
<td>Colombia Colombia</td>
<td></td>
</tr>
<tr>
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<td>Daughter</td>
<td>Live-in</td>
<td>79</td>
<td>M</td>
<td>4</td>
<td>College Graduate</td>
<td>2006</td>
<td>Colombia Colombia</td>
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<tr>
<td>Hernando</td>
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<td>M</td>
<td>Son</td>
<td>Not live-in</td>
<td>79</td>
<td>M</td>
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<td>2006</td>
<td>Colombia Colombia</td>
<td></td>
</tr>
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<td>Silvia</td>
<td>63</td>
<td>F</td>
<td>Sister</td>
<td>Live-in</td>
<td>72</td>
<td>F</td>
<td>0</td>
<td>Vocational School</td>
<td>2005</td>
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<td>Jael</td>
<td>59</td>
<td>F</td>
<td>Daughter</td>
<td>Not live-in</td>
<td>82</td>
<td>F</td>
<td>6</td>
<td>High School</td>
<td>2004</td>
<td>Colombia Colombia</td>
<td></td>
</tr>
<tr>
<td>Clara</td>
<td>60</td>
<td>F</td>
<td>Daughter</td>
<td>Not live-in</td>
<td>82</td>
<td>F</td>
<td>6</td>
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<td>Consuelo</td>
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<td>3</td>
<td>Graduate Degree</td>
<td>1989</td>
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C-R = Care-receiver; M = Male; F = Female
B. Demographic Data

Descriptive statistics were used to analyze the data. The statistics reflected the maximum variation possible in the sample of good informants. Table 4 summarizes the most relevant statistics for this qualitative study.

C. Findings

Analysis of the interviews with the Latino/Hispanic caregivers revealed three overarching (universal) themes in caring for a family member suffering from Alzheimer’s disease: (a) caregiving has consequences, (b) caregiving fulfills a duty, and (c) caregiving is satisfying. Components of each theme and how each component played a role in the overall caregiving experience were identified. Three major components of the theme caregiving has consequences were identified. These components were the physical, emotional, and financial aspects of caregiving. The components of the theme caregiving fulfills a duty were caregiving is learned and caregiving is my duty. The third theme, caregiving is satisfying, encompassed three components: the opportunity to give back, knowing they were doing their best, and sacrificing. The researcher explored the themes and their components as shown in Table 5.

1. Caregiving has consequences.

Caregivers described caregiving duties as having caused major changes in every aspect of their lives. Marriages, employment, friendships, living arrangements, and family relationships were impacted by caregiving. All caregivers used words and expressions that related to the three major components linked to the theme caregiving has consequences. These components were the physical, emotional, and financial aspects of caregiving.
Table 4

Sample Statistical Description

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<td>Caregiver’s age</td>
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<tr>
<td>Care-receiver’s age</td>
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<td>Years since diagnosis</td>
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<td>Years of primary caregiving</td>
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<td>Care-receiver’s children</td>
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Table 5

Themes and Their Components

I. Caregiving has consequences
   A. Caregiving is physically challenging
   B. Caregiving is emotionally draining
      1. Loss of companionship
      2. Relinquishing social activities
      3. Feeling isolated
      4. Always thinking about the care-receiver
   C. Caregiving is financially detrimental
      1. Caregivers must reduce the number of work hours
      2. Giving up work all together
      3. Being hired as a caregiver by family members

II. Caregiving fulfills a duty
   A. Caregiving is my duty
      1. Duty to family (Deber con la familia)
      2. Respect (Respeto)
      3. Distribution of responsibilities among siblings
   B. Caregiving is learned

III. Caregiving is satisfying
   A. Caregiving is my opportunity to give back
   B. Caregiving is knowing that I am doing my best
   C. Caregiving is a sacrifice
Every participant described the emotional, physical, and financial aspects of caregiving as having detrimental effects on their lives, and how these three components affected each other. With one exception, the caregivers cried during the interviews as they described how the physical and financial demands worsened the feeling of emotional inability to balance all the demands of caregiving. Caregivers illustrated how the physical demands of caregiving tasks felt more strenuous as time went on and how they felt drained financially and emotionally. Trying to balance the physical, emotional, and financial demands of caregiving appeared to render the caregivers emotionally unable to nurture themselves or others. Caregivers found it very difficult to achieve a balance in these three areas. Those who were able to manage the financial impact of caring for a relative described themselves as physically exhausted and emotionally unsatisfied. Caregivers who felt they were handling the physical demands of their duties, described feelings of isolation and sadness, and worried about their finances constantly. Several caregivers, who had come to terms with a new lifestyle limited by their finances and who felt physically able to continue their caregiving duties, shared how emotionally starved they felt. For the majority of the caregivers, the physical impact of their duties was felt before the financial or emotional consequences.

a. Caregiving is physically challenging. The caregivers without exception described a feeling of being constantly tired or having no energy. A feeling of exhaustion, fatigue, being worn out, and about to fall apart were some of the descriptors used by caregivers to illustrate how they felt physically. Caregivers attributed feelings of exhaustion to the actual physical effort required to care for the care-receiver. Care-receivers required partial or total assistance with all activities of daily living, constant supervision, and in most cases constant interaction for distraction. As the disease progressed, caregivers found that
more heavy lifting was required to care for their relative. The physical symptoms mentioned by caregivers ranged from mild symptoms like transient headaches to severe complaints such as low back pain. All caregiver faced unique physical challenges. For some caregivers, the hardest parts were the dressing and feeding tasks, while others described difficulties with the ambulation and bathing or lack of sleep and rest. Invariably, caregivers presented with complaints that included joint pain, migraines, gastritis, frequent colds, irritability, weight loss, lack of appetite, and a feeling of having no energy to go farther.

Caregivers whose family member was in the early stages of Alzheimer’s disease spoke of the constant expenditure of energy needed to continuously supervise the care-receivers as they would supervise a young child. The house had to be safety proofed, all activities needed close supervision, and they had to allow twice as much time for any activity in order to involve the care-receiver. Some of the caregivers also had to deal with a care-receiver’s aggressive behaviors and changes in personality. Care-receivers could become agitated, sexually inappropriate, fearful, or frustrated. Finding objects hidden by the care-receivers, taking over all the household chores (from paying bills to cleaning), and fulfilling their own responsibilities placed a tremendous demand on the caregivers’ physical endurance. Caregivers described no end to the chores, and noted that completion of any task was delayed because the care-receiver interrupted the activity or needed physical care. Several caregivers told of waiting until the care-receiver went to sleep to finish all the incomplete tasks, calling this tactic their “catch up” game.

Caregivers whose care-receiver had moderate Alzheimer’s disease stated that the more physically challenging activities were following the person whenever wandering occurred, including getting up during the night, increased need for help with activities of
daily living, and the constant cleaning up after their relative. Because of the care-receivers’
increased restlessness and difficulty in carrying out purposeful movements, there was a need
to clean the eating area each time the care-receivers ate and to pick up items after any
activity. In addition, the physical demands increased as the care-receivers had more frequent
episodes of urinary and bowel incontinence. The constant movement and activity of the care-
receivers in this stage made the caregivers walk, follow, and juggle the completion of chores
with the constant supervision. Caregivers described their own activity as nonstop, 24 hours a
day, seven days a week. Rosie described some daily activities with her mother:

I wish I didn’t have to do that, go to the bathroom by herself and pick up after herself,
but she can’t anymore, so I have to do it for her all day long. The other day, a couple
of days ago, I was trying to get some blood out of this area [points to her buttocks]
and like turn her, and she couldn’t. It was hard. I went to get a pillow. When I came
back she was not in the room. I found her in the kitchen getting food from the
refrigerator. Her hands were all dirty with caquita (feces), so I had to clean her, throw
all that food in the trash. It never stops.

Caregivers caring for a care-receiver with severe Alzheimer’s disease did not
experience lesser physical demands even though, in general, they no longer dealt with a
combative, wandering, or lost care-receiver. Although the care-receivers’ mobility was very
limited or they were bedridden and in most cases nonverbal, the caregivers still faced
physical challenges. Caregivers provided care for a person completely incontinent of bowel
and bladder function, and entirely dependent on the caregiver for all activities of daily living.
Caregivers described lifting, turning, diapering, and dressing the care-receiver as the most
physically challenging aspect of the caregivers’ duties. Nancy described some of the tasks
involved in her father’s care:

El es muy pesado porque ya no puede ayudar. Voltearlo para cambiarle el pañal es
difícil, el pesa mucho. A veces lo puedo sentar en la cama pero me da miedo que se
caiiga. Ya no lo puedo bañar en la ducha, toca hacerlo en la cama. [He is very heavy
because he cannot help any longer. Turning him to change his diaper is difficult, he weighs a lot. Sometimes I can sit him in bed, but I am afraid he is going to fall. I cannot bathe him in the shower anymore; I have to do it in bed.

In addition to the physical challenge caused by the constant supervision of the care-receiver or the heavy lifting needed to accomplish activities of daily living, the caregivers talked about a lack of sleep and its impact on their lives. The lack of rest and sleep was reflected in the caregivers’ statements of lack of energy and feeling tired (cansado), sleepy (con sueño or somnoliento), and exhausted (exhausto or rendido). The caregiver’s lack of sleep was caused by the care-receivers constant level of activity during the day and at night. Care-receivers who were not bedbound could wander at any time. Caregivers described care-receivers who would get up at night to search drawers, look for food, attempt to cook by themselves, drive to the bank to get cash, or perform any other activity that had been part of their past. Care-receivers who perceived danger were described as very difficult to calm down, distract, and take back to bed.

Caregivers used different strategies to protect the care-receivers and handle the situations to minimize disruption. For one caregiver, the only strategy that worked was to go along with the care-receiver regardless of how illogical the situation was. For instance, this caregiver would get dressed in the middle of the night and take her relative to the bank. Upon seeing the lights off and no one on the streets, she would state that they would return in a few
hours. This caregiver had learned that arguing was pointless and that by going along with the care-receiver she could return to bed sooner.

Caregivers were unable to take a nap during the day because the care-receiver needed supervision or was being disruptive with behaviors such as combativeness, desired to leave the house, or was severely confusion. A caregiver stated, “If she does not sleep, I don’t sleep, and she never naps or sleeps through the night. I am always sleepy. I could go to sleep right now, right here.” Caregivers providing care for bedbound care-receivers also presented with sleep deprivation issues. For most of them, the cause was the need to turn the care-receiver several times during the night to prevent skin breakdown and cleaning the care-receiver after periods of bowel incontinence. Several caregivers stated that if the care-receiver had been incontinent of urine only, they preferred to wait until the next day to clean and change the care-receiver.

Those caregivers who did not live with the care-receiver also complained of lack of sleep. These caregivers shared that many times they were so tired it was hard to fall asleep, or that they would wake up easily and stay awake for long periods before being able to fall asleep again. Being away from the care-receiver was also a factor. Caregivers worried about the care-receiver and their needs. A daughter who had hired nursing assistants to replace her at night worried that the care-receiver could be maltreated, his belongings stolen, or that the assistant would fall asleep and not take care of the care-receiver. Often, this caregiver, unable to sleep, would call her father’s home to get an update on his status from the hired help. Another caregiver who did not live with the care-receiver shared that she could not sleep well because she felt many pains and aches. This complaint of physical symptoms was common among caregivers.
Nancy, a daughter caring for her father, who had the help of a live-in housekeeper and a nursing assistant every evening for five hours, cried while giving an account of her current physical status:

Terminé con problemas de la espalda y ahora hasta del tunel carpiano, debo dormir con ferulas, pero a veces el dolor del cuello y de la espalda no me dejan dormir, por eso me levanto cansada. . . [I ended up with back problems and now even carpal tunnel, I must sleep with splints on, but sometime the pain in the neck and the back don’t let me sleep. That is why I am tired when I get up.]

b. Caregiving is emotionally draining. Caregivers reported feeling emotionally drained or empty (vacio), a feeling of being unable to or having difficulty giving or nurturing others. Caregivers described how assuming responsibility for major life decisions for the care-receiver and, in several instances for the entire family, was often one of the most emotionally charged duties they were experiencing. Caregivers who had been designated by the care-receivers or other family members as the caregivers and who had power of attorney for either health care or financial decisions felt that a great deal of their emotional energy was invested in “keeping peace” with their relatives. These caregivers described the tension that was created by having their decisions questioned by other family members. They felt they received ongoing criticism, rather than support, and in some cases had to deal with the resentment of other family members who were being the designated decision maker.

In addition, the constant juggling of the new responsibilities like grocery shopping, paying bills, and household chores, to name a few, with their own responsibilities as spouses, employees, or children was described by the caregivers as causing the feeling that they were “stretched out.” Added to all these sources of emotional stress, the caregivers had to witness
the gradual deterioration of their relative. This observer role was described as emotionally painful.

Caregivers who had been providing care for more than two years mentioned a strong sense of guilt that they had been slow in coming to terms with as they understood the disease process. In contrast, caregivers who cared for relatives in the early stages of Alzheimer’s and had not been providing care for more than two to three years, discussed their frustration and anger related to the constant questions, repetitive words, shoplifting, argumentative behavior of the care-receivers, and the lack of gratitude displayed by the care-receiver. Two of the caregivers, both women caring for their husbands, shared that sometimes they wondered if their husbands were “doing it just to upset” them. Crying, Paulina related how angering it was to have her husband refuse to eat because he thought she was trying to poison him: “After everything I do for him, how can he possibly think that I am here to hurt him?” Paulina’s husband had been diagnosed with Alzheimer’s two years prior to the interview.

Several of the caregivers whose relatives were bedbound and could no longer communicate verbally related how at the beginning they had been angry. The caregivers had questioned if the care-receiver was only pretending to gain attention, getting even with the caregiver for past issues, or simply lying. Julio described how his mother had been “smart enough to hide the burned pots, but not to remember to turn the stove off.” With time, the caregivers had come to understand that the behaviors were caused by the disease and not been directed at them with a hurtful intention. Regardless of this insight gained over time, the veteran caregivers shared their pain, their sense of guilt, the worry that they could have done more for their relative, and the fear to be seen by others as not fulfilling their role and expectations.
A major cause of the emotional stress that caregivers endured was dealing with change. There were drastic changes in the caregivers’ lives related to assuming the responsibility of caring for a relative with Alzheimer’s disease. In addition to the change in physical and financial demands, caregivers experienced a change in roles and in their ability to socialize. Four domains emerged related to change in their lives: loss of companionship, relinquishing social activities, feeling alone, and always thinking about the care-receiver.

(1) Loss of companionship. Regardless of the quality of the relationship between the caregiver and the care-receiver prior to the Alzheimer’s disease diagnosis, the loss of a companion, a partner, a spouse, a parent, or a grandparent was emphasized by each of the caregivers. The loss of the person was described as the most drastic change and the most emotionally painful part of the caregiving experience. The inability to have a logical conversation with the family member with Alzheimer’s disease was described consistently by the caregivers as sad (triste) and painful (dolorosa). The caregivers also described how the loss of the person affected the entire family, not only the primary caregiver.

Hernando, a son, described how it felt to have his father unavailable to converse with him anymore:

Últimamente si he notado que la conversación no puede ser como lo era antes, anteriormente o siempre yo tuve buena comunicación con él, yo converse con él siempre de diferentes temas de la vida diaria de las situaciones que nos ocurrían a ambos, las situaciones que me ocurrian a mí, siempre yo lo buscaba como un consultor, indudablemente ya me doy cuenta que la situación ahora es totalmente diferente, entonces se siente ese vacío, por lo menos ayer tuve la oportunidad de estar con él como hora y media más o menos y fue un tiempo en que no fue provechoso, lo que habíamos podido conversar, dialogar en otras oportunidades no lo pude hacer, sino simplemente le pregunte cosas vagas y sé que recibo las mismas respuestas y lo que hago es como llevar una conversación como se le lleva a un niño o algo así, que no es trascendental, que no llega a tocar el aspecto de la
Rosita described some of the things she missed about life with her husband from before the diagnosis of Alzheimer’s disease:

The worst part…losing his companionship. He retired a little bit after I did. I retired at 55, and when he was 62 he retired. He was an orphan and he always enjoyed family life and puttering in his garage. But after we were both retired he would come in and tell me, “It’s coffee break time.” So, we would go and get our coffee mugs filled there and sit on the patio and just be there. I would save bread, the end of the bread, and he would cut it up and throw it for the birds, and then we’d sit there and watch them come in. I mean, it was a very wonderful time, a very peaceful time. I saw our lives continue in this peaceful time, in this peaceful fashion. Never, ever, ever in my wildest dreams did I even remotely think that my poor husband was going to suffer to the degree that he has suffered.

(2) Relinquishing social activities. Caregivers had to give up activities outside the house that allowed them to socialize with others. The inability to leave home to socialize with friends and acquaintances, work, attend church, engage in
volunteering, or interact with other people was referred to by the caregivers as a major change that was emotionally draining. Some caregivers gave up their activities one by one as the needs of the care-receiver slowly became greater. For other caregivers, giving up the opportunities to interact with others was drastic and done at once. This was the case for caregivers who quit their jobs and moved to a different neighborhood or city to assume complete care and responsibility of their relative. In general, the caregivers attempted to involve their relative with Alzheimer’s disease in family and social gatherings as long as it was possible. This was done in an attempt to entertain or distract the care-receivers and to maintain their activity as well as to maintain the caregivers’ opportunities for interaction. As the disease progressed and the caregivers came to the realization that public places were no longer an option for their relative because of their disruptive behaviors, agitation, hallucinations, or incontinence, the caregivers relinquished engaging in socialization.

Nancy took her father daily for a five-minute ride to the mall for a cup of coffee:

_Era mi oportunidad de ver gente así no los conociera, una oportunidad de salir todos los días. Pero terminó el día que salió del carro y ahí mismo al frente de la entrada del almacén empezó a bajarse los pantalones porque tenía que orinar. El vigilante vino a ver qué andaba mal y yo estaba tratando de explicarle a papá que él no podía orinar allí. El estaba disgustado, no quiso entrar al carro, la gente nos estaba mirando, el vigilante pensó que yo estaba maltratando a mi papá y le seguía preguntando qué pasaba. Cuando entendió que papá no estaba bien, terminó hablando con mi papá y de alguna manera convenciéndolo de que yo lo llevaría al baño de inmediato. Fue terrible. Ese fue el final de nuestras salidas diarias._

[It was my chance to see people even if I did not know them, a chance to go out every day. But it ended the day he got out of the car and right there, in front of the store’s entrance started to pull his pants down because he had to urinate. Security came over to see what was wrong as I was trying to tell dad he could not urinate there. He was upset, refused to get back in the car, people were looking at us, the guard thought I was being abusive and kept asking dad what was happening. When he understood that dad was not well, he ended up talking to dad and somehow convincing him that I would take him to the restroom right away. It was awful. That was the end of our daily outings.]
Feeling isolated. Caregivers felt isolated (aislados). This feeling of isolation appeared to be the result of the loss of companionship and the loss of opportunities to socialize. The lack of social contact outside the home and the inability to maintain a coherent, logical conversation with their relative lead the caregivers to live in what a caregiver described as the world of Alzheimer’s. By this, the caregiver meant a world where he was alone and anything was possible. To survive, he had to go along with whatever past his mother remembered. It is a world where there is no future. This caregiver wondered sometimes if he was becoming just as confused as his mother was because he went along with whatever was her reality.

Muchas veces buscamos a mi papá por todos los cuartos, yo le llevo la idea porque ya aprendí a hacer eso. Pero a veces me pregunto, ¿que es lo que estoy haciendo? Yo sé que mi padre está muerto desde hace muchos años, así que es cosa de locos estario buscando en la casa, o decirle a mi mamá que viene más tarde que esté pendiente en la ventana. [Many times we look for my father in every room, I go along with the idea because I already learned to do that. But sometimes I ask myself what is it that I am doing? I know that my father has been dead for many years, so it is crazy for people to be looking for him in the house, or to be telling my mother to pay attention by the window because he is coming later.]

