THE EFFECTS OF ACCULTURATION ON THE MEXICAN-AMERICAN DEMENTIA CAREGIVER EXPERIENCE

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ACKNOWLEDGMENTS To all the many people that were instrumental in helping me to get to this point in my intellectual development: Thank you.

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by

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There is a paucity of research to understand the experience of the Mexican-American caregiver of family members with dementia. The proposed study will investigate how acculturation affects the caregiver experience in the Mexican-American culture. Correlations between caregiver burden, problem behaviors, and positive aspects of caregiving will be computed and compared between participants at two acculturation levels. More caregiver burden and more positive aspects of caregiving are hypothesized to exist in the group with low acculturation, although the correlations between these two variables are expected to be similar in the acculturation groups. These results would imply that acculturation affects Mexican-American caregivers in both positive and negative ways.

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CHAPTER I Introduction

Statement of problem

There is much evidence to suggest that caregivers of family members are at risk for developing health problems due to the stress of caregiving (Bookwala, Yee, & Schulz, 2000; Rose-Rego, Strauss, & Smyth, 1998). Caregiving of people with Alzheimer's dementia (AD) is particularly stressful because of the nature of the disease (Clipp & George, 1993; Ory, Hoffman, Yee, Tennstedt, & Shulz, 1999). Recent studies have suggested that taking care of family members suffering from AD is more stressful than taking care of family members without dementia (Ory et al., 1999) and more stressful than taking care of family members with other medical disorders (Clipp & George, 1993). Understanding the many factors that affect the caregiver experience is important because programs designed to relieve these factors have shown to reduce caregiver burden and increase the quality of life for the person with AD (Schulz, Burgio, Burns, Eisdorfer, Gallagher-Thompson, Gitlin et al., 2003; Toseland & Rossiter, 1989).

In exploring