Julio welcomed his siblings’ phone calls even though his mother usually interrupted them. These phone calls were the only link to the outside world. On weekends when one of his siblings relieved him, he would be so tired that he preferred to sleep and read for relaxation. Although he felt isolated, he felt that he did not have the energy to go out and engage in social activities. Other caregivers who were able to have sporadic periods of respite shared this feeling. The physical exhaustion and the lack of emotional energy rendered most caregivers unable or unwilling to socialize despite feelings of isolation that they preferred not to have.
Several caregivers who lived with other family members (siblings, children, or in-law relatives) in addition to their relative with Alzheimer’s disease also expressed feelings of loneliness despite the presence of others in the home. Although daily contact and conversation with others was possible, caregivers often felt that they were alone. One of the live-in caregivers caring for her mother also lived with two brothers, her daughter, her 9-month-old grandchild, and two school-age nieces. One of the brothers slept in the same room with his mother with Alzheimer’s disease. The caregiver described how her mother choked often with phlegm and coughed forcefully, many times having a bowel movement because of the cough. The caregiver would juggle taking care of the phlegm, and cleaning her mother without help while her brother would watch television lying on the bed next to her mother’s. This caregiver found it annoying that her brother would not help spontaneously, but did not complain to him or ask for his help. Crying, the caregiver stated she would not want to lose his company.

I don’t say anything. I guess just having somebody, a body there, is better than being completely alone. The kids have to do their homework, my daughter takes care of the baby. He is all I have every evening when I am taking care of mom. I don’t even want to ask him to have his own bedroom.

(4) Always on my mind. Caregivers, whether living with their relative or not, male or female, children or spouse, with hired help or caregiving alone, agreed that their relative was always on their mind. The caregivers related how this was different from the time before Alzheimer’s diagnosis. The ability to engage in other activities without worrying about their relative appeared to have been lost. Regardless of the reassurance offered by formal caregivers, family members, or friends, the caregivers were in a constant state of worry about the care-receiver’s welfare.
Yo voy a misa casi todos los días si puedo. Pero no tengo paz ni allá por que siempre estoy pensando ¿cómo estará? Me afán mucho que algo llegue a pasar mientras yo estoy en misa, es solo una hora, pero no puedo dejar de pensar en él. [I go to church almost every day if I can. But I am not at peace, not even there because I am always thinking how he would be. It worries me a lot what can happen while I am at mass, is only one hour, but I cannot stop thinking about him.]

Teresa, the long-distance caregiver also described the constant worry. Teresa made several phone calls a day to her mother and to the group home nursing staff. Every activity that Teresa carried out was with her mother in mind. In order to visit her mother every month for three to five days, Teresa had to plan all her activities and per-diem work carefully.

c. Caregiving is financially detrimental. All caregivers, regardless of socioeconomic status, faced long-term detrimental consequences, including loss of income, loss of time required in the work force for pension or retirement, loss of health insurance benefits, and depletion of family leave time. In addition to the loss of income, the expenses generated by caregiving itself were numerous. Caregivers mentioned medical bills, medications, incontinence products, home safety accessories, and special nutritional supplements as expenses that quickly added to the financial strain they faced. Some caregivers were able to afford paid help, but the vast majority could not. Although there were respite programs available, the caregivers did not use them, partly because of the cost involved. Caregivers who were no longer in the work force and had retired felt that their financial security had been compromised. The additional expenses generated by caregiving negatively affected their fixed income.

Three domains emerged under the theme that caregiving is financially detrimental. The first related to the gradual reduction in the number of paid work hours of the caregiver, and the second to the decision that the caregiver could no longer work at all. The third
domain was identified in the interviews conducted with caregivers who had several siblings. The siblings assumed the financial responsibility of hiring the caregiver.

(1) Caregivers must reduce number of work hours. Caregivers who were employed at the time their relative was diagnosed with Alzheimer’s disease tried to stay employed as long as possible. Reducing the number of work hours created not only a decrease in income, but in general a loss of benefits. These benefits included health care insurance, prescription medication coverage, paid time off, and, in every case, less income set aside for retirement.

A caregiver described the slow decline in the number of hours she remained employed. She took advantage of a day care program for people with Alzheimer’s disease. Three times a week her mother attended this program for about six hours. The caregiver dropped her mother at the center on her way to work and picked her up six hours later. This arrangement worked for about two years until her mother was no longer eligible for the program due to her limited mobility and worsening urinary and bowel incontinence. At that time, the caregiver decided to keep her mother at home and contract the services of a home health agency even though they were not paid or reimbursed by her medical insurance plan. Within six months, the caregiver’s finances worsened to the point that she felt that she was working only to make enough money to pay for her mother’s paid caregivers. In an attempt to maintain an income, the caregiver set up a consulting service from home and kept some of the hired help. Eventually she closed her business and assumed completely the care of her mother. At that time, the caregiver had to apply for government financial assistance benefits and completely give up any expenses that were not necessary for her and her mother. Another caregiver shared that her sister relieved her two days a week from taking care of
their father. The caregiver did not use this time for respite. Instead, she cleaned houses to earn some income.

(2) Giving up work altogether. For other caregivers, the only option was to give up work completely. Rosie, for instance, quit her job in a different city and moved in with her mother. Rosie felt that this was the only possible way that she could ensure her mother’s safety. She never considered becoming a long-distance caregiver who could make many phone calls to meet caregiving needs. Long-distance caregiving involved coordination of in-home care, sporadic visits, providing financial support, managing money, getting medical information, and arranging all aspects of care for the care-receiver. Rosie went from a full-time salary to no monthly income except for her mother’s social security benefits. Rosie had to learn to navigate the world of financial assistance and found this difficult and ironic because at one time she would have considered her mother to be rich.

Another caregiver found himself without a job at the time his mother was diagnosed with Alzheimer’s disease. His belief system led him to think that this was no coincidence. He felt that the termination of his work contract was a sign that he needed to have the time to care for his mother. He assumed the leadership in the care of his mother and notified his siblings of his decision to move in with his mother.

Mi contrato estaba terminando. Resolví que eso estaba pasando por alguna razón superior a mí y pensé que era una señal de que yo debería estar con mi madre. Decidí no buscar trabajo y me fui a vivir a casa de mi madre. Les avisé a mis hermanos que yo me haría cargo de ella, pero que iba a necesitar ayuda económica de ellos porque ya no trabajaría más. [My contract had ended. I decided that this was happening for a reason superior to me and I thought that it was a signal that I should be with my mother. I decided not look for a job and I moved in with her. I notified my siblings that I would take charge of her care, but that I would need financial help because I would not be working any longer.]
(a) Being “hired” by family members as the caregiver. Four caregivers in this study were receiving a fixed amount of compensation for their caregiving work. They were all children caring for one of their parents. This arrangement appeared to be more feasible in those families with at least four adult children. The financial arrangement was proposed by the other siblings or by the caregiver. In Nancy’s case, her two brothers brought up the idea after seeing how Nancy struggled to care for their father and still keep open a clinical bacteriological laboratory she owned. Nancy’s brothers figured the amount of money that the laboratory was actually producing and “hired” Nancy as the primary caregiver. Two brothers and one sister covered the cost of Nancy’s compensation. Nancy was married, had two adult children, and was the youngest of four children. According to her, she was the closest to her parents, especially her father. The oldest sister had spent most of her adult life overseas.

Nancy worked from nine in the morning until eight at night. Nancy did not live with her parents. She was not only in charge of caring for her father with Alzheimer’s disease, but in charge of also caring for her mother who was 85 years old and needed assistance with bathing and dressing. A 60-year-old lifelong employee of her parents assisted Nancy. This live-in employee was considered a family member and in addition to cooking, would walk Nancy’s mother to church every afternoon. This employee assisted Nancy to turn and bathe her father. Nancy put her father to bed and returned the next morning. This routine went on for more than three years until Nancy felt physically unable to go on. She had severe pain in her arms and lower back and had neglected to seek medical care. Nancy felt very uncomfortable asking for time off during the week or to be late in the mornings. She described how agreeing to receive a salary made her feel like a true employee. She refrained
from doing things like being a few minutes late, and felt a total inability to voice how tired she was physically and emotionally. She felt that asking for additional help was not proper as she was already being paid. One of Nancy’s brothers took the initiative of creating a schedule to rotate weekends. Each sibling took turns during the afternoons on Saturdays and Sundays. Their help consisted in visiting and entertaining their mother. Nancy’s pain continued to get worse but she did not ask for assistance. It was the live-in employee who talked to Nancy’s mother and told her that Nancy was very tired and in a great deal of pain. Nancy’s mother suggested hiring additional help, and a nursing assistant started working daily for six hours in the afternoon. Nancy stated that she had welcomed the help, but above all it had been her mother’s suggestion to the siblings and not Nancy’s. She did not want to convey to her parents for any reason that she was tired of them as people.

Yo me sentía terrible de ir a decir algo. Por nada del mundo quería yo que mi mamá fuera a pensar que yo estaba cansada de ellos. A mí me dolían las manos, el cuello, la espalda. La empleada fue la que le dijo a mi mamá que me dolían las manos y que ella me veía muy cansada. Mi mamá me preguntó un día si sería buena idea traer más ayuda porque la empleada le había dicho que yo estaba mal. Fue un gran alivio que esto saliera de ella y no de mí. Yo no quería quejarme. [I felt terrible to say anything. For no reason in the world [did] I want my mother to think that I was tired of them. My hands hurt, my neck, my back. It was the employee who told my mother that my hands hurt and that I looked tired. My mother asked one day if it would be a good idea to hire more help because the employee had told her that I was not doing well. It was a great relief that this came from her and not from me. I did not want to complain.]

In contrast to Nancy, Julio, who had become a live-in, 24 hours a day, seven days a week caregiver for his mother formulated a proposal for his siblings. After moving in with his mother, he assumed the total control of finances and formulated a budget. He presented a comparison of what it would cost to hire someone to look after their mother to his five siblings, and what it would cost to pay him a small salary. Every sibling agreed to contribute
financially. However, none of the siblings who lived in the same city offered respite for Julio, and he waited for it to be something spontaneously offered. One of Julio’s sisters who lived overseas made sure that he had written materials for Alzheimer’s disease caregivers, and twice a year she traveled to take care of her mother to relieve Julio for an entire week. Seeing that this was not enough respite and that he was feeling exhausted, Julio talked to his siblings. He pointed out that any paid employee was entitled to breaks and time off. He would take care of his mother during the week, but expected to have weekends off. He presented two alternatives. The first one was to hire nursing help, which would increase the amount of money contributed by each sibling, or each sibling could take turns on weekends. At the time of the interview, Julio had been preparing annual rotation schedules for close to five years. The siblings received their schedules with a year’s notice so that they could make proper arrangements. Although this provided Julio with much needed respite, he felt he should have never had to ask. This help, according to Julio should have come spontaneously. Unlike Nancy, Julio was very assertive and did not allow receiving a salary from his siblings to be a factor in not asking for help.

2. Caregiving fulfills a duty.

The second overarching theme was *caregiving fulfills a duty*. The researcher identified this theme in every interview, including the interviews conducted during preliminary work. Caregivers felt a strong sense of duty to family members, especially to elders. Caregivers emphasized the difference between having to do something and wanting to do something. Even though caregiving was very difficult, it needed to be done in order to fulfill one’s responsibility. Caregivers voiced the tremendous difficulties of caregiving as described under the theme *caregiving has consequences*. However, not one of the caregivers
wanted a stranger to assume their caregiving responsibilities. Two major component emerged under the theme caregiving fulfills a duty: caregiving is my duty and caregiving is learned.

a. Caregiving is my duty. Caregivers described a strong sense of duty to their care-receiver. Caregivers felt that the responsibility for the well-being of their relative with Alzheimer’s disease was theirs and no one else’s. Wives caring for their husbands described a sense of duty to their spouses, regardless of the quality of their marital relationship prior to the diagnosis of Alzheimer’s disease. Aida, for instance, expressed a strong sense of duty to care for her husband even though for many years they had simply lived under the same roof. Aida lived with her husband and four single adult children who worked. Aida described her husband as not generous and shared:

*Por primera vez en su vida hace dos semanas me dijo que quería ir al banco a sacar efectivo para comprarle la navidad a los muchachos. Hasta me dijo que me había oído decir que yo quería unas medias y que quería comprármelas. El nunca, nunca había hecho algo así. No supe qué pensar de que sea el Alzheimer el que le haga finalmente pensar en nosotros.* [For the first time in his life – two weeks ago he told me that he wanted to go to the bank to get cash to buy Christmas’s presents for the children. He even told me that he had heard me say that I wanted to buy socks, and he wanted to buy them for me. He never, never had done something like that. I did not know what to think about being his Alzheimer’s – what finally made him to think about us.]

Despite an unhappy marriage, Aida described at length her responsibility and duty as a wife, a Catholic, and a human being to the father of her children. She had never considered placing her husband in an institution and hoped he could die at home cared for by her. Aida did not describe her husband as nurturing or loving. Instead, she described how throughout her married life she had felt she was alone. She had raised their children practically on her own, and had financially supported the household. She had worked as a preschool teacher
until she retired. The lack of a fulfilling marriage did not cause Aida to have doubts when the
time to become her husband’s caregiver came. There was absolutely no hesitation. *Como
esposa, como católica, es mi deber. Aparte de eso, ¿Qué le estaría yo enseñando a mis hijos si no lo hiciera?* [As a wife, as a catholic, is my duty. Besides that, what would I be teaching my children if I did not do it?] During Aida’s interview, her daughter and son returned with their father. They had been on an outing to allow time for the interview. Soon the daughter joined the interview and she shared how Aida frequently refused to have help. Catalina stated:

> Yo sé que mi mamá necesita descanso, cambiar de ambiente, hablar con otras personas. Ella está aquí todo el día con mi papá. ¡Pero ella no deja que le ayudemos! Parece que si las cosas no se hacen exactamente como ella las hace, entonces la ayuda no sirve. Yo quisiera que ella saliera los fines de semana cuando uno de mis hermanos o yo me nos podemos quedar con mi papá, pero no, no quiere. No deja. [I know that my mother needs rest, a change of environment, to talk with other people. She is here all day long with my father. But she does not allow us to help her! It appears that if things are not done exactly the way she does them, then the help is not useful. I would like her to go out on weekends when my brothers or I can stay with my father, but no! She does not want to. She does not allow it.]

Aida explained that although the care-receiver was the children’s father, she was still alive, and, therefore, as a wife, it was her duty to care for him. She admitted to accepting some help to bathe her husband because he could fall. In Aida’s opinion, only the youngest of the three brothers knew how to help and was familiar with the routines. The other two brothers were seen by both Catalina and Aida as willing to help, but not knowing how to do so.

Paulina, Nelly, Maria, and Rosita, like Aida, also described feeling a need to care for their husbands. These husbands were described as loving, caring, and devoted. These attributes, in the words of these wives, strengthened their sense of duty, and they had the
conviction that what they were doing was the right thing to do. They felt that having received love and nurturing from their husbands made caregiving for them a natural decision.

Two husbands, who participated in the preliminary study, also described this strong sense of duty. With almost identical words, Eduardo and Peter stated that caregiving was a duty of love, and they were sure that their wives would have done the same for them.

Children caregivers, whether sons or daughters, described the feeling of duty to their parents. Nancy, who cared for her mother and father, stated she felt privileged to have the opportunity to be their caregiver. Rosie, despite not being close to her mother before the diagnosis of Alzheimer’s disease, felt that despite the things her mother had done and said to her in the past, she would not want anyone else to assume care of her mother. Rosie stated there were many things she wished she did not have to do, like cleaning her mother many times during the day because of her bowel incontinence. Rosie had to supervise her mother constantly, especially because her mother would have feces on her hands and go the refrigerator for food. Rosie saw herself as the only person who could care for her mother:

One caregiver was a granddaughter who at the age of 16 assumed full responsibility for the care of her grandmother during the day. This caregiver attended school at night to obtain her high school diploma. During the day, her mother kept a full-time job to ensure that there was a steady income and health care insurance coverage. Her mother still needed to work a few years to be eligible for a small pension. When her mother retired, the granddaughter was 22 years old. Both the granddaughter and her mother were participants in this study. They were interviewed separately in their home. At the time of the interview, the granddaughter was 26 years old, had a baby, and her mother had been retired for four years. They continued to live in the same house with the grandmother. After the mother retired, the
day caregiving duties were no longer the granddaughter’s primary responsibility. The mother, who supplemented her income making and selling chocolates from home, assumed caregiving. The granddaughter continued to be the main support for the mother. These two caregivers described strong feelings of duty toward the grandmother. They saw their role as one that no one else could have or should have fulfilled despite having other relatives living in the same household. The granddaughter elaborated on how many people questioned her decision to stay at home caring for her grandmother. She felt that most people saw her decision as unfair to her while she thought it was the right thing to do.

In addition to feeling that caregiving was their duty, the caregivers described what they thought were the reasons to feel that caregiving was a responsibility to be fulfilled by family. Three domains emerged: that a person had a duty to family above all; that caregiving was done also out of respect for the person, especially elders; and, that caregiving should be a shared responsibility when there were several children.
Duty to family (Deber con la familia). Most caregivers described a sense of pride in belonging to a strong family unit. Caregivers emphasized their descriptions of close-knit family units in which family obligations were clearly acknowledged and met. The family was honored through hard work and by placing family members and the needs of the family before any other wants or needs, especially if they were individual needs.

Caregivers mentioned a strong work ethic and providing adequate financial support to meet the needs of the family to highlight the worth of a person, especially the family member affected by Alzheimer’s disease. For instance, when Nancy explained why she felt it was a privilege to be the primary caregiver to her father, she described him in the following manner:

"Mi papi siempre fue el mejor papá, el mejor esposo. Para el mi mamá y sus hijos siempre estuvieron por encima de cualquier cosa. A todos nos dio amor, enseñanzas, y apoyo. Nunca nos hizo falta nada. El siempre se aseguró de que mi mamá tuviera lo que necesitara y de que el día que el no estuviera eso continuara siendo así. Mi mamá no puede quejarse de absolutamente nada. El la consintió en todo. Yo sé que él tuvo ofertas de negocios maravillosos fuera de la ciudad, pero el mantuvo la unidad de la familia y nos enseño a estar unidos y a ver unos por otros. Nunca le pasó por la cabeza estar separado de la familia por ganar más dinero. Su familia siempre estuvo primero. Por eso para mí fue muy fácil decidir que yo cuidaría de él hasta el final. [My daddy was always the best father and husband. For him, my mother and his children always were above anything else. He gave us all love, teachings, and support. We never lacked anything. He always made sure that my mother had what she needed, and that the day he was no longer here, it would continue to be that way. He spoiled her in everything. I know that he had marvelous business offers outside of the city, but he kept the family together, and taught us to be united and to be there for each other. It never crossed his mind to be separated from the family to earn more money. That is why it was so easy for me to decide that I would take care of him to the end.]

Expressions such as “mom had to be first,” “family comes first,” and “my sister needs me and I will do what it takes to be there for her” were mentioned by every caregiver. These expressions were the caregivers’ way to explain why they had become caregivers to
their relative with Alzheimer’s disease. There was no difference in these expressions between the caregivers that were very close to their relatives, and the caregivers that lived out of town or had not had a close relationship to their care-receiver prior to the diagnosis of Alzheimer’s disease. Rosie, for example, lived three hours away from her mother and described herself as not being “very close” to her mother. Rosie opted for not elaborating on the things that her mother had done to her in the past. However, when Rosie was faced with the fact that her mother was being neglected by a drug addict son and that her mother’s money had been misused by a granddaughter, Rosie left her full-time employment and moved in with her mother. Rosie did not speak about her mother in the praising and admiring terms that other caregivers like Nancy described their relatives. However, the reason to become the caregiver was the same: “Family comes first.” Crying, Rosie elaborated: “Regardless of what she has done to me in the past, she is my mother, she is my blood, and she is my family. I would never abandon her.”

In addition to explicitly stating that family came first, several caregivers engaged in descriptions that denoted pride in how crises were handled by the family. Rosita elaborated on how her son had not hesitated at all to bring her parents to live with him, his wife, and two children, ages 15 and 11. Rosita used to live alone with her husband, but once he was diagnosed with Alzheimer’s disease, her son immediately changed living arrangements. Rosita’s son bought a new house that would accommodate his parents as well as his own family. Rosita’s daughter-in-law was in charge of giving her rides wherever needed. Rosita shared that she had the best son she could ask for and that her daughter-in-law was like her own daughter. The two grandchildren helped to supervise their grandfather in the afternoons while doing their homework or when Rosita needed to go out for errands. The son took his
father out for walks to allow Rosita some time by herself. Occasionally, he took his father to the children’s sports practices, even though it was very stressful due to his father’s wandering. It was obvious that Rosita felt very proud of the manner in which her son and his family had chosen to remain close, take them in, and provide financial and emotional support.

Other caregivers illustrated this sense of pride on how family members contributed in times of crisis. Nelly spoke about the duties each one of her children had assumed to the extent of their possibilities. One of the sons contributed financially, while others spent time with their father, another coordinated medical appointments, and provided rides. Silvia, caregiver for her sister who insisted on living alone, described the tremendous support she felt from her husband. Neither Silvia nor her sister had children. Silvia described her husband as her main support and the person without whom she would have fallen apart a long time ago. Teresa, a long-distance caregiver described how she obtained financial support from two sisters, one brother, and two nieces to pay for her mother’s group home. Virginia described how she took turns to allow her sister time away from their father, and how other siblings contributed with house work, yard work, or money.

Most caregivers brought up the topic of nursing homes, or homes specialized in the care of Alzheimer’s disease patients when they were asked why they had become caregivers. When the topic was not mentioned, the researcher introduced it. Caregivers were emphatic in their comments about placement. Nursing homes were simply not an option, regardless of the financial abilities of the family. Caring for their relatives was a family duty that they needed and wanted to fulfill. Natalia said:
Jamás se me ha pasado por la mente la idea de dejar a mi papá en un ancianato. Las personas que están allí es porque han sido completamente abandonadas por sus familias. Pienso que quienes dejan a sus seres amados allí no tienen corazón, o nadie les enseñó lo que es una familia. No creo que esas personas tengan valores de familia. Me moriría de tristeza de saber que mi papá está en un sitio de esos. [It has never crossed my mind to leave my father in a nursing home. People who are there is because they have been completely abandoned by their families. I think that those who leave their loved ones there have no heart, or no one taught them what a family was. I do not believe those people have family values. I would die of sadness knowing that my father was in a place like that.]

Aida, Catalina’s mother, spoke at length of how each one of her four children was contributing to the household to ensure that the needs of her husband with Alzheimer’s disease were being met. Aida was the caregiver who had tremendous difficulty allowing others to help her. She gave credit to each one of her children for their contributions. Just like her daughter, Catalina, Aida stated that nursing home placement for her husband was completely out of the question. Aida stated she would take care of her husband until he died or she died. It was her duty as a wife.

None of the caregivers spoke positively about nursing home placement. Caregivers described institutionalization as a failure to meet the family duty of caring for each other. Institutionalizing their relatives was equivalent to discarding them as unappreciated and unloved objects. Nursing homes were described by caregivers as warehouses, places where older people would be neglected, and, above all, places for those who had absolutely no family member to take care of them. Placing a relative in a nursing home showed lack of love and respect. Other caregivers like Paulina stated that a nursing home would be the last resort if she was physically unable to provide safe care for her husband. Prior to nursing home placement, she would try hiring help at home. She described placement as a terribly sad step she did not want to experience. The only care-receiver who was not at home was
Teresa’s mother. This care-receiver was not in a nursing home. Rather, Teresa had found a group home where only four residents lived. Teresa was complimentary of the individualized care that was being provided to her mother in a small, family-like setting.

(2) Respect (Respeto). Central to the descriptions given by caregivers about their families and the duty of family members to care for each other was the value of respect (respeto). Respect was reflected in the caregivers’ descriptions of the reasons to become caregivers. Children caregivers spoke about the treatment they owed their parents, not only because they were their parents but also because they were older. The elderly deserved to be treated with the utmost respect and not taking care of them was the equivalent to being very disrespectful. Some caregivers described not respecting elders, parents, older siblings, or grandparents as lacking self-respect. Natalia clearly articulated this idea: "Si yo no respeto a mi abuelita, no me respeto a mí misma." [If I do not respect grandma, I do not respect myself.]

Respect for their elders was also mentioned as one of the reasons for not liking the idea of institutionalization. Older people according to caregivers were to be loved, respected, and cared for. Institutionalizing a loved one was seeing as a valid reason to lose the respect of family members and other people. Caregivers described caregiving as a sign of respect from wives for husbands, children for parents, grandchildren for grandparents, and siblings for older siblings.

Three caregivers, who described their relationship to the care-receiver as not close, or not ideal, placed special emphasis on caregiving, more as a sign of respect than a sign of love. These caregivers were Rosie, Aida, and Paulina. Rosie assumed caregiving duties because the care-receiver was her mother, not because she felt especially close to her.
I am a caregiver because, well, it has…it's like, my mother and myself are so much alike, and I think, I never had a really good relationship with my mom, cause she was always jealous of me. So, now I, it's like I tell her, “I'm being your mom now, Mom,” instead of her being my mother. It's hard for me to say that. at the beginning I was totally in love with my mother because I wasn't, because I had a lot of issues with her. But, fortunately I've been educated enough to where I can see a lot of things and I've been able to resolve my issues with my mother. Not her, having to contribute to it. Now I can say I love my mom. Sorry…it's just because I would love to do things with her, like take out vacations and other places like that. But it's, you know, we may still able to do one or two of them, like take her on a cruise. More than anything, I am a caregiver because caregiving is an obligation, a responsibility.

Aida had been in an unhappy marriage for more than 35 years. Paulina had been married for 25 years and although she did not describe her marriage as unhappy, loving her husband was not listed as one of the reasons to take care of him. These three caregivers mentioned respect for parents and husbands, duty to a relative, and a moral inability to abandon their family member as the primary reasons for their caregiving. In contrast, the other caregivers listed loving their relative as a motivator for caregiving.

(3) Distribution of responsibilities among siblings. Children caregivers who had siblings and were caring for a parent described the dynamics of decision-making as complicated, especially if they had a large family. The greater the number of siblings, the more intricate the dynamics. The first issue was the designation of one of the children as the caregiver, which occurred in several ways. Rosie, for instance, had only one brother, and it was clear that his addictions rendered him incapable of caring for his mother. So, Rosie was the only person available to care for mother.

Nancy, the youngest of four siblings, saw herself as the closest of the four to her parents. She was not asked by her siblings to assume the role of caregiver. She simply decided it was her privilege, and saw her oldest sister as someone who could not do a good job because she had spent most of her adult life outside of the country.
Virginia shared how even though she was the oldest daughter of six children, her father in giving his power of attorney to a much younger daughter had made her the main decision-maker. This younger sister was a registered nurse. Virginia and her sister Josefina were the primary caregivers and resented the harsh treatment they received from their younger sister. Teresa, also a registered nurse, was not the oldest daughter, either. She was designated by her dying father as her mother’s caregiver. Teresa had eight brothers and sisters. Julio had two brothers and two sisters, one of whom lived overseas. Julio became the primary caregiver because he was unemployed at the time of his mother’s diagnosis with Alzheimer’s disease.

Three of the caregivers, Rosie, Catalina, and Consuelo, assumed their roles because each was the only daughter. All three had brothers. Consuelo’s case was unusual in that she not only cared for her mother with Alzheimer’s disease but also cared for her 60-year-old brother with mental retardation.

Catalina had the support of her three brothers but made it clear that because they were men, they did not think of everything that was needed. Catalina believed she was the most capable of the four children to become the primary caregiver in the event her mother died, because she was a woman.

Children caregivers in Colombia distributed duties among their siblings in a way similar to caregivers in the United States. However, the geographical proximity of children to their parents, and the culturally acceptable practice of adult children living with their parents appeared to allow children more involvement in caregiving. For instance, Catalina and her three brothers lived with their parents, and they worked and contributed financially to the household. The youngest brother, a jeweler, worked from home when he could. He was in
charge of driving, taking his father for medical appointments, and bathing him. Another brother was in charge of coordinating legal and medical matters, and the third brother did grocery shopping. Catalina made sure that her younger brother and her mother, Aida, could get out of the house by staying with her father, especially during weekends. Aida retained power of attorney and was the final decision-maker.

In Nancy’s case, her siblings did not contribute to the parents financially, but they paid Nancy a salary equivalent to what she would have earned had she continued working in her laboratory. The three siblings took turns on weekends to relieve Nancy, and they often took their mother out until one of the brothers died of a massive myocardial infarction. At the time of the interview, Nancy spoke about how considerate her brothers had always been. There appeared to be no major conflict among the siblings, and she described their relationship as one where they looked out for each other. The mother played a major role in decision-making. Nancy, however, shared that she resented that her sister came on weekends to sit and visit, but was not really involved in the hands-on care of her father:

"Ella viene los sábados y domingos cuando es su turno, y se sienta toda la tarde a hacer visita. Toma café, charla con mi mamá, la entretiene, pero no mueve un dedo para ayudarle a la enfermera con mi papá. El es muy pesado y eso es duro para una sola persona." [She comes Saturdays and Sundays when it is her turn, and sits down all afternoon long visiting. Drinks coffee, chats with my mother, entertains her, but does not move a finger to help the nurse with my father. He is very heavy and that is hard for only one person.]

What Nancy resented most was how quick her siblings were to point out things that needed to be done, but never offered praise or appeared to notice positive things. Nancy stated:

"Viene de visita solamente, y solo tienen ojos para ver que falta hacer. Por ejemplo, si mi papi tiene las patillas largas, de inmediato mi hermano le dice a mi mamá, dígale a Nancy que le corte las patillas a mi papá. Pero nunca dicen, como está mi
papá de buenmozo, peluqueado, o sus uñas arregladas, o mi papá no tiene ni una sola llaga a pesar del tiempo que pasa en cama. Eso sí no lo dicen. [They come to visit only, and they only see the things that still need to be done. For example, if daddy’s sideburns are a little long, my brother immediately tells my mother, tell Nancy to cut dad’s sideburns. But they never say, how handsome dad looks! His hair is cut, or his fingernails well kept, or he does not have a single bedsore despite the time that he stays in bed. That, they don’t say.]

Virginia described the distribution of tasks as very hard on her sister, Josefina, who received compensation from a younger sister, Margarita, a registered nurse, for the time she spent caring for their father. Their father had given Margarita his power of attorney, and because of her education Margarita was given the task of coordinating medical care and refilling of prescriptions medications. Margarita was the primary decision maker. None of the children lived with the father who had Alzheimer’s disease. Virginia lived with her husband and a college-age daughter. Crying, Virginia stated:

At the beginning we all thought it was going to be great that Margarita had the power of attorney and all that. She is the nurse! So who could be better to teach us how to take care of my father. She had the education none of us did. But is not like that. We can’t do anything unless she approves. She just yells at us for every little thing. There are things that make no sense, like taking my father to the doctor because his bladder was hurting. She made me go downtown with him for an appointment. I tried to tell her that my father was on hospice and that someone would come out to the house to see him. Forget it. If Margarita says it, you had better do it or else. She is horrible to Josefina! a lot worse than she is with me. I try to ignore her as much as I can. And she is a nurse! a nurse like that I don’t want at my bedside. She is my sister, but she is a b----. I am sorry to have to tell you that. We were taught better. This is not what my mother taught us about caring for each other. It is not. Margarita has made this very, very hard for all of us. One of my nieces offered to come and help during the week. Margarita turned her down and told her that what was really needed was help on weekends. My niece has a baby, how is she going to just leave him? Other relatives kind of want to help, but they do not want to have to put up with Margarita.

Conflict such as the one described by Virginia was not unique to children caregivers in the United States. Adult children caregivers in Colombia also described conflict situations
when asked if there had been any positive or negative things happening because of caregiving.

Jael and her sister, Clara, described how despite their efforts to be more involved in the care of their mother, the sister who still lived at home had slowly formed an allegiance with a live-in worker. This alliance distanced the other five sisters as far as possible from their mother. The sister that lived at home had a full-time job and was minimally involved in her mother’s care. Although the other sisters had the time and were willing to care for their mother, they were not allowed to do so freely. Three sisters had decided to step aside, but Jael and Clara did not because they thought their mother’s care was negligent. They felt that their mother should not have the same diaper on from the time she went to bed until noon the next day when the employee would bathe her. On several occasions they had fed their mother after being told by the employee that their mother had refused to eat. Jael and Clara had decided to show up unannounced, especially during the week when the other sister was at work. Rather than leave their mother in bed all day, they came in to sit and read and talk with her, take her for walks, and enroll her in a music therapy program within walking distance. Despite the employee’s protests and her overt negative criticisms of how they were doing things, they bathed and groomed their mother, fed her, and procured activities for several hours daily. They were confronted by the live-in sister who argued that if they kept doing things their way, she would lose a longtime trusted employee. Jael and Clara confessed that they could not be happier if that happened because that would create an immediate need for all sisters to become involved. At the time of the interview, Jael and Clara had been asked by their sister to help only on Sundays when the employee had time off.
b. Caregiving is learned. Without exception, caregivers stated the manner in which they had been raised when asked why they had become caregivers. Bilingual caregivers emphasized that Hispanic/Latino families instilled in their children the importance of family and respect for authority and the elderly. Colombian caregivers did not speak about Hispanic/Latino culture; they simply described close relationships to an extended close-knit family and highlighted the values of respect, honesty, and unity. Caregiving had been modeled to the caregivers, especially during their childhood. Grandparents, parents, aunts, and uncles performed this role modeling. Those caregivers who, like Brandi, did not grow up around grandparents, mentioned their parents, especially their mothers, as the people they had seen caring for others.

Natalia, the granddaughter caregiver, described in detail growing up living in her grandmother’s house. She still lived there at the time of the interview. Natalia talked about coming back from school in the afternoons and spending time with her grandmother every day. Natalia enjoyed doing grocery shopping with her grandmother and followed her everywhere. The grandmother was a caregiver to her husband, her four adult children, and several grandchildren.

Virginia described growing up in a large extended family that got together very often. Virginia felt that her mother had tried to prepare her and her sisters to be caregivers from the time they were little girls.

My mom was brought up to care for her father because she was left without a mother very young. So she did a lot of caring for cousins and then her father. And then … so my mom always … I remember being young at home, she would say, “Your dad’s getting here from work, go ahead and go take his shoes off and go look after him.” Or if he was out working in the back yard or something, “Go take your dad a glass of water. Go ask your dad if he wants to have lunch now.” So she was always preparing us, I guess, in a way, for later on. Which you don't realize until now, why she was
asking us to do all this, because she was more concerned about him than with her. I guess for us, too, because I've always felt my dad, my dad would say, my dad would say, one time, "Tu eres la unica que es mas amable y mas considerada." [You are the one that is most polite and considerate]. And things like that, because I was brought up that way. You know, my mom would ask us, “Okay, go, go see what your dad needs. Go, go.” And, I didn't mind it, being a kid, you know. I guess being second born and being a girl, you like your dad.

Aida, Paulina, Nelly, Virginia, Carmela, Silvia, Rosita, Jael, Clara, and María all described their mothers as having had a tremendous influence in how they perceived caregiving and their duty to their relative with Alzheimer’s disease. Their mothers had modeled admirable caring behaviors in times of tremendous adversity such as early widowhood, wartime, immigration to a different country, health problems, and economic recession. These caregivers’ ages ranged between 58 and 75 years of age. Rosita, for instance shared:

I think my mother must have written the book on being a nurturer. She took care of my stepfather with emphysema and high blood pressure and all the other allergy problems he had plus being number one grouch. And she did that without knowing how to drive a car, waiting until he felt like he was going to have a good day to drive her to the store to get her groceries. Never complained. Then he, I don’t know what he was thinking about, asked her if she would mind if his older brother, who was a bachelor that never married, and was having emphysema problems, if she would mind if he would move in. So now, we’re talking about taking care of two people. Uh huh. The laundry, the cooking, the cleaning up, bathing, and everything. I do not measure up to her. I drive. I only have my husband to take care of. I now have a hospice to help me. I don’t have any of the pressures she had. So, I really sometimes don’t think I’ll measure up to how strong she was. And I think Latino women are nurturers, innate nurturers, that they have that capability or that they feel the obligation, and nothing stands in their way. They don’t think about themselves.

In contrast, Julio, Hernando, Natalia, Catalina, Susana, Nancy and Brandi did not focus their description on the examples set by their mothers alone. This younger group of caregivers included descriptions of a caring paternal figure in their earlier formative years. This figure was a father, uncle, or grandfather. Nancy’s description of her father, previously
mentioned in the section “Duty to family,” showed that she believed taking care of her father was a privilege. Hernando and Susana echoed that sentiment. Their father, now with Alzheimer’s disease, had previously been the person who directed the household in every aspect; he had provided guidance, love, and discipline as Hernando and his siblings grew up.

Most caregivers spoke about their childhood as the time during which they believed they had learned about caregiving in an informal way. Brandi eloquently summarized: “No one taught us what caregiving was, no one told us how to do it. We lived it! Every day, that is why it is part of who we are.”

3. Caregiving is satisfying.

The third overarching theme was caregiving is satisfying. The researcher identified this theme in the majority of interviews. Caregivers described a sense of satisfaction in being able to fulfill a duty to their relative. Regardless of the difficulties they faced, caregivers described this sense of satisfaction as something positive and enriching in their lives. For instance, Nancy stated that, although caregiving was very difficult and she resented a few
things from her siblings, she felt privileged and honored to be able to care for her father. She would not want anyone else to do it, even if her siblings did not pay her. Nancy stated:

_Usted me ve llorando, porque esto es muy, muy duro, pero le aseguro que nada antes en mi vida me había dado tanta satisfacción. Con el tiempo voy a poder mirar atrás y sentirme en paz conmigo misma de que pude pasar todo este tiempo con mi papi y le pude dar mucho amor, todo mi amor. Le doy gracias a Dios por darme la oportunidad de poder cuidar a mi papi._ [You see me crying, because this is very, very hard, but I assure you that nothing before in my life had given me so much satisfaction. With time, I will be able to look back and feel at peace with myself that I could spend all this time with daddy and I was able to give him much love, all my love. I give thanks to God for giving me the opportunity to take care of daddy.]

Caregiving was satisfying primarily because the caregiver was able to fulfill a duty to the family. In the process of fulfilling this duty, caregivers felt that this was a unique opportunity to give back to the care-receiver, to do their best for their care-receiver, and to make some necessary sacrifices to ensure that the care-receiver was well cared for.

a. Caregiving is my opportunity to give back. Caregivers mentioned giving back to the care-receiver for all the positive things done in the past or given to the caregiver or the entire family. The only caregiver who did not see caregiving as an opportunity to repay the care-receiver was Rosie. She described her relationship with her mother as not very close, and stated that despite everything her mother had done in the past to her, she would continue to be her caregiver. The other caregivers elaborated on the things they had received from the caregiver prior to the diagnosis of Alzheimer's disease – both tangibles and intangibles.

_Yo tengo el deber como hijo y es lo que yo les tuve que decir a mis hermanas, que todos debíamos tener la misma responsabilidad de cuidar por ella y que gracias a Dios, nosotros podíamos en algo retribuirle a ella lo que hizo por nosotros, cosa que no nos dio lugar a hacerlo con mi papá. Mi papá falleció en un accidente de tránsito, entonces no pudimos darle a mi papá lo mismo que a mi mamá, ambos se esmeraron muchísimo con nosotros, mi papá no le pudimos recompensar o dar, algo de lo que hizo con nosotros, porque fue de un momento a otro que el se nos fue._
Entonces yo les decía, ya que Dios nos dio la posibilidad de retribuir en algo lo que ellos hicieron, no la podemos perder, poco a poco lo admitieron, porque cada una tenía sus obligaciones personales, su casa, pero entonces como le tocaba el tema sentimental pues todos tenían la misma obligación, no que por que a usted le estamos pagando, usted tiene. Todos teníamos la obligación. [I have a duty as a son, and that was what I had to tell my sisters, that we all had the same responsibility to take care of her, and that, thank God, we could give back in part everything that she had done for us; something that we could not do with my father, my father died in a car accident, then we could not give my father the same that my mother. They both were very good to us, my father we could not reward or give back some of what he did for us, because it was from one moment to the next that he was gone. Then I told them, now that God gave us the opportunity to give back some of what they did for us, we can’t lose it. Little by little they admitted it, because each had their personal obligations, their houses, but then I would touch the sentimental side because we all had the same obligation. Not that because we are paying you, you have to. We all had the obligation.]

Silvia described her sister with Alzheimer's disease as the person who had set the best example in life for her. Her sister had dropped out of high school and returned to the small town where she had been born to take care of her father after he had a stroke. Silvia’s sister would return to school to obtain her high school equivalency at the age of 45 after her father died. She worked and attended school at night, and became a prominent political activist in her town. After receiving several death threats because of her activism, Silvia’s sister had to return to the metropolitan city in Colombia and would struggle to make a living there. Silvia described her sister as a person who never stopped learning, stood for what she believed, and was always there for her. At the age of 69, she had obtained a master's degree in history and political science. Silvia felt that just as her sister had taken care of their father, now she had the best opportunity to do something for her sister.

Nancy mentioned how her father had always been her biggest supporter during times of crisis. He had financially and emotionally sustained her whenever she needed help. They shared the same profession and had been in the clinical laboratory business together after she
graduated from college. She felt she had been privileged in being the youngest of the four children. Being *la chiquita* (the little one) had allowed her to be the center of her father's attention. Likewise, Natalia saw caregiving for her grandmother as doing no less than what her grandmother had done for her as a little child – ensure each one of her needs were met.

Wife caregivers, except Aida, described caregiving as an opportunity to give back to their husbands. Paulina stated that although her husband had not been the most affectionate and generous person, he had always been a gentleman, respectful of her and her two children from her first marriage. Paulina wanted to repay her husband for their time together. Nelly, Rosita, and Maria explicitly talked about giving back all the love and affection they had received from their husbands.

b. Caregiving is knowing that I am doing my best. A second component of the theme *caregiving is satisfying* was *caregiving is knowing that I am doing my best*. In general, caregivers recognized their limitations and tried to make the best of their situations. Knowing that they were doing their best to care for their relatives gave them a sense of satisfaction. Caregivers had limitations such as time, energy, financial resources, and physical strength. Each caregiver faced a unique situation, but each took pride in doing what was humanly possible to do for a relative. Several caregivers described caregiving as an opportunity to bring out the best in them as human beings. Caregivers also talked about not knowing what they were capable of doing and enduring until they became caregivers.

Silvia did not know that she could think very quickly of excuses to distract her sister, and she described how her husband joked about her ingenuity and creativity. Because her sister refused to have anyone living with her, Silvia made up endless excuses to be in her apartment. Once a week, her sister attended a senior citizen program that offered outings.
Because her sister refused to pay for such outings, Silvia created a series of lies to convince her that the program was free of charge thanks to a very generous woman, who also paid for housekeeping services for those who attended the program. Silvia and her husband paid for these services even though they were a major expense they had not planned for in their retirement budget. Silvia had to create opportunities to run errands with her sister for banking, collecting her pension check, making payments, and grocery shopping. Silvia's husband, who had come home toward the end of the interview, said that he was able to deal with Silvia’s sister for no more than five minutes. He admired Silvia's patience and creativity to remain as close as possible to her sister.

Julio also exemplified creativity. He described in detail some of the strategies that he had used to be able to care for his mother. The first strategy was the creation of a card with his mother's identifying data. In Colombia, there was no Safe Return program like the one offered in the United States by the Alzheimer's Association. Julio created an identification card that was printed on at least 30 different colors. Julio's mother agreed to wear her identification as a pin as long as the color matched her clothes. Bathing had become an issue because Julio's mother was afraid of the shower and fought getting in the bathtub. Julio bought a children's plastic pool and several water toys. His mother began to enjoy bath time in the backyard. Similarly, taking his mother in his car had become dangerous because she would become agitated, pull on the steering wheel, and be a major distraction. During a trip, Julio played the radio and discovered that his mother would try to sing if she recognized the song. Julio prepared a large print songbook with the lyrics of songs that he thought might have been part of his mother's youth. He bought compact discs and would play them whenever his mother was in the car. She quickly got used to riding in the back seat, bringing
her songbook along, and singing while Julio could drive safely. In addition, Julio created medication charts, daily menus, and a schedule of daily routines and activities to guide his siblings on weekends. Julio acknowledged that he had not known before he became a caregiver that he had such organizational skills.

Other caregivers described having physical strength to lift or do house chores when they thought they had no strength left at all. Caregivers described how caregiving had given them the opportunity to discover abilities they did not know they had, and in several instances had felt a rush of energy that had allowed them to survive the moment.

No se de donde es que de pronto saco alientos para hacer las cosas. Cuando ya pienso que llegue al final y no puedo más. Y de pronto algo le pasa a papá o se necesita algo y es como una reserva de energía que yo no sabía que existía o que yo tenía y termino haciendo algo que yo misma habría dicho que era imposible de hacer. [I do not know where I get the energy to do things all of a sudden. When I think that I am at the end and I cannot do more, all of a sudden, something happens to father or something is needed. It is like a reserve of energy that I did not know existed or I had, and I end up doing things that I would have said to myself were impossible to do.]

Caregivers who had been taking care of their relatives with Alzheimer's disease for an average of four years or more described a feeling of peace with themselves. This feeling was a mixture of satisfaction and relief. They were satisfied that they had been able to assume caregiving duties, and felt that they had done their best under their specific circumstances to provide care. Caregivers like Brandi, Maria, Paulina, Nelly, and Susana, whose care-receivers were still in the early stages of Alzheimer's disease, did not voice this sense of satisfaction. There remained a great deal of learning about the disease and what lay ahead.

Nelly and Susana described in their interviews that their care-receiver was still allowed to go to the neighborhood park alone. If he did not come back within thirty minutes, either Susana or Nelly, whoever was at home, would go out and look for him. On three
different occasions he had been found at a nearby church. Paulina described her frustration trying to reorient her husband to place and time. These caregivers were not at a point at which they understood the disease process. Other caregivers, such as Nancy, Rosita, Carmela, Natalia, Julio, and Consuelo, talked about having the certainty that they were doing their best. Knowing this gave caregivers a strong sense of satisfaction. Consuelo, who cared for a brother with mental retardation and her mother with Alzheimer’s disease stated:

_Poder cuidar de mi hermano y de mi mamá al mismo tiempo no ha sido fácil por que he debido responder económicamente por ellos y asegurarme de que el dinero que dejó mi papá para ellos continue ganando intereses. Pero ya he aprendido que si he dado lo mejor de mí misma y que he hecho lo mejor que podía. Hasta he aprendido a ser más asertiva. Me da mucha paz saber que el día que mi mamá muera yo sabré que sí hice lo mejor que se pudo y que no ahorre esfuerzo por darle lo mejor. [To be able to care for my brother and my mother at the same time has not been easy because I have had to answer for them financially, and at the same time ensure that the money left by my father for them continues to gain interest. But I have learned that I have given the best of me and I have done the best I could. I even learned to be more assertive. It gives me great peace to know that the day my mother dies, I will know that I did do the best I could and that I did not save any effort to give her the best.]_

c. Caregiving is a sacrifice. The idea of sacrificing time, employment, money, socializing, and all the things that caregivers give up to care for their relatives with Alzheimer’s disease was described as necessary in order to fulfill a duty to family. The majority of caregivers spoke about this sacrifice positively. Caregivers felt that caregiving for a loved one with Alzheimer’s disease was difficult and sad, an experience that was emotionally painful, physically exhausting, and financially detrimental. However, caregiving was seen as something that was done with resignation and became an offering to God. Several caregivers described caregiving as a God-sent challenge that God would not have given them if they had not been able to handle it. In addition to being a family duty, caregiving was also described as a Christian duty.
Es un sacrificio, lo primero es la fe de nuestra religión que no estamos solos que aunque las cosas se miren oscuras y tristes a... tiene que uno pensar en los sacrificios que nuestro Dios hizo por nosotros, entonces lo que uno hace es simplemente cumplir con una obligación. [It is a sacrifice, first it is part of our religion that we are not alone even though things look dark and sad eh...one has to think in the sacrifices that our Lord made for us, then what one is doing is simply to fulfill an obligation.]

Caregivers also described the sacrifices made for their care-receivers as their ultimate way to demonstrate love. Caregivers talked about their duties as an opportunity to sacrifice for their loved ones in the same way that the loved ones had sacrificed in the past or would have sacrificed for the caregiver if the roles had been reversed. Rosita said:

I do it because he’s my best friend. And it’s not necessarily in that order, I do love him, and he is my best friend. He would have done the same thing for me, I’m almost positive, if he was in good health and I wasn’t.

Caregivers also described sacrificing for their care-receivers as a value. This value was important to maintain the family structure and to have self-respect and the respect of others. Caregivers described not sacrificing for their care-receivers as a sign of lack of love for their families. Sacrificing for their relatives was the respectful thing to do.

Caregivers also described their sacrifices for their care-receivers as inspiring life-changing experiences. Several caregivers described the need to help others, especially those affected by Alzheimer's disease. Teresa, for instance, wrote the book *¡Mi mamacita tiene Alzheimer!* (*My beloved mother has Alzheimer’s!*). Teresa was inspired to do this after feeling that none of the publications or programs to which she had access truly addressed the Latino/Hispanic perspective on family, respect, and customs. Teresa continues to be a long-distance caregiver while advocating for family caregivers through her activism in national associations. Likewise, Martha, who was interviewed informally and with whom the researcher completed several hours of field observations, was a caregiver to her father with
Alzheimer's disease for 10 years. Upon his death, Martha decided to create an Alzheimer’s association to support caregivers. This institution offers support services to Alzheimer's caregivers free of cost. Martha, with the support of her husband and adult children, dedicates the vast majority of her time to interview caregivers, generate referrals to neurologists, run support groups, and loan durable medical equipment.

Other caregivers like Julio felt that the strategies used to care for his mother needed to be shared with others. Julio decided to volunteer one morning a week at a local community center dedicated to support Alzheimer's caregivers. Julio attended support groups to share what he had learned as a caregiver. When asked what was one of the things that he told caregivers when they came to the Fundación Julio replied:

> Siempre les digo a los cuidadores que nuestro trabajo como cuidadores es aprender a dar y recibir amor, y que lo más importante para poder cuidar a alguien es darles mucho amor. La paciencia es importante, pero el amor lo es más. Cuando nos convertimos en cuidadores hacemos que el mundo sea un lugar con más amor. [I always tell caregivers that our job as caregivers is to learn to receive and give love, and that the most important thing to be able to take care of somebody, is to give that person lots of love. Patience is important, but love is more important. When we become caregivers, we make the world a place with more love.]

### 4. The language of caregiving.

The second aim of this study was to describe the culturally and linguistically relevant expressions and terminology used by bilingual and monolingual Latino/Hispanic Alzheimer's disease caregivers to describe or express the consequences of caregiving. Preliminary work results (Appendix A) supported the idea that the English word *burden* and the Spanish word *carga* were not used by the caregivers to describe their experience.

The cultural inappropriateness and incongruence of the words *burden* and *carga* that emerged during preliminary work was confirmed in this study. Caregivers did not use these
words to describe their caregiving experience. The caregivers qualified their experience in general as difficult *(difícil)*, hard *(dura)*, challenging *(un reto)*, frustrating *(frustrante)*, sad *(triste)*, lonely *(solitaria)*, and stressful *(tensionante or estresante)*. Monolingual caregivers described the caregiving experience as *dura* (hard), *desgastante* (producing a great deal of wear and tear), *pesada* (heavy, tough), *fatigante* (fatiguing), *extenuante* (exhausting), *agotadora* (exhausting), and *difícil* (difficult). Different terminology and expressions emerged as the researcher asked caregivers to elaborate specifically about the emotional and financial impact of caregiving.

The descriptions of the emotional impact caused by caregiving included mental stress *(estrés mental, tensión mental)*, worrisome *(preocupante)*, lonely *(solitaria)*, and frustrating *(frustrante)*. In addition, caregivers described feeling isolated *(aislados)*, a sensation of having “too much to do” *(demasiados pendientes, demasiado por hacer)*, and feeling emotionally drained *(emocionalmente drenados, or vacíos)*. All these expressions and terminology had equivalent words in Spanish and vice versa.

Caregivers described the financial impact of caregiving as negative *(negative)*, worrisome *(preocupante)*, and difficult *(difícil)*. The financial situation *(situación financiera, or, situación económica)* was described in general as difficult. It was only in this context that one bilingual caregiver spontaneously used the word *burden*. Likewise, only one monolingual caregiver used the expression “*carga financiera.*”

Taking care of my mother has created a tremendous financial burden. I am no longer employed, and we live off her social security checks, on Medicaid, Medicare, and food stamps. Because no one from the home health agency would want to take care of my mother because she was too much work, the women didn't want to come back, so the manager told me I could become her provider for six bucks an hour. Is nothing, but that is the only extra money I can make. I need the respite but they don't want to come so that's what I have to do.
Julio, whose background was accounting, was the only monolingual caregiver that used the word *carga*. He talked about his decision not to be employed, and the contributions of his siblings to cover a small salary for him.

Entonces, ella sin ahorros, yo sin trabajo, y los gastos de sus medicamentos, citas al médico, gastos de la casa, pañales, el Ensure, eso sumaba. La carga financiera era excesiva así que mis hermanos empezaron a ayudar. La carga entre todos se hizo más liviana. [So, she had no savings, I had no job, and the expenses of her medications, medical appointments, house expenses, the diapers, the Ensure, all that added. The financial burden/load was excessive so my siblings started to help. Between all of us, the load became lighter.]

None of the caregivers spontaneously used the words *burden* or *carga* except the two aforementioned examples. These examples were clearly related to financial matters. The researcher introduced the word burden during the last part of the English interview with bilingual caregivers. The answers given by the caregivers in this study were almost identical to the answers offered by bilingual caregivers in the preliminary study. When the caregivers were asked what the word burden meant to them, they offered the following explanations:

“Burden is something that you do because you have to, but not because you want to”;

“Burden is having too much on your plate and you not being able to handle it anymore”;

“[Burden] is something very difficult that a person has to do and that the person does not enjoy at all. It is something, eh perhaps…painful? Maybe a struggle? I really don't know how to tell you what it means”; and “Burden is something hard that you can't do.”

When the caregivers were asked to translate the word burden to Spanish they hesitated and could not offer a single word to convey the meaning. Rather the caregivers engaged in explanations and used code-switching to illustrate the idea. Caregivers offered the following:
Burden es como que uno no puede hacer algo, uno quiere pero no puede hacerlo porque es demasiado difícil. [Burden is like one cannot do something; one wants to but cannot because it is too difficult.]

Burden es having too much in your plate, pero si digo eso en español, no tiene sentido alguno. [Burden is having too much in your plate, but if I say that in Spanish, it does not make any sense.]

Burden, eh, burden? no, no se, stressed, como que uno no puede manage las cosas. Como que es too much. [Burden, eh burden? No, I don't know, stressed, like you cannot manage things. Like it is too much.]

Burden … no, no encuentro una palabra en español. No sé cómo se dice en español. [Burden… no, I do not find a word in Spanish. I do not know how to say it in Spanish.]

After trying to obtain the meaning of the word burden from the caregivers, the researcher asked if burden was something that they had experienced. Even though all caregivers had described the idea that they were juggling too many things, had an excess of responsibilities, and all these things were having a negative physical, emotional, and financial impact, the caregivers denied experiencing burden. Likewise, the interviews conducted in Spanish included questions about the word carga.

Two caregivers, Paulina and Aida, admitted to feeling that caring for their husbands was a carga. Rosie, a bilingual caregiver, denied feeling that her mother was a carga, but clearly used the mechanism of linguistic code-switching to express burden.

The following are the excerpts from the interviews with the three caregivers who used the words carga or burden. Paulina and Aida were monolingual Spanish speakers. Paulina, as mentioned before, had been married for 25 years but did not see her marriage as a very happy relationship. She felt respected by her husband, and highly valued his companionship.
Researcher: *Paulina, ¿tu sientes que cuidar tu esposo es una carga?* [Paulina, do you feel that taking care of your husband is a carga?]

Paulina: *Sí, si hay momentos en que....* [Yes. Yes, there are moments in which...]

Researcher: *Hay momentos... ¿en que tu sientes que es una carga?* [There are moments ...in which you feel that it is a carga?]

Paulina: *¡Sí!, si cuando me desespero, si, si siento que es una carga, además siento que, podría haber otras personas, que estuvieran pendientes de él también, los hijos de el alguno que dijera, muestra a ver lo llevo hoy, no, eso no sucede, ellos, ellos realmente se descargaron totalmente en mí, los hijos, los hijos, porque tu sabes que el es separado, pero de los hijos nadie, nadie viene, ni los hermanos, es decir, eso es para mi no mas, no, ellos ni siquiera preguntan por el, ninguno de la familia de él, ni los hermanos, ni los hijos, y me da una tristeza de ver ese vació tan grande y él lo debe tener, lo debe tener, además no lo expresa, no lo expresa, pero, pero...* [Yes! Yes, when I get desperate, yes, I do feel that it is a carga, besides I feel that, there could be other people to look out for him, his children, one that could say, I will take him today, no, that does not happen, they, they really unloaded everything on me. His children, the children, because you know he was divorced, but none of the children come by, no one comes by, neither do his brothers, so, this is just for me. No, they don't even ask for him, none of his relatives, not his brothers, neither his children, and I get very sad to see that emptiness, so big, and he must have it, he must have it, besides he does not express it, does not express it, but, but...]

Aida, who described her marriage as very unhappy, had been married for 35 years.

She shared:

Researcher: *Aida, ¿sientes que cuidar de tu esposo es una carga?* [Aida, do you feel that taking care of your husband is a carga?]

Aida: *Pues sí, es obviamente una carga, por que estar pendiente las 24 horas, a veces ni deja dormir, o sea es súper cansón, pero digamos que la situación está controlada y que hemos ido aprendiendo a manejarlo, entonces ya sabemos que si se pone a esculcar en los cajones, es por que se esta poniendo mal si, ya sabemos que por las noches se pone, se empieza a poner de mal genio, medio grosero, entonces digamos que ya tenemos como la situación controlada y nos estamos amoldando a ella, pero pues obviamente es una carga pues de aquí a quien sabe cuánto tiempo estar cuidando una persona y...* [Well yes, it is obviously a carga, because you are constantly there, sometimes you don't even let him sleep, it's super tiresome, but we say that the situation is under control and that we have been learning to deal with it, then we already know that when he starts to fish in the drawers, he is feeling bad, we already know that at night he does, he starts getting ill-tempered, a little coarse, then we say that we already have their situation under control and we are adapting to it, but in any case it is a carga, after all, who knows how long it will be taking care of a person and...]

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vivir en función de eso. [Well, yes, is obviously a carga, because to be looking after him 24 hours, sometimes he does not let me sleep, I mean, is super tiring, but we can say that the situation is controlled and that we have been learning to manage him, then we know that if he is searching drawers, is because he is getting bad, we already know that at night he gets, he starts getting angry, somewhat rude, then, we can say that we have the situation kind of controlled and we are adapting to it, but it is.] obviously a carga and who knows for how long to take care of a person and to live in function of that.

The following excerpt illustrates the use of code-switching by a bilingual caregiver who did not use the word burden when interviewed in English, but when interviewed in Spanish, borrowed English words to express how she felt. The caregiver spoke Spanish, but used intrasentential code-switching each time that she expressed burden. Intrasentential code-switching is the use of words from a second language in the middle of a sentence.

Researcher: ¿Rosie, tu considerarías cuidar de tu mamá una carga? [Rosie, would you consider taking care of your mother a carga?]

Rosie: Sí, muy grande, una carga muy grande, que nadie la quiere hacer, pero estuvo tan abusada porque nadie quería tomar los pasos necesarios para que ella estuviera mejor en la casa, si me hubiera hecho eso todo mi mamá estuviera ay en la casa de ella, pero pues ya ni en su casa o puede estar por que todo, la casa esta completamente destruida. [Yes, very big, a very big carga, that no one wants to take care of, but she was so abused because no one wanted to take the necessary steps for her to be better in her house, if I had done all that my mother would be there in her house, but she can not be there anymore because is completely destroyed.]

Researcher: Cuéntame una cosa Rosie, cuando te pregunte antes que palabras usarías para describir tu experiencia, todas las cosas por las que estas pasando, no usaste la palabra carga, hasta que yo le mencione. [Tell me something Rosie, when I asked before about the words that you would use to describe your experience, all the things you are going through, you did not use the word carga until I mentioned it…]

Rosie: ¡Aha!

Researcher: ¿Por que? [Why?]
Rosie: A... por que yo, no, no quizás no la, no la entendí, en ingles quizás te pude haber dicho a... porque en español... [Ah... because I, no, perhaps I did not, I did not understand it, in English perhaps I could have said... because in Spanish...]

Researcher: ¿Como la dirías en inglés?[How would you say it in English?] Rosie: It's a very difficult task.

Researcher: Difficult, anything else?

[Prolongued silence]

Researcher: ¿La llamarías un burden?[Would you call it a burden?] Rosie: Yes! It's a big burden!

Researcher: Pero no lo llamaste "burden" cuando te pregunte como era. [But you did not call it burden when I asked you what it was like.]

Rosie: ¿Es, es carga, carga "burden"?[Is, is a carga. Is a carga burden?] Researcher: No se, ¿tu que piensas?[I do not know, what do you think?]

Rosie: No... Una carga es algo que llevas en ti, jejeje si. I will call it a burden, yes, a big burden. [No, a carga is something that you carry with you, [laughs], yes. I will call it a burden, yes, a big burden.]

Researcher: Bueno eso me lo dices ahora que yo traigo las palabras a la conversación, pero cuando te pregunte por las descripciones, esa palabra ¿no paso por tu mente? ¿alguna razón especial para que no la usaras?[Well, you say this now that I have brought the words to the conversation, but when I asked you to describe, that word, did not cross your mind? Any special reason for you not to use it?]

Rosie: (Caregiver completely code-switches to English) OK, because you asked me to describe how I fell about my mom's situation, and I was telling you sometimes it's happy, sometimes it's sad, sometimes it's frustrating, some frustrations, sometimes it's anger, those are descriptive words that I'm giving you. But, I've always seen it as a burden, always, it's a burden, it's a burden I have to carry. Whether I like it or not, I have to carry that burden. My mom has nobody. I don't like it, but I'd rather do it than somebody else take over my mom's burden and not take care of her. (Code-switch back to
Spanish.) *No, no la van a cuidar como yo la cuido.* [No, they are not going to take care of her the way I did.]

**Researcher:** So that burden is for you to carry, not for anyone else to carry? Tell me about it.

**Rosie:** Because, *nadie, nadie le puede cuidar como yo, yo se que todo el tiempo ella, ella no está ahí , , yo sé cómo cuidar a mi mama,* , *Diosito no más me dio eso, porque yo, yo he sentido todo eso, siento todo, siento lo que siente mi mama,* es que yo se que nadie me la va *cuidar como yo la cuido.* [Because, no one, no one can take care of her the way I do. I know that all the time, she, she is not there. I know how to care for my mother, God gave me only that, because, I, I have felt all that, I feel all that my mother feels. No one is going to take care of her the way I do.]

**Rosie:** (Code-switch) It's a huge burden. I hate it! *Pero prefiero hacerlo yo a que verla a que la maltraten, de cualquier forma.* [But I prefer to do it rather than having others maltreat her in any way.] And that's my way of coping out, by saying God made me. Because I know if I didn't she would have to go to a nursing home but I wouldn't be there to see her. Nobody's going to do it. Nobody else is going to do it. It's a very hard job. That's why it's burdensome. Overall it's a burden, but within that burden we have our good moments as well. There are the good moments of being a burden, but it is a burden. And if anybody tells you different they're lying. Down inside, they wish they didn't have to. And on the other hand, (Code-switches completely back to Spanish.) *mi tía que cuido de su marido tan enfermo por muchos años me dice: "todavía quisiera tener a mi papito".* No sé si yo llegue a decir lo mismo. [my aunt who took care of her husband so sick for many years tells me, “I would still like to have my daddy.” I don’t know if I every will say the same.]

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**a. Neither a burden nor a carga.** With the exception of Rosie, Paulina, and Aida, none of the caregivers said they had experienced *burden* or a feeling that their relative was a *carga*. The answers of the caregivers to the question about whether they had experienced or were experiencing burden were emphatic. Caregivers denied feeling burdened or that their care-receiver was a burden. Similar answers were obtained from the caregivers when interviewed in Spanish.
Rosita shared: “No, he is my husband and I love him. He would have done the same for me. He is not a burden for me. This is hard, but he is not a burden.” Virginia and Brandi did not understand the meaning of the word *carga* and thought it meant to be *encargado(a)* (to be in charge of) or *al pendiente* (to be paying attention). They both denied that caring for their fathers was a burden and reinforced that it was their duty. Virginia stated: “I don’t see it as a burden, I am glad I can help and I know my mother was preparing us for this in the way she raised us.” Brandi shared: “Doing what I do is not a burden; of course there are days when it is frustrating, and I have to juggle a lot, but he is my father and I know I am doing what is right.” In contrast, Maria understood the word *carga*, but asked the meaning of *burden*. She did not understand the meaning of the word *coping* either. Maria stated:

*Nunca he pensado que él es una carga, me molesta mucho que sigue llegando a la casa con cosas que no hemos comprado, se las echa a la bolsa y no me doy cuenta cuando; y los errores que hizo con la aseguranzan fueron terribles, pero nosotros hemos sido muy felices, y por alguna razón Dios permitió que fuera él y no yo la que tuviera la enfermedad. Tal vez otras personas lo vean como una carga, y si es así, entonces le digo que yo la llevo con mucho amor.* [I have never thought that he is a carga, it bothers me much that he continues getting home with things that he have not bought, he puts them in his pockets and I don’t realize when; and the mistakes he made with the insurance were terrible, but we have been very happy, and for some reason God allowed that it was him and not I who would have the disease. Perhaps other people see it as a carga, and if it is that way, then I tell you that I carry it with much love.]

Monolingual caregivers expressed their dislike for the word *carga* as a descriptor of their care-receivers or what they did. Nancy was emphatic when she stated:

*Cuidar de mi papi y de mi mamá nunca ha sido una carga. Como le dije antes, yo le doy gracias a Dios por haberme dado la oportunidad de ser yo quien se encargara de él hasta el final. Ha sido doloroso ver como su vida se ha ido extinguiendo lentamente y yo creo que el final está muy cerca, pero nunca lo he visto o lo veré como una carga. Me hace muy feliz saber que pude cumplir con mi deber de hija y que le he dado todo mi amor.* [To take care of daddy and my mother has never been a carga. Like I told you before, I give God thanks for giving me the opportunity to be the one taking care of him until the end. It has been painful to see how his life has been extinguishing slowly, and I believe that the end is very near, but I have never
seen or will see it as a carga. It makes me very happy to know that I was able to fulfill my duty as a daughter and that I have given him all my love.

Julio denied feeling that caring for his mother was a carga. Additionally, he explained the difference between a carga and an obligation.

Mi madre nunca ha sido una carga. Es que una cosa es una carga y otra es la obligación que todos tenemos con nuestros padres. Yo he podido hacerme cargo de mi madre y hacerlo bien. Si la persona que cuidó no fuera mi madre, tal vez sería una carga porque yo no tendría ninguna obligación moral con ella. Pero poder darle el cariño que necesita hace que esto no sea una carga. [My mother has never been a carga. One thing is a carga, and another thing is the obligation that we all have with our parents. I have been able to be in charge of my mother and do it well. If the person that I care for was not my mother, perhaps it would be a carga because I would not have any moral obligation to her. But to be able to give her the affection/love that she needs makes this not a carga.]

Silvia said: “Esa palabra es horrible, es como hablar de la carga que se lleva en los camiones, es tratar a mi hermana como un objeto.” [That word is horrible, [it] is like talking about the load that trucks carry; it is treating my sister like an object.] This sentiment was echoed by other caregivers.

The expressions burden and carga were not used by the caregivers to spontaneously describe their experience. Despite the tremendous difficulties that caregivers faced physically, emotionally, and financially, caregivers accepted caregiving as a family duty that had positive and negative aspects. Caregivers did not admit to experiencing burden, and expressed their dislike for the idea that their care-receiver would be considered a burden or a carga.

The most salient of the positive aspects was being able to fulfill a duty to a family member. Knowing that they were doing their best to care for their care-receivers was very important to the caregivers. In addition, sacrificing for their care-receiver was seen by caregivers as something positive.
V. DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

This chapter presents a summary of the findings followed by a discussion of the findings as they relate to the literature. Implications for nursing practice, education, and research are addressed. In addition, implications for health care related to the well-being of Alzheimer’s caregivers are discussed. The chapter concludes with the limitations and strengths of the study.

A. Summary and Discussion of Findings

The purpose of this ethnographic study was to uncover and explore the manner in which monolingual and bilingual Latino/Hispanic AD caregivers describe the experience of caring for a relative. The use of ethnographic methodology facilitated the exploration of the concepts of burden and carga within the context of Latino/Hispanic culture.

1. Themes and their components.

Three overarching themes emerged during the formal and informal interviews that were supported by the narrative and found in the artifacts included in the study. These themes were caregiving has consequences, caregiving fulfills a duty, and caregiving is satisfying. The researcher explored the themes and their components as shown in Table 5.

a. Caregiving has consequences. Caregivers described three main consequences of caregiving. These consequences were caregiving is physically challenging, caregiving is emotionally draining, and caregiving is financially detrimental. These findings are consistent with current dementia caregiving literature.
The physical consequences described by the caregivers in the study have been previously reported. For instance, Vitaliano, Zhang, and Scanlan (2003) reported that caregivers of people with Alzheimer’s disease and other dementias are more likely than non-caregivers to report that their health is fair or poor. In this study, caregivers reported headaches, lower back pain, neck muscle pain, insomnia, carpal tunnel, and a general feeling of exhaustion. Due to the qualitative nature of this study, stress hormones, blood pressure, and immune function were not measured. The literature, however, reports that caregivers of people with Alzheimer’s disease and other dementias are more prone to have reduced immune function (Vitaliano et al.) and high levels of stress hormones (Vitaliano et al.; Von Kanel et al., 2006).

Caregiving for a relative with Alzheimer’s disease was described by the caregivers as emotionally draining. The major contributor to emotional stress was change. The researcher identified four domains related to change in the caregivers’ lives: loss of companionship, relinquishing social activities, feeling alone, and always thinking about the care-receiver. These findings are consistent with data from the Alzheimer’s Association and National Alliance for Caregiving (2004). Their report on Alzheimer’s caregiving in the United States reflects that more than 40 percent of family and other unpaid caregivers of people with Alzheimer’s rate the emotional stress of caregiving as high or very high. This was true for caregivers in South Texas and Colombia. In addition caregiver stress, especially the stress caused by the care-receivers’ behavioral symptoms has been found to be associated with nursing home placement (Buhr, Kuchibhatla, & Clipp, 2006). There were no care-receivers placed in nursing homes in Colombia. In South Texas there was one care-receiver in a nursing home and one in a group home. The caregiver who had her husband in a nursing
home described a high degree of emotional stress. Experiencing the same or worse stress once a relative is institutionalized has also been reported (Schulz et al., 2004). Caregivers were very reluctant to institutionalize their care-receivers and became creative in their strategies to keep them at home. The high degree of resourcefulness of Colombian dementia family caregivers has been reported by De la Cuesta and Sandelowski (2005). These authors saw caring for a relative with dementia in Colombia as a *craft* that transformed the material world in which care-receiver and caregiver live. Being able to care for their relative at home was a priority for caregivers.

Caregivers described the detrimental financial consequences of caregiving. Three domains were identified in this area: *caregivers must reduce the number of work hours, giving up work altogether, and being hired by family members as the caregiver* (primary). The first two domains have been well documented in the literature. The Alzheimer’s Association and the National Alliance for Caregiving (2004) have reported that among caregivers of people with Alzheimer’s disease and other dementias, only 57% were employed full-time or part-time. Employed caregivers reported taking time off, going in late, leaving early, and turning down promotions because of caregiving. Of the caregivers in that study, 8% quit work completely. The caregivers in the current study mentioned all these situations. Three of the caregivers had quit working completely to assume caregiving duties for their relatives. Of particular interest and not found in the literature, was the consistent manner in which financial responsibility was assumed by siblings and extended family members (two granddaughters) to compensate the relative assuming primary responsibility for the care-receiver or to cover the care-receiver’s expenses. It appeared that financial support for the care-receiver or for the sibling in the caregiver role was a top priority. This
may be explained by the cultural value of *familismo*. This value, often seen as the most important concept in understanding Latino/Hispanic culture, relates to the set of attitudes which reflect the importance given to family membership in terms of support, sacrifice, and involvement (Freeberg & Stein, 1996). The caregivers reported sibling involvement. Those siblings not living close to the care-receiver contributed with occasional respite time, emotional support for the caregiver, and money. There were no differences in the degree of involvement and financial support offered between the monolingual and the bilingual siblings.

b. Caregiving fulfills a duty. The second overarching theme was caregiving fulfills a duty. Caregivers expressed at length their reasons for adopting the caregiver role. The researcher identified two components: *caregiving is my duty* and *caregiving is learned*.

In the caregivers’ descriptions about fulfilling their caregiving duties to their families, three domains emerged: *duty to family, respect, and sharing responsibilities among siblings*. The values of *familismo* and *respeto* permeated every interview as caregivers described their motives for caregiving and how they were performing the day-to-day activities of caring for their care-receivers. It has long been recognized in the literature that although Mexican-American families stress the importance of extended family support, nuclear family households are the norm for this Latino/Hispanic subgroup (Keefe & Padilla, 1987). Mexican-Americans have also been reported as tending to discourage disruptive behavior among family members (Hampson, Beavers, & Hulgus, 1990). Colombian caregivers in this study clearly described their sense of duty to family, tended to live in close proximity or with the care-receiver, and avoided conflict and confrontation. Attitudes about familismo also had great relevance to this Latino/Hispanic subgroup, now the most numerous of the South
American Latino /Hispanic subgroups living in the United States (U.S. Census Bureau, 2007). Caregivers of Mexican descent in the study, born or not in the United States, also described the importance of family support. Consistent with findings reported by Sabogal et al. (1987), attitudes consistent with familismo appeared to have endured across levels of acculturation among US Latinos/Hispanics of different nationalities.

Duty to family, respect, and helping each other were described by caregivers as values that had been acquired while growing up in their homes. Placing more importance on the well-being of the family than on a single individual, and sharing the responsibility of caring for a family member can be explained by a sense of collectivism related to family interactions. Familism and collectivism play a central role in how Latinos/Hispanics interact and perceive themselves (Chong & Baez, 2005). The harmony embodied in a sense of collectivism can be seen as essential to Latino/Hispanic caregivers’ sense of belonging and self-worth. In a Latino/Hispanic’s life, it is extremely important to achieve a balance between work and family with equal emphasis placed on meeting the expectations of both employer and family (Chong & Baez). This may explain in part the tendency of family members to hire the caregiver, and the reluctance that the caregivers may have had to take or ask for time off.

Caregiving is learned surfaced in the caregivers’ descriptions of their motives to adopt the caregiver role. Caregivers had seen caregiving behaviors modeled for them, especially as young children. Most caregivers described how their grandparents had been caregivers or how the grandparents had been cared for. The two caregivers who grew up without grandparents in their family nucleus described caregiving behaviors demonstrated by their mothers. Caregiving behaviors appeared to be the result of a felt obligation toward
parents as a result of the interaction of *familismo* and collectivist attitudes. Social learning theory proposes that people learn new expectations and behaviors by observing the behavior of others and the consequences of that behavior; they then perform that behavior with the expectation of similar consequences (Bandura, 1977). Bandura (1986) also noted the effectiveness of observational role modeling to learn behaviors. Role modeling enables persons to learn from role models that are presented to them, leading them to pattern-observed behavior, resultant rewards, and consequences into their own set of behaviors. Piercy and Chapman (2001) reported that role modeling was often more powerful than the actual relationship with the care-receiver in assuming caregiving activities.

c. Caregiving is satisfying. The third overarching theme was *caregiving is satisfying*. Three major components emerged as caregivers talked about the satisfaction they derived from being able to provide care to their relatives: caregiving is my opportunity to give back, caregiving is knowing that I am doing my best, and caregiving is a sacrifice. Caregivers described a profound sense of satisfaction from having the chance to repay the care-receiver for affection, care, support, and teachings from the care-receiver. It was important for caregivers to know that under their specific circumstances they were doing their best to provide care. This appeared to give caregivers a sense of peace with themselves. In addition to knowing that they were doing their best, several caregivers mentioned that caregiving had allowed them to bring out the best within themselves as human beings. Caregivers felt that the major changes in their lives and the negative physical, emotional, and financial impact of caregiving were sacrifices for them, but these were seen as something positive. For several caregivers sacrificing for their care-receivers had become an inspiring life-changing experience.
Sacrificing for their relative was seen as a moral obligation and something to be proud of. This sense of pride, especially among females, has been reported by Jolicoeur and Madden (2002) in their description of the “good daughters” role in Mexican-American daughter caregivers living in the U.S. In their study, Jolicoeur and Madden reported that the “good daughter” role was highly valued by all women in the study; even though role expectations were more traditional among Spanish-speaking daughter caregivers than English-speaking daughter caregivers. “Caregiving was considered by both groups to be an integral part of being a good daughter” (p. 116). Caregivers in Colombia and in South Texas provided descriptions consistent with Jolicoeur and Madden's report.

B. Linguistic Exploration Results

The second aim of this study was to describe the culturally and linguistically relevant expressions and terminology used by bilingual and monolingual Latino/Hispanic AD family caregivers. The conceptual orientation supported the idea that the words burden and carga lacked cultural congruency with Latino/Hispanic values and role fulfillment expectations.

Consistent with preliminary work, bilingual caregivers did not spontaneously use the word burden to describe their perception of the caregiving experience. Only one caregiver used the word burden by code-switching during the Spanish interview. This caregiver understood the meaning of the word carga as something that you carry and stated her mother was not a carga. The other five bilingual caregivers denied experiencing burden. Of these five, only two understood the meaning of carga and did not see their care-receivers as such. The remaining caregivers thought that carga meant estar al pendiente (to be attentive to) or estar encargado de (to be in charge of). The youngest of the Mexican-American caregivers stated she had never heard the word carga.
In contrast, all Colombian caregivers were familiar with the word *carga*. Two of the caregivers admitted to feeling that caregiving for their husbands was a *carga*. The remaining caregivers emphatically denied seeing the care-receiver or the caregiving experience as a *carga*. These caregivers engaged in explanations of why their relative was not seen as a *carga*. These findings confirm that for English-speaking Latino/Hispanic caregivers the word *burden* is not culturally appropriate (Calderon-Rosado & Tennstedt, 1998; Gallagher-Thompson, Solano et al., 2003; John & McMillian, 1998; Roth et al., 2003). In addition, findings support the assertion that just as *burden* is not acceptable to English-speaking Latino/Hispanic caregivers, the word *carga* is just as culturally incongruent for bilingual and Spanish-speaking Latino/Hispanic caregivers. These findings apply to two Latino/Hispanic subgroups, Mexican-Americans and Colombian caregivers.

The caregiving literature from Spain is currently using the word *malestar* to describe the difficulties faced by dementia caregivers (Losada, Márquez-González, Peñacoba, Gallagher-Thompson, & Knight 2007). *Malestar* can be translated to English as *discomfort* and in some cases as *malaise*. This Spanish word appears to be much more culturally sensitive for labeling the emotional as well as the physical consequences of caregiving without conflicting with the sense of duty and role fulfillment expectations described by Latino/Hispanic caregivers.

It was particularly interesting that the three caregivers in the current study who used either the word *burden* or *carga* were the caregivers who described a poor relationship with the care-receiver prior to the diagnosis of Alzheimer's disease. One bilingual daughter described her relationship with her mother as very distant and stated that she had many issues. A monolingual wife caring for her husband had been in an unhappy marriage for 35
years, and a second monolingual wife, also caring for her husband, described her marital relationship as less than optimal. In the preliminary study, a Puerto Rican caregiver also used the word *burden*. Initially the researcher believed this was due to her educational background as a family nurse practitioner. It was felt that the caregiver had provided an analysis of her situation to the researcher. Upon review of the preliminary data, the researcher found that the relationship between this caregiver and the care-receiver (an ex-mother-in-law) had been a distant one. It appears that the quality of the relationship between a caregiver and a care-receiver prior to the diagnosis of Alzheimer’s disease plays a role in how the caregiver perceives the demands of caregiving.

Table 6 summarizes the terminology used by bilingual and monolingual caregivers in this study to describe their caregiving experience. Table 7 summarizes the terms and expressions used by caregivers to explain the meaning of *carga*. All bilingual caregivers agreed that there was no Spanish word to translate what they understood as *burden*.

C. Implications of Findings for Nursing Education, Practice, and Research

The findings of this research study have implications for nursing education, practice, and research due to the number of older adults in the United States growing in an unprecedented manner. The number of Latino/Hispanic older adults continues to escalate (U.S. Department of Health and Human Services, 2003). Latino/Hispanic older adults are estimated to increase to 2.9 million in 2010 and 13.8 million in 2050 from the 1.5 million in 2000 (Hayward & Zhang, 2001). The number of Latino/Hispanic elders affected by Alzheimer’s disease could increase more than sixfold, from fewer than 200,000 today to more than 1.3 million by 2050 (Alzheimer’s Association, 2004).
Table 6

Caregiving Descriptors

<table>
<thead>
<tr>
<th>Bilingual Caregivers</th>
<th>Monolingual Caregivers</th>
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<tbody>
<tr>
<td>Unbearable</td>
<td>Responsibilidad (responsibility)</td>
</tr>
<tr>
<td>Overwhelming</td>
<td>Dificultad (difficulty)</td>
</tr>
<tr>
<td>Frustrating</td>
<td>Desesperación (despair)</td>
</tr>
<tr>
<td>Sad</td>
<td>Obligación (obligation)</td>
</tr>
<tr>
<td>Depressing</td>
<td>Deber (duty)</td>
</tr>
<tr>
<td>Powerlessness</td>
<td>Sacrifice (sacrifice)</td>
</tr>
<tr>
<td>Holding back</td>
<td>Una cruz pesada (a heavy cross)</td>
</tr>
<tr>
<td>Difficult</td>
<td>Tarea pesada que se hace con amor (heavy job done with love)</td>
</tr>
</tbody>
</table>

Hard

Challenging

A load you carry with love

A heavy cross

Something you wish you did not have to do
Table 7

Meaning of Carga

<table>
<thead>
<tr>
<th>Meaning of Carga</th>
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<tbody>
<tr>
<td>Objeto pesado (heavy object)</td>
</tr>
<tr>
<td>Peso (weight)</td>
</tr>
<tr>
<td>Bulto (sack)</td>
</tr>
<tr>
<td>Encargado (in charge of)</td>
</tr>
<tr>
<td>Al pendiente (attentive, paying attention to)</td>
</tr>
<tr>
<td>Algo que se lleva (something you carry)</td>
</tr>
<tr>
<td>Algo que se tira (something you dispose of)</td>
</tr>
<tr>
<td>Lo que se lleva a cuestas (what you carry on your back)</td>
</tr>
<tr>
<td>Molestia permanente (permanent bother)</td>
</tr>
<tr>
<td>Lo que llevan los camiones o los animals (what is carried by trucks or animals)</td>
</tr>
<tr>
<td>Dificil y que esclaviza (difficult and enslaving)</td>
</tr>
</tbody>
</table>
1. Implications for nursing education.

Providing adequate nursing care to the increasingly aging and culturally diverse population in the United States requires nurses that understand cultural differences and know how to deliver care in a culturally competent manner. Findings in this study reinforce the importance of inclusion of cultural competence courses in all levels of nursing education.

Nursing programs must continue to include in their curricula cultural competence content to solidify the students’ awareness, understanding, and sensitivity toward people of different ethnic and cultural backgrounds. In the case of Latino/Hispanic caregivers, students need to learn that it is important to assess how these caregivers and their families view their caregiving duties rather than assume that the experience is burdensome as it may be perceived by European-Americans. Being able to assist caregivers in health-seeking behaviors may depend greatly on the understanding that nurses have of what is valued by Latino/Hispanic caregivers.

Nursing schools must ensure that when clinical settings are not available for students to be in contact with people of various cultures, appropriate teaching strategies are implemented. The use of case studies, vignettes, and seminar discussions could prove useful in increasing students awareness of a particular culture’s worldviews of family life, health, and disease. The ultimate delivery of culturally competent nursing care starts with culturally sensitive nursing education.

2. Implications for nursing practice.

Latinos/Hispanics have dramatically changed the demographic profile of the United States. Delivery of culturally competent nursing services to this population is a priority if we are to continue attempting to close the existing gap and disparities in the delivery of care as
documented by the Institute of Medicine (2003). Developing a strong command of the Spanish language is seen by many health care providers as the main solution. In fact, this is not a realistic goal for most health care providers wishing to establish a trusting relationship with Latino/Hispanic patients. Speaking Spanish obviously improves the ability of nurses to communicate during clinical encounters. However, knowledge of the Latino/Hispanic culture and the values that motivate patients’ decisions and behaviors can allow nurses to be more effective and provide personal and respectful nursing care. Nurses providing care for Latino/Hispanic patients with Alzheimer’s disease and their caregivers must have an in-depth knowledge and understanding of Latino/Hispanic diversity, central cultural values, health beliefs and practices, and effective communication strategies. Implying that a caregiver is experiencing burden or that a care-receiver is a burden or a carga without explicit validation from the caregiver may not be the best way to promote communication with caregivers and their families.

The caregivers interviewed outside of their homes mentioned gratitude for the opportunity to “talk to someone,” “to have a conversation,” or for a “chance to get out of the house to be with someone.” The caregivers interviewed in their homes were gracious and kind, welcoming the researcher, and spending at least an hour longer talking after the semi-structured interview had finished. Caregivers caring for bedbound and completely dependent relatives insisted that the researcher meet their relatives. The isolation described by most caregivers may explain in part these behaviors. Caregivers are in need of human contact and interaction, especially with someone that is willing to listen in a nonjudgmental manner. Nurses are in a privileged position to provide caregivers this type of interaction.
In addition, the value of *personalismo* is exemplified in the situations described above. Latinos/Hispanics value highly the sincere interest that a person shows in them. Nurses can use this knowledge to initiate and maintain productive and therapeutic relationships with the Latino/Hispanic caregivers. Contrary to the individualistic view that a nurse must remain professional, not share personal information, or intrude in the personal situations of patients, Latinos/Hispanics trust and engage those who ask, “How are you?” and who are willing to make the time to listen to the answer. Nurses must be prepared to engage in active listening and not assume that an encounter with a Latino/Hispanic caregiver will be limited to a specific health concern about the caregiver or the care-receiver. Disregarding this type of interaction with a Latino/Hispanic caregiver would be going directly against the values of *personalismo* and *respeto*.

3. Implications for nursing research.

Further qualitative research is needed to explore the influence of collectivism in Latino/Hispanic Alzheimer’s disease caregiving. In addition, the possibility that there are variants of the concepts of *burden* and *carga* or that there are culture-specific forms of these concepts has been confirmed with two different Latino/Hispanic subgroups. Theory informed by an understanding of the Latino/Hispanic culture is needed. This theory should specify the basic nature of the concepts of *burden* and *carga* in this culture and the manner in which these concepts relate to constructs and other concepts.

Although reliable caregiver burden instruments are available, these instruments have been normed with non-Latino/Hispanic populations. Perhaps an item-level analysis of these instruments is necessary to corroborate that the items on the instrument reflect the nature of burden and carga. Further scale-level analyses would also need to be conducted to confirm
that the scores obtained with the instrument relate well to other scores obtained using instruments that measure other constructs and concepts in the manner dictated by the culturally informed theory. Qualitative research could also be used to explore the degree of measurement equivalency of the existing burden instruments. This research could assist in learning from Latino/Hispanic AD caregivers whether the items in the instruments make sense to them and if important items have not been included.

Both qualitative and quantitative research are needed in the Latino/Hispanic caregiving area to provide reasons why burden instruments may not be equivalent across cultures, to dictate the direction in which modifications need to be made to achieve equivalence, or to develop new instruments for Latino/Hispanic caregivers.

It has been recognized that acculturation permeation findings apply to various Latino/Hispanic subgroups in the U.S. Attitudes consistent with *familismo* have been shown to endure across levels of acculturation among U.S. Latinos/Hispanics (Sabogal et al., 1987). Although the findings of this study support that *familismo, personalismo*, and *respeto* influence the perception of the caregiving experience in two Latino/Hispanic subgroups, this researcher believes that much research is needed to clarify the construct of acculturation.

The ethnographic methodology used in this study allowed for the exploration of the perception of caregiving within the context of Latino/Hispanic culture. The concepts of caregiver satisfaction and caregiver duty were found during the analysis. Substruction of these concepts is needed to formulate definitions that will add to the clarity of a culturally informed theory of caregiving.
a. Specific research plan. As a result of the current ethnographic study, this researcher proposes the addition of the concepts of caregiver satisfaction and caregiver duty fulfillment as concepts extremely relevant to the Latino/Hispanic perception of the caregiving experience. These two concepts are kinds of Caregiver Perceptions. The concepts need to be added at the same level of abstraction of caregiver burden. Caregiver satisfaction is the degree of balance perceived by the caregiver between the changes made to care for another and the sense of duty or responsibility. Caregiver duty fulfillment is the degree to which a person feels honored to be a dutiful caregiver and responsible for another. Figure 2 depicts a culturally informed conceptual orientation of caregiving, in which culture and language play a moderating role in the relationship between caregiver expenditure and caregiver coping, and between caregiver coping and the three possible caregiver perceptions: duty fulfillment, satisfaction, and burden.

Replication of this study with other caregiver populations and with other Latino/Hispanic Alzheimer's subgroups will further inform the conceptual orientation with the goal of adding linkages necessary for the formulation of a culturally informed theory of caregiving. In addition, a qualitative study aimed at replication of the current study using a non-Latino/Hispanic bilingual interviewer will provide descriptions of the caregiver experience potentially not disclosed to an interviewer of the same cultural background.

Conducting focus groups to initiate the cross-cultural validation of translated burden scales is imperative. These focus groups can assist in the clarification of the instrument items to ensure that they make sense to the caregivers, and that all important aspects of the concept have been included. The possibility that measures developed for the concept of burden in the majority population may not be assessing the same concept in Latinos/Hispanics must be
Figure 2
Culturally Informed Conceptual Orientation of Caregiving
ruled out. Additionally, further qualitative exploration of the concepts of caregiver satisfaction and caregiver duty fulfillment is needed. This exploration will provide the basis for the development of instruments to measure these two types of caregiver perception not taken into consideration in current theoretical models.

There is an immediate need for a mixed-methods study. This researcher proposes a three-phase study that uses mixed methodology in the collection, analysis of data, and integration of findings with preliminary dissertation work (Appendix A). This study involves ethnographic interviews of monolingual (Spanish only) and bilingual (Spanish and English) Latino/Hispanic Alzheimer’s caregivers. In addition, the study involves exploration of the cross-cultural validity of the Spanish and English versions of the Screen for Caregiver Burden (SCB) and comparison of the burden scores to scores obtained by administering measures of quality of life to a group of bilingual caregivers.

Once clarification of the concepts of caregiver burden, caregiver satisfaction, and caregiver duty fulfillment has been achieved, and measures have been developed guided by the culturally informed theory of caregiving, design of interventions will follow. These interventions aimed at supporting the caregivers and improving their quality of life and health will be guided by the culturally informed theory. Alternatively, intervention programs currently in existence and that have proved effective for other populations can be culturally and linguistically adapted and delivered to Latino/Hispanic Alzheimer's caregivers.

D. Implications for Healthcare Policy

Caregiving consequences extend beyond the physical, emotional, and financial negative impact on families as described in this study. Alzheimer's disease caregiving has
tremendous consequences in terms of costs to the caregiver, their families, and society at large.

Family caregivers are a tangible and substantial savings to our health care system and economy. Therefore, the well-being of family Alzheimer's caregivers is in the best interest of society. Caregivers allow care-receivers the opportunity to remain at home as long as possible. However, the health of caregivers is at risk. Without support, caregivers become ill and, in turn, create a need for more health care services. Programs that support the caregiver to continue in their caregiving role are needed to maintain the emotional and physical health of caregivers.

Government financial resources need to be allocated to support the dissemination of caregiver support programs that have proved to be effective. These programs need to be tailored to ensure that they are culturally sensitive, linguistically congruent, and accessible to caregivers of all cultures. In addition, these programs need to take into consideration the wide range of caregivers with different cultural values, beliefs, and practices.

E. Limitations of the Study

A possible limitation of the study was that a Latino/Hispanic bicultural/bilingual researcher conducted all interviews. It is possible that caregivers may have felt judged by someone of their own culture and may not have disclosed negative feelings toward caregiving or the care-receiver. However, review of the audiotapes and transcripts of the interviews give the impression that the caregivers described their experience richly, showed great emotion, and expressed gratitude for the opportunity to be heard. On the other hand, a researcher from the same culture, able to navigate during interactions without violating culturally-prescribed rules and values, and willing to listen, may have created an
environment of trust for the caregivers. Replication of the study with a bilingual non-Latino/Hispanic interviewer would provide valuable comparison data.

Another limitation of the study was the inability to obtain an understanding of how collectivistic views and the premorbid relationship between the caregiver and the care-receiver may have affected the perception of the caregiving experience. It is possible that in a larger sample the apparent patterns observed would have been clearer. However, the aim of this ethnographic study was the exploration of the caregiving experience, and the sample was determined by the richness of the description until redundancy of data was reached.

Inclusion of Latino/Hispanic caregivers born in Mexico, Colombia, and the U.S. limited the findings of this study to these subgroups. In terms of perception and terminology used to describe the caregiving experience, these findings should be applied with caution to other Latino/Hispanic subgroups until those groups are studied.

F. Strengths of the Study

The choice of ethnographic methodology to accomplish the aim of exploration of the perception of the caregiving experience in the context of Latino/Hispanic culture is a major strength of this study. Ethnographic methodology allowed for analyses that helped refine a culturally-informed theoretical concept orientation of caregiving in Latino/Hispanic populations. The study confirmed that inclusion of the moderating role of culture and language is needed in this conceptual orientation. In addition, the study pointed to the need for further clarification of the influence of collectivistic views and the premorbid relationship between the caregiver and the care-receiver on the perception of the Alzheimer’s disease caregiving experience. The use of maximum variation sampling increased the probability of
capturing the caregiving experience as seen by a variety of caregivers. The group of participants included males and females of varied ages, living arrangements, socioeconomic status, language spoken, nationality, and length of stay in the United States. In addition, the care-receivers were males and females at various stages of Alzheimer's disease. The wide range of variation in the sample allowed the researcher to capture caregivers’ descriptions of many aspects of their experience.

Participant observations, a key element in ethnographic methodology, were conducted extensively in a varied number of settings in which caregivers interact and provide care. Conducting interviews in the caregivers’ homes was initially thought by the researcher to be disruptive and not conducive to accrual of rich data. However, the contrary was found to be true. The monolingual caregivers were interviewed in their natural setting allowing the researcher to obtain a better picture of their limitations, challenges, resources, and creativity. Home interviews increased the number of participants and uncovered family dynamics that might not have surfaced in another setting. Caregivers were particularly proud to show the modifications made to the environment and made a point of introducing the researcher to the care-receivers.

A fourth strength of this study was the inclusion of monolingual Spanish-speaking caregivers. Data collected on these caregivers allowed for cultural and linguistic comparisons not previously reported in the literature. A fifth strength was the inclusion of Latino/Hispanic Alzheimer’s caregivers of three different nationalities. Findings on the Mexican-American caregivers were consistent with extant literature, and findings on Colombian and Mexican caregivers contribute to the body of caregiving research literature. Inclusion of 14 Colombian
Alzheimer’s caregivers contributes to increasing knowledge about this Latino/Hispanic subgroup.

A sixth strength of the study was the ability of the researcher to interview all caregivers in either English or Spanish. This avoided the need to train interviewers, transcription in the source language to then translate to English, back translation to Spanish for comparison, and finding consensus with the assistance of bilingual investigators. Instead, this study provided data obtained and analyzed in the source language. The findings were reported in English, avoiding completely the cultural, contextual loss of meaning often caused by translation. The complete avoidance of interpreters and translators facilitated the acquisition of the emic perspective of the caregivers by the researcher.

Related to the sixth strength was the ability of the researcher to speak the caregivers’ language. The researcher was born and raised in Bogotá, Colombia, and lived there for 19 years. After immigrating to the U.S., the researcher continued to travel often to Colombia and maintained very close ties with family and friends. The researcher was familiar with the culture, language, and norms prevalent in Colombia. In addition, the researcher had lived in South Texas for 16 years at the time data were collected. This afforded the researcher familiarity with Latino/Hispanic culture in Texas, and, most important, with the English and Spanish variations commonly used in the area.

A seventh strength of the study was the constant reflection, analysis, and validation sought by the researcher. In addition to keeping a journal and field notes, the researcher engaged in constant peer debriefing to allow questioning cultural assumptions about the caregivers.
In conclusion, this study had limitations and strengths. Despite the aforementioned limitations, this ethnographic study is innovative in that it is one of the first to explore the perceptions of the Latino/Hispanic Alzheimer’s disease caregiving experience including bilingual and monolingual caregivers of different Latino/Hispanic subgroups. Findings of this study will contribute to the generation of culturally informed theory that will in turn guide interventions geared to support Latino/Hispanic Alzheimer’s caregivers.
Appendix A

Preliminary Research
**Preliminary Study**

A preliminary study was conducted between January 2005 and December 2006. The researcher tested the appropriateness of an ethnographic interview guide to refine the aims of the current study. The participants were recruited from a pool of research participants in an ongoing National Institutes of Health grant studying the stress and relaxation response of AD caregivers.

Data were collected from tape recorded semi-structured interviews with bilingual (English/Spanish) Latino/Hispanic Alzheimer’s caregivers ($N = 8$), administration of English and Spanish versions of the Screen for Caregiver Burden (SCB), and demographic data obtained at the end of each interview. Three caregivers were Mexican-American; two, Mexican; two, Puerto Rican; and one Peruvian.

The interviews were conducted in two stages. During the first stage (in English), the caregivers were asked to describe their caregiving experience. During the second stage (in Spanish), the caregivers were asked to focus their description on the difficult aspects of caregiving. Additionally, the caregivers were asked for a Spanish word or expression that would summarize the feeling of burden. A bilingual, bicultural transcriptionist transcribed the recorded interviews verbatim. The researcher reviewed all transcripts for accuracy and coded the interviews.

Several themes emerged from the data: emotional inability, physical inability, and financial burden as three distinct kinds of negative caregiving consequences. In addition, as the caregivers were asked if they had experienced burden, cultural beliefs of family life, respect for elders, filial duty, and sense of pride emerged. A strong dislike for institutionalization as an option was expressed. Lastly, the cultural inappropriateness of the
words *burden* and *carga* became evident either because the caregivers did not understand the word or thought it was offensive to them or to the care-receivers.

**Emotional inability.**

All caregivers described what caregiving was like for them, clearly separating the physical from the emotional demands. Rather than using *burden* as a descriptor, the caregivers talked about excessive demands placed on them, feeling cornered, concerned, alone, isolated, torn, worried, frustrated, or simply perceiving that there was a problem that created a weight in their minds.

The following were statements typical of the caregivers. “Emotionally I was drained. Emotionally I was not able to function anymore. I was crying a lot, I was angry at her.” A woman caring for her ex-mother-in-law described in tears: “Emotionally I am starved. I am starved for having somebody hold me and give me care and love me, and I have had to give up friendships.”

All caregivers expressed a sense of powerlessness: “I feel powerless; something was taking her and I could not stop it.” Another daughter caregiver stated: “The stress, not on the physical part, but the stress that your mom was leaving you and you want to spend every single moment with her that you could.”

**Physical inability.**

Caregivers described the physical demands and limitations imposed by their caregiving duties. Feeling burned out, physically exhausted, sleep deprived, unable to give, strained, and mentally unable to process more information, were common descriptions of the physical health of the caregivers.
A caregiver described the physical inability: “I got very sick. I had to; I could hardly move my shoulders. I remember that this was because of the stress.” One wife related: “I would say the worst part was getting him dressed and being unable to change his diaper, because he was too heavy for me.” The woman caring for her ex-mother-in-law stated the following to describe her degree of sleep deprivation. She talked about what she would have done the day of the interview after dropping her mother in law at the day care: “Today I could have stayed home and gone to sleep. That is my friend, my bed! Hah! That is my closest friend, is my bed!”

Financial burden.

The word burden was used by one of the participants (a retired nurse practitioner) to describe the negative financial impact of assuming caregiving duties: “Well, when I said that it became burdensome I meant financially … each medication was over a hundred dollars so that is financial burden, was tough.” The remaining participants shared the frustration of being under financial strain without using the word burden. One woman related: “I was very frustrated because I was a very, very active person. I socialized well, I went places, theater, ballet. And then all of a sudden I was home bound and could not afford it.”

In turn a husband shared:

I need to feel that I am accomplishing something, so I used to go down to the entrance and add gravel to the path that leads to the house. I can't do it anymore because we have not been able to afford any more gravel.

The experience of burden.

None of the participants used the word burden to describe their experience. Participants were asked: "Some caregivers have shared that being a caregiver for a relative with Alzheimer's is a burden. Is that something that you have experienced?” The only
caregiver who acknowledged experiencing burden was the woman caring for her ex-mother-in-law. Her response was atypical and perhaps due to her professional background. The caregiver was a retired family nurse practitioner. She stated:

Absolutely, absolutely. It is a burden but it is not always. I don't always feel that way. But the truth, yes, I do feel it is a burden and anybody that says that they don't feel that way they're crazy you know.

In contrast, a male caregiver stated: “No, there are times you might perceive caregiving as a real burden. But for me… I look at it as an obligation of a husband for his spouse. I don't really think it bothers me that much.” A daughter related: “Never! I don't consider my mother a burden, it is just part of life…I am lucky to have her at 86 years old.” This sentiment was echoed by all other caregivers in statements such as: “I don't feel it is a burden at all because I look at it that, when we were growing up she took care of us. So I don't look at it a as burden. Nope! Not at all!”

Cultural themes.

Participants explained why the felt they had not experienced burden. Strong regard for family, respect for elders, a sense of responsibility or duty, faith, and pride were common themes expressed by all caregivers.

Family. Caregivers identified strong family ties, growing up close to their grandparents, watching their grandmothers and mothers care for the whole family, and belonging to a giving and caring family unit as factors that influenced how they felt about caregiving.

All participants described their childhood as a time when values were ingrained. They described emotional and geographical closeness to their grandparents. A Peruvian caregiver stated: “It is the way that we were raised. They (parents) are a part of us. We cannot let them
go. You become a very strong, powerful family with a lot of respect.” A woman caring for her mother commented:

I mean, watching my mother take care of her kids, and then her grandkids and great-grand kids, and how she took care of her mother… My sisters and I have a role model, it is that mothering in us that makes us better caregivers.

**Respect.** All participants spoke about respect as a central value and a reason to assume caregiving responsibilities. Showing respect for elders was mentioned by all caregivers caring for their parents, spouses, or in-law relatives. The ways in which respect is shown were described by the participants as: venerating elders, assuming responsibility for elders’ care, ensuring that the elders did not feel abandoned, involving grandchildren in grandparents’ care, feeling indebted to parents for care received in earlier years, loving their parents, and not institutionalizing their loved ones.

**Filial duty.** Caregivers spoke of a strong sense of responsibility that motivated them to provide care. This duty to the family member, regardless of whether a parent, in-law, or spouse, stemmed from a sense of obligation. In addition, two caregivers mentioned that caregiving was assumed by the oldest daughter in their families.

**Pride.** Pride in one’s heritage arose when talking about the option to place the relative with Alzheimer’s disease in a nursing home. The caregivers described how no one would take care of their loved one as well as they would do it, and how early placement would be equivalent to being a bad child. This theme emerged when caregivers described the financial constraints imposed by caregiving and when they talked about the dislike for institutionalization of the care-receiver. Embarrassment about having to request financial assistance, having to use Medicaid, and not being able to afford things in general, were
topics mentioned by the caregivers. Fulfilling the responsibilities of a caregiver gave participants a sense of pride.

**Dislike for institutionalization.** This theme was present in all interviews, both English and Spanish. The participants described their feelings towards the option of placement of their loved one. This decision was not easy for Latino/Hispanic caregivers. Placement was seen as equivalent to uncaring, unloving, irresponsible, failure to fulfill a family responsibility, warehousing of the elderly, abandonment, and being a “bad child.”

**Meaning of burden.**

When asked the question, “What does the word burden mean to you?” the participants engaged in descriptions such as: “It’s a feeling of holding back,” “a weightless load,” “a cross given by God,” “a load you carry with love,” “something you carry in your mind,” “something you wish you didn't have to do,” and “something that weighs you down.” In addition, a participant felt that burden meant to have many problems, but if the person could adapt, then it was no longer a burden, just a problem.

**Burden or carga?**

When the interview in English was finished, all participants were asked to code-switch to Spanish. Participants were first asked for a word in Spanish that carried the meaning of the English word *burden*. None of the participants was able to offer a single Spanish word with the meaning they intended. Participants offered long explanations and expressions paraphrasing what they had expressed in English, or simply code-switched back to English as in the following examples:

*Burden? Es como una cosa que se carga en la mente, pero es un load that you carry with love, si me entiende?* [Burden? It is like something that you carry in your mind, but it is a load that you carry with love, do you understand me?]
A daughter caring for her mother explained:

Burden *es tener too much on my plate, pero si le digo que tengo muchas cosa en mi plato, eso no se va a oír bien, eso se oye muy chistoso.* [Burden is to have too much on my plate, but if I tell you that I have too many things on my plate (in Spanish), that is not going to sound good; that sounds very funny.]

The participants were asked about the word *carga* (load) as an equivalent for burden. They all agreed that the meaning of the word was approximate. The participants added words such as *frustración* (frustration), *desesperación* (desperation), *amargura* (bitterness), *molestia* (bother), and *difícil* (difficult) to better explain what burden was. A female caregiver added: "*Burden no tiene sentido ninguno.*" [Burden does not make any sense.]

When participants were asked in Spanish if caregiving for their relative could be considered a carga, there was general agreement that the word was negative, offensive, too strong, and, for most participants, out of the question. A husband shared:

*Para mí, cuando dicen carga es como decirte que tienes un bulto ahí y te está molestando y tienes que deshacerte de el.* [To me, when they say carga is like saying that you have a sack there and that it is bothering you and you have to get rid of it.]

**The Screen for Caregiver Burden (SCB)**

This instrument was chosen because it taps into several domains, including care-recipient behaviors, disruptions in family and social life, and caregiver affective response (Vitaliano et al., 1991). The SCB measures objective burden (presence of potentially distressing situations for the caregiver) and subjective burden (the distress caused by the behavior). The content and face validity of the SCB were apparent through comparisons with other burden measures and the extant literature on problems in Alzheimer’s disease caregiving. The scaling of the items was designed to assess both subjective and objective burden. The construct validity was established via relations between the SCB scores and
other theoretically relevant constructs such as vulnerabilities, psychological distress, and psychosocial resources. The internal consistency reliabilities of the SCB were respectable, and test-retest reliabilities were high considering that it was used at 15 and 18 months, versus other measured used at 1 to 3 day intervals (Vitaliano et al.) The internal consistency of the SCB was $\alpha = .88$ and $\alpha = .89$, and the test-retest reliability, $.64 (p < .001)$ and $.70 (p < .001)$. Because it lacks subscales, the SCB is a tool of rapid administration.

The results of the preliminary study showed that the bilingual caregivers ($N = 8$) scored almost identically in objective burden (number of potentially negative experiences) in the Spanish and English versions of the SCB. The objective burden mean in the English version was 14.5, and the objective burden mean in the Spanish version was 14.4. The highest possible score was 25.

The subjective burden scores (appraised distress in response to the experience), showed differences according to the language in which the instrument was presented. The caregivers consistently scored higher in the English version. The mean subjective burden in the English version was 43.75, while the subjective burden reported in the Spanish version was 42.25. The statistical significance of this difference was not determined given the small number of participants in the study. The difference, however, pointed to the need for cross-cultural validation of this instrument and the possibility that the terminology used and the language in which the questions are asked play a role in the perception of distress.

The researchers' conclusions were: (a) terminology currently in use to describe burden (i.e., $carga$, $sobrecarga$) may lack cultural sensitivity and linguistic congruence; (b) the Spanish version of the SCB appeared to have a lack of cultural validity resulting from the literal translation of the instrument from English to Spanish; and (c) themes related to the
Latino/Hispanic influence on the role of being a caregiver appeared not to be considered by the SCB (Arévalo & Lewis, 2006).
Appendix B

Demographic Information Data Sheet - English
Demographic Information

1. Name __________________________

2. Phone #: Home _________________ Work ________________

3. Age ______________

4. Gender: □ Male  □ Female

5. Marital Status
   □ Single (never married)
   □ Married __________ years
   □ Separated __________ years
   □ Divorced __________ years
   □ Widowed __________ years

6. Caregiver’s Children
   Number ________________
   Age ______ Gender □ Male □ Female
   Age ______ Gender □ Male □ Female
   Age ______ Gender □ Male □ Female
   Age ______ Gender □ Male □ Female
   Age ______ Gender □ Male □ Female

Care-receiver’s Children, if different
   Age ______ Gender □ Male □ Female
   Age ______ Gender □ Male □ Female
   Age ______ Gender □ Male □ Female
   Age ______ Gender □ Male □ Female
   Age ______ Gender □ Male □ Female
7. Caregiver’s Place of Birth ____________________________
   Carereceiver’s Place of Birth ____________________________

8. Where Raised?
   Caregiver: ____________________________
   Care Receiver: ____________________________

9. Primary Language of Caregiver ____________________________

10. Primary Language of Care Receiver ____________________________

11. Education (mark highest level attained)
   □ less than high school
   □ high school graduate
   □ technical/vocational school
   □ some college
   □ college graduate
   □ graduate/professional degree ____________________________ (specify)
   □ other ____________________________ (specify)

12. Employed □ Unemployed □ Retired □
    Current occupation, or occupation most of adult life: ____________________________

13. Relationship of Caregiver to Care Receiver
    Spouse □ Child □ Other ____________________________
    (explain)

14. Care Receiver’s Age ______

15. Care Receiver’s Gender □ Male □ Female

16. Do the caregiver and care receiver live in the same house?
    □ Yes □ No
If no, indicate average frequency of contact between caregiver and care receiver during the past month.

__________________________ Number of days per week
__________________________ Number of hours per day

17. Approximate year of onset of care receiver’s disease ________________

18. Approximate date of diagnosis of care receiver’s disease ________________

19. Does the care receiver attend day care or have any other hired help at home in addition to the caregiver?

☐ Yes ☐ No

If yes, for how many days per week? ________________

How many hours per day? ________________

20. Annual Household Income

☐ Less than $20,000

☐ Between $20,000 and $29,999

☐ Between $30,000 and $39,999

☐ Between $40,000 and $49,999

☐ Between $50,000 and $59,999

☐ More than $60,000
Appendix C
Demographic Information Data Sheet - Spanish
Información Demográfica

1. Nombre ________________________________

2. Teléfono #: Casa________________________ Trabajo________________________

3. Edad __________

4. Sexo: □ Masculino □ Femenino

5. Estado Civil
   □ Soltero (a) (nunca se ha casado))
   □ Casado (a) __________ años
   □ Separado (a) __________ años
   □ Divorciado(a) ________ años
   □ Viudo (a) __________ años

6. Hijos
   Número _________________
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino

Hijos de quien recibe cuidado si son diferentes:
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
   Edad _____  Sexo  □ Masculino  □ Femenino
7. Sitio de nacimiento
Del (a) cuidador(a) __________________________
De quien recibe cuidado _______________________

8. ¿Dónde fue criado(a)?
El (la) cuidador(a) __________________________
Quien recibe cuidado: _______________________

9. Primary Language of Caregiver _______ SPANISH ______________

10. Primary Language of Care Receiver _______ SPANISH ______________

11. Educación (marque el nivel más alto que haya obtenido)
□ Menos de bachillerato
□ Bachillerato
□ Técnico/Vocacional
□ Algo de universidad
□ Pregrado-Universitario
□ Pos-grado/Grado profesional ___________________ (especifique)
□ Otro __________________________ (especifique)

12. Empleado □ Desempleado □ Pensionado □
Ocupación actual, u ocupación que ha tenido durante el mayor tiempo de su vida adulta:

13. Relación del(a) cuidador (a) con quién recibe cuidados
Esposo(a) □ Hijo(a) □ Otro ___________________ (explique)

14. Edad de quien recibe cuidado __________

15. Sexo de quien recibe cuidado □ Masculino □ Femenino
16. El (la) cuidador(a) y quien recibe cuidado, ¿Viven en la misma casa?
   □ Sí    □ No
   Si no es así, indique el promedio de la frecuencia con que han estado en contacto durante el último mes.
   ______________________ Número de días por semana
   ______________________ Número de horas por día

17. Año aproximado en que quien recibe cuidado empezó a tener su enfermedad:
   ____________

18. Año aproximado en que quien recibe cuidado fue diagnosticado
   ____________

19. La persona que recibe cuidado, ¿Va a un centro de cuidado diurno o recibe alguna ayuda paga (remunerada) en casa aparte del(a) cuidador(a)?
   □ Sí    □ No
   Si contestó “Sí”, ¿por cuantos días a la semana? ____________
   ¿Cuántas horas al día? ____________

20. Ingresos Anuales de la Familia
   □ Menos de 20 millones
   □ Entre 20 millones y 29 millones
   □ Entre 30 millones y 39 millones
   □ Entre 40 millones y 49 millones
   □ Entre 50 millones y 59 millones
   □ Más de 60 millones
Appendix D
Ethnographic Interview Guide - English
INTERVIEW GUIDE

BILINGUAL CAREGIVERS

1. Tell me what being a caregiver is like for you.
   Probe: Tell me about a typical day.
   Probe: What effect does being a caregiver have on you?
   Probe: How has being a caregiver changed your life?
   Probe: How have you been most affected by being a caregiver?

2. Does being Latino/Hispanic influence in anyway how you feel about being a caregiver?
   Probe: In what ways?
   Probe: Does being Hispanic make you feel that you care for
       ___________ in a different manner?
   Probe: What made you become ___________’s primary caregiver?
Appendix E
Ethnographic Interview Guide - Spanish
MONOLINGUAL (SPANISH) CAREGIVERS

1. ¿Digame como es ser un(a) cuidador(a) como usted? (Tell me what being a caregiver is like for you.)
   
   Probe: ¿Cómo es un día típico suyo?
   
   Probe: ¿Qué efecto ha tenido en usted el ser cuidador(a)'
   
   Probe: ¿Cómo ha cambiado su vida el ser cuidador(a)'
   
   Probe: ¿Cómo lo ha afectado a usted más el ser cuidador(a)'

2. Ud. piensa que ser Latino(a)/Hispano(a) influyen en como se siente usted como cuidador(a)? (Do you believe that being Latino/Hispanic influences in any way how you feel about being a caregiver?)

   Probe: ¿De qué manera?

   Probe: ¿Ser Hispano(a) hace que ud. cuide de _________ de una manera diferente? (Does being Hispanic make you feel that you care for _________ in a different manner?)

   Probe: ¿Qué lo hizo convertirse en el (la) cuidador(a) principal de _________? (What made you become _________’s primary caregiver?)
Appendix F
Consent to Participate - English Version
SUBJECT CONSENT TO TAKE PART IN A STUDY OF
FACTORS INFLUENCING LATINO/HISPANIC CAREGIVERS' PERCEPTION OF THE EXPERIENCE OF CARING
FOR A RELATIVE WITH ALZHEIMER'S DISEASE

The University of Texas Health Science Center at San Antonio
To be conducted at the Graduate School of Biomedical Sciences and School of Nursing

INFORMATION ABOUT THE RESEARCH

What is the research about?
We are asking you to take part in a research study of Latino/Hispanic Alzheimer’s Caregivers. We want to learn the manner in which Latino Alzheimer’s caregivers perceive the caregiving experience. We are asking you to take part in this study because we want to learn from you the concepts and terminology used by bilingual and monolingual Latinos to describe their perception of the impact of caregiving on their lives.

Who is conducting the study and how many people will take part?
Lyda Consuelo Arévalo RN, MSN is conducting the study. A total of 40 of people will take part in this study.
The John A Hartford Foundation, Building Academic Geriatric Nursing Capacity Scholarship Program, a non-profit agency that promotes scientific research, is partly funding this study. This means that the Hartford Foundation is providing money to the University so that the study investigator can conduct the study.

What will happen if you agree to be in the research?
If you decide to take part, we will ask you to be interviewed for about 45 minutes to an hour, and complete a short demographic data sheet. Information you provide in during the interview will be recorded, however the information will not be linked to you.

What are the risks of participation in the research?
It is possible that you may experience some discomfort as you talk about your experience as a caregiver.

Would there be problems if you decide to stop taking part in this research before it is finished?
No. You can decide to withdraw from the study at any time. You can decide to not answer any question you are asked.

Are there benefits to taking part in this research?
There is no benefit to you for participating in this study. The knowledge gained from this study may benefit other caregivers.

Will there be any compensation for participation?
You will receive a $20.00 dollar IHEB or Wal-Mart card as compensation for your time spent during the interview and time spent filling out the data sheet. You will receive the card when you complete the interview and data sheet. If you are contacted for a second interview, you will receive an additional $15.00 card.

Will there be any costs related to the research?
There is no cost to you.

CONFIDENTIALITY

What is Protected Health Information (PHI)?
Protected Health Information is information about a person’s health that includes information that would make it possible to figure out whose it is. We will use the term “your PHI” as a shorter way of saying “your protected health information.” According to the law, you have the right to decide who can see your PHI. If you choose to take part in this study, you will be giving your permission to the investigators and the research study staff (individuals carrying out the study) to see and use your health information for this research study. In carrying this research, the health information we will see and use about you will include: information you give us during...
THU OF TEXAS
HOSPITALS
"SUBJECT CONSENT TO TAKE PART IN A STUDY OF
FACTORS INFLUENCING LATINO/HISPANIC CAREGIVERS’ PERCEPTION OF THE EXPERIENCE OF CARING
FOR A RELATIVE WITH ALZHEIMER’S DISEASE

your participation in the study such as during interviews or from questionnaires. We will get this information by
asking you.

How will your PHI be shared?

Because this is a research study, we will be unable to keep your PHI completely confidential. We may share your
information with people and groups involved in overseeing this research study including:

• the sponsor of the study (The Hartford Foundation)
• the investigators at the University of Texas Health Science Center at San Antonio
• The Institutional Review Board and the Compliance Office of the University of Texas Health Science
Center at San Antonio, and other groups that oversee how research studies are carried out.

Parts of your PHI may be photocopied and sent to a central location or it may be transmitted electronically, such as
by e-mail or fax.

The groups receiving your health information may not be obligated to keep it private. They may pass information
on to other groups or individuals not named here

If you decide to participate in this study, you will be giving your permission for the groups named above, to see and
share your health information. If you choose not to let these groups see and share your health information as
explained above, you will not be able to participate in the research study.

How will your PHI be protected?

In an effort to protect your privacy, the study staff will use code numbers instead of your name, to identify your
health information. Initials and numbers will be used on any photocopies of your study records. If the results of
this study are reported in medical journals or at meetings, you will not be identified.

Do you have to be in this study?

Being in the study is voluntary. You are free to choose not to be in this study or to stop being in this study at any
time. You are also free not to let the researchers and other groups see and share your health information. If you
choose not to be in the study or not to let the researchers and other groups use your health information, there will
be no penalties. In other words, you will still be able to get medical treatments without being in the study and it will
not affect your eligibility for any health plan or any health plan benefits or payments for which you may be eligible.

What if you change your mind?

You can decide not to take part in the study at any time. Just talk to the researcher staff about it. Also, you may ask
the researchers to stop using your health information at any time. However, you need to say this in writing and
send your letter to Lyda Arevalo, . If you tell the researchers to stop using your health information, your participation in the study will end and the study staff will stop collecting new health information from you and about you for this study. However, the study staff will continue to use the health information collected up to the time they receive your letter asking them to stop.

Can you ask to see the PHI that is collected about you for this study?
The federal rules say that you can see the health information that we collect about you and use in this study

How long will your PHI be used?

By signing this form, you agree to let us use and disclose your health information for purposes of the study at any
time in the future. There is no expiration date because we do not know how long it will take us to finish doing all
of the analyses and we will need to use your health information for as long as it takes.

What to do if you have questions or need to report a problem.

If you have questions now, feel free to ask us. If you have additional questions later, Lyda C Arevalo RN, MSN, can
be reached at . If s/he is not available, Sharon Lewis RN, PhD can be reached at . The University of Texas Health Science Center committee that reviews research on human subjects (Institutional
Review Board) will answer any questions about your rights as a research subject.
SUBJECT CONSENT TO TAKE PART IN A STUDY OF FACTORS INFLUENCING LATINO/HISPANIC CAREGIVERS' PERCEPTION OF THE EXPERIENCE OF CARING FOR A RELATIVE WITH ALZHEIMER'S DISEASE

You will be given a signed copy of this form to keep. You do not waive any of your legal rights by signing this form.

SIGN THIS FORM ONLY IF ALL OF THE FOLLOWING ARE TRUE:

- You have voluntarily decided to take part in this research study.
- You authorize the collection, uses and sharing of your protected health information as described in this form.
- You have read the above information.
- Your questions have been answered to your satisfaction and you believe you understand all of the information given about this study and about the use and disclosure of your health information.

Signature of Subject

Date and Time Signed by Subject

Printed Name of Subject

Signature of Witness

Signature of Person Obtaining Consent

Printed Name of Witness

Printed Name and Title of Person Obtaining Consent

Date & Time Signed by Witness

Date & Time Signed By Person Obtaining Consent

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Dear Principal Investigator:

Re: IRB Protocol #HSC20070672E

Title: Factors influencing Latino/Hispanic caregivers' perception of the experience of caring for a relative with Alzheimer's disease.

FINAL EXEMPT DETERMINATION

This protocol was determined to be EXEMPT: on June 28, 2007 under DHHS Regulation 45CFR46.101(b) category (2) - Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects, and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.).

One English consent form was also approved.

Your annual Exempt Status Report will be due: June 2008

Study Sites: UTHSCSA
Appendix G
Consent to Participate - Spanish Version
The University of Texas
Health Science Center at San Antonio
Mail Code 7830
7703 Floyd Curl Drive
San Antonio, Texas 78229-3900

TO: Lyda Arevalo
FROM: Institutional Review Board
SUBJECT: Notice of Expedited IRB Amendment Review

Protocol Number: HSC20070672E
Factors influencing Latino/Hispanic caregivers' perception of the experience of caring for a relative with Alzheimer's disease.

REQUESTS:
☐ Revised Consent Form(s)
☐ Protocol Modification/Addendum
☐ Change in Title
☐ Addition/Deletion of Investigator
☒ Spanish Translation of Consent Form(s)
☐ Other

ACTION:
☒ Approve
☐ Clarification Required
☐ Disapprove

Comments: This is in reference to your request dated June 29, 2007.
Expedited approval was given on July 6, 2007 to Spanish translations of consent form for the above referenced protocol.
This action will be conveyed to the IRB-1 at its next convened meeting on July 17, 2007.

DATE OF NEXT IRB REVIEW: May 1, 2008
DATE OF IRB APPROVAL EXPIRATION: June 28, 2008

Roy R. Estrada, PhD(c), C.I.P.
Associate Director Institutional Review Board

Study Sites: UTHSCSA
Please retain this document in your IRB correspondence file
CONSENTIMENTO DEL SUJETO PARA PARTICIPAR EN EL ESTUDIO DE INVESTIGACIÓN DE FACTORES QUE INFLUYEN LA PERCEPCIÓN DE LA EXPERIENCIA DE CUIDADORES LATINOS/HISPANOS QUE CUIDAN DE UN PARIENTE CON ENFERMEDAD DE ALZHEIMER

The University of Texas Health Science Center at San Antonio (Universidad del Estado de Tejas, Centro de Ciencias de la Salud) Conducido en Graduate School of Biomedical Sciences (Escuela de Postgrado en Ciencias Biomédicas) y School of Nursing (Escuela de Enfermería)

INFORMACIÓN SOBRE LA INVESTIGACIÓN

¿De qué se trata la investigación?

Le pedimos que participe en un estudio de investigación de Cuidadores Latinos/Hispanos de personas con enfermedad de Alzheimer. Queremos aprender acerca de la manera en que los cuidadores de Alzheimer Latinos/Hispanos perciben la experiencia de cuidar. Le estamos pidiendo que participe en esta investigación porque queremos aprender de usted los conceptos y terminología usada por Latinos bilingües y monolingües para describir la percepción del impacto de ser cuidador en su vida.

¿Quién está conduciendo el estudio y cuántas personas participarán en el estudio?

Lyda Consuelo Arevalo RN, MSN está conduciendo el estudio. Un total de 40 personas participarán en este estudio.

La John A. Hartford Foundation, Programa de Becas Building Academic Nursing Geriatric Capacity (Construyendo Capacidad Académica de Enfermería Geriátrica), una organización sin ánimo de lucro que promueve la investigación científica, está patrocinando parcialmente este estudio. Esto significa que la Hartford Foundation está proporcionando dinero a la universidad para que la investigadora del estudio pueda conducir la investigación.

¿Qué sucederá si usted decide estar en la investigación?

Si usted decide participar, nosotros le pediremos que nos permita entrevistarle por aproximadamente 45 minutos a una hora, y que complete un formulario corto con información demográfica. La información que nos de durante la entrevista será grabada, sin embargo, la información no podrá ser conectada a usted.

¿Cuáles son los riesgos al participar en la investigación?

Es posible que usted experimente alguna incomodidad al hablar acerca de su experiencia como cuidador.

¿Habrá problemas si usted decide dejar de participar en esta investigación antes de que se haya completado?

No, usted puede retirarse del estudio en cualquier momento. Usted puede decidir no contestar cualquier pregunta que se le haga.

¿Habrá beneficios al participar en esta investigación?

No hay ningún beneficio para usted por participar en este estudio. Los conocimientos ganados de este estudio podrían beneficiar a otros cuidadores.
CONSENTIMIENTO DEL SUJETO PARA PARTICIPAR EN EL ESTUDIO DE INVESTIGACIÓN DE FACTORES QUE INFLUYEN LA PERCEPCIÓN DE LA EXPERIENCIA DE CUIDADORES LATINOS/ HISPANOS QUE CUIDAN DE UN PARIENTE CON ENFERMEDAD DE ALZHEIMER

¿Tendrá alguna compensación por la participación?

Usted recibirá una tarjeta por $20.00 dólares del HEB o de Wal-Mart como compensación por el tiempo gastado durante la entrevista y el tiempo gastado completando el formulario de datos. Usted recibirá la tarjeta cuando complete la entrevista y el formulario de datos. Si usted es contactado para una segunda entrevista, usted recibirá una tarjeta adicional por $15.00.

¿Habrá algunos costos relacionados a la investigación?

No hay ningún costo para usted.

CONFIDENCIALIDAD

¿Qué es Información Protegida de Salud (siglas en Inglés PHI)?

Información Protegida de Salud es información sobre la salud de una persona la cual incluye información que haría posible saber de quién es. Nosotros utilizaremos el término "su PHI" como una manera más corta de decir "su información protegida de salud (your protected health information)". De acuerdo a la ley, usted tiene el derecho de decidir quién puede ver su información de salud. Si usted decide participar en este estudio, usted le dará su permiso a los investigadores y al personal del estudio de la investigación (individuos que realizan el estudio) para ver y usar su información de salud para este estudio de investigación. Al realizar esta investigación, la información de salud que veremos y usaremos sobre usted incluirá: información que usted nos de durante su participación en el estudio tal como durante la entrevista o en el formulario de datos. Nosotros obtendremos esta información preguntándosela a usted.

¿Cómo será compartido su PHI?

Debido a que este es un estudio de investigación, no podremos mantener su PHI completamente confidencial. Podríamos compartir su información de salud con las personas y grupos que están involucrados en revisar este estudio de investigación, incluyendo:

- el patrocinador del estudio (The John A. Hartford Foundation)
- Los investigadores en la University of Texas Health Science Center at San Antonio
- El Institutional Review Board (Junta Institucional de Revisión) y la Compliance Office (Oficina de Cumplimiento) de la University of Texas Health Science Center at San Antonio, y otros grupos que revisan, en cómo se han realizado los estudios de investigación.

Partes de su PHI pueden ser fotocopiadas y enviadas a un lugar central o pueden ser transmitidas electrónicamente, tales como por correo electrónico o fax.

Los grupos que están recibiendo su información de salud pueden que no estén obligados para mantenerlo en forma confidencial. Ellos pueden pasar la información a otros grupos o individuos no nombrados aquí.

Si usted decide participar en este estudio, usted dará su permiso a los grupos nombrados.
CONSENTIMIENTO DEL SUJETO PARA PARTICIPAR EN EL ESTUDIO DE INVESTIGACIÓN
DE
FACTORES QUE INFLUYEN LA PERCEPCIÓN DE LA EXPERIENCIA DE CUIDADORES
LATINOS/HISPANOS QUE CUIDAN DE UN PARIENTE CON ENFERMEDAD DE ALZHEIMER

anteriormente, para ver y compartir su información de salud. Si usted elige no dejar que estos
grupos vean y compartan su información de salud como es explicado anteriormente, usted no
podrá participar en el estudio de investigación.

¿Cómo será protegido su PHI?
En un esfuerzo para proteger su privacidad, el personal del estudio usará números de códigos en
lugar de su nombre, para identificar su información de salud. Se usarán sus iniciales y números
en algunas fotocopias de sus expedientes del estudio. Si los resultados de este estudio son
reportados en revistas médicas o en juntas, usted no será identificado.

¿Tiene que estar en este estudio?
Participar en el estudio es voluntario. Usted es libre de decidir no participar en este estudio o
dejar el estudio en cualquier momento. También es libre de no autorizar a los investigadores y otros grupos que
vean y compartan su información de salud. Si usted decide no participar en el estudio o no
autorizar a los investigadores y otros grupos usar su información de salud, no habrá penalidades.
En otras palabras, usted todavía puede recibir tratamientos médicos sino participa en el estudio y
no le afectará su elegibilidad para cualquier plan de salud o beneficios del plan de salud o pagos
tos a los que usted pudiera ser elegible.

¿Qué sucederá si cambia de parecer?
Usted puede decidir no participar en este estudio en cualquier momento. Hable con el personal de
la investigación sobre su decisión. Usted puede pedir a los investigadores suspender el uso de su
información de salud en cualquier momento. Sin embargo, usted necesita informarse por escrito
y enviarlo a Lyda Azévalo, Coordinador de Investigación, 8600 Medical Center Dr., Austin, TX
si usted pide a los investigadores suspender el uso de su información de salud, su participación en el
estudio terminará y el personal del estudio dejará de obtener información de salud de usted y
acerca de usted. Sin embargo, el personal del estudio continuará usando la información de salud
obtenida, hasta el momento que ellos reciban su carta pidiéndoles dejar de usar su información.

¿Puede usted preguntar para ver su PHI obtenido en este estudio?
Los reglamentos federales indican que usted puede ver su información de salud acerca de usted y
usado en este estudio

¿Por cuánto tiempo va a ser usado su PHI?
Al firmar este documento, usted está de acuerdo en permitirnos usar y divulgar su información de
salud para propósitos del estudio en cualquier momento en el futuro. No habrá fecha de vencimiento
debido a que no sabemos cuánto tiempo nos tomará acabar de hacer todos los análisis y
necesitaríamos usar su información de salud por todo el tiempo que tome.
CONSENTIMIENTO DEL SUJETO PARA PARTICIPAR EN EL ESTUDIO DE INVESTIGACIÓN
DE
FACTORES QUE INFLUYEN LA PERCEPCIÓN DE LA EXPERIENCIA DE CUIDADORES
LATINOS/HISPANOS QUE CUIDAN DE UN PARiente CON ENFERMEDAD DE ALZHEIMER

¿Qué debe hacer si tiene preguntas o necesita reportar un problema?

Si tiene preguntas ahora, síntasé libre de hacerlas. Si tiene preguntas adicionales después, Lyda C
Arévalo RN, MSN,
puede ser localizada en el [Teléfono]. Si ella no está disponible, Sharon Lewis RN, PhD., puede
ser localizada en el [Teléfono].

El comité de The University of Texas Health Science Center que revisa las investigaciones en
sujetos humanos (Institutional Review Board) podrá contestar cualquiera pregunta sobre sus
derechos como sujeto en la investigación [Teléfono].

Se le dará una copia firmada de este documento para que guarde. Usted no renuncia a ninguno
de sus derechos legales al firmar este documento.

FIRME ESTE DOCUMENTO SOLAMENTE SI TODO LO SIGUIENTE ESTÁ
CORRECTO:

• Usted ha decidido voluntariamente participar en este estudio de investigación.
• Usted autoriza la obtención, usos y compartir su información protegida de salud como
   está descrito en este documento.
• Usted ha leído la información antes mencionada.
• Sus preguntas han sido contestadas a su satisfacción y usted cree que entiende toda la
   información dada sobre el estudio y sobre el uso y divulgación de su información de
   salud.

Firma del Sujeto [Firma]
Fecha y Hora Firmada por el Sujeto

Nombre del Sujeto en Letra de Molde

Firma del Testigo
Firma de la Persona que está Obteniendo el Consentimiento

Nombre del Testigo en Letra de Molde
Nombre y Título (en Letra de Molde) de la Persona
que está Obteniendo el Consentimiento

Fecha y hora firmada por el Testigo
Fecha y hora firmada por la Persona que está Obteniendo
Consentimiento

Página 4 de 4
LITERATURE CITED


Robinson-Shurgot, G., & Knight, B. G. Preliminary study investigating acculturation, cultural values, and psychological distress in Latino caregivers of dementia patients. *Journal of Mental Health and Aging* (in press).


*Research in Nursing & Health, 18*(2), 179-183.


*Journal of the American Medical Association, 292*(8), 961-967.


VITA

Lyda Consuelo Arévalo-Flechas was born to Lyda Flechas de Arévalo and Luis Felipe Arévalo Valbuena on January 29, ___ in Bogotá, Colombia. Lyda graduated from Sociedad de Cirugía de Bogotá, Hospital San José, Bogotá, Colombia, with High Honors in surgical technology in 1985. In 1987 she received an AAS in nursing with high honors from Broome Community College in Binghamton, New York. She later received her BSN from State University of New York in Binghamton in 1991. In 1999, she was awarded her MSN with high honors from the University of Texas Health Science Center at San Antonio (UTHSCSA). She was admitted to the doctoral nursing program at UTHSCSA in 2003. Lyda is a dedicated mother of two children: Leslie Sierra-Arévalo, born in 1994, and Michael Sierra-Arévalo, born in 1990. She is currently a Clinical Assistant Professor in the School of Nursing at UTHSCSA and a John A. Hartford Foundation's Building Academic Geriatric Nursing Capacity Pre-Doctoral Scholar (2006-2008). A member of Sigma Theta Tau International Honor Society of Nursing since 1998, Lyda was named to The National Dean’s List for 2006-2007 and received The Chancellor’s List Graduate Academic honor award for 2005-2006. She is also the recipient of the John A. Hartford Foundation Claire M. Fagin Post-Doctoral Fellowship award for 2008-2010. Lyda has also been a recipient of the Castella Nursing Pre-Doctoral Fellowship in Geriatric Research Award and the Sony and Barbara Wulfe Living Endowment Award to conduct qualitative studies in Latino caregivers. Abstracts co-authored with S. L. Lewis include “Lost in Translation: What does burden mean to Latino caregivers?” in *The Journal of the American Geriatrics Society* in 2006; “White hijas and Hispanic/Latina daughters: Are they different caregivers?” in the Conference Proceedings of *The Gerontological Society of America; Late Breaker Poster Sessions* in November 2007; and, and “Comparing stress management in Hispanic and white daughter caregivers” in *Communicating Nursing Research* in 2008. She is the co-author with C. M. Carillo-Martinez of “Reuse and recycling practices in a Colombian Hospital” published in the *AORN Journal* in November 2007. Lyda is also the author of “Is caregiver burden a carga for Hispanic/Latino Alzheimer's caregivers?” in *Communicating Nursing Research* in April 2008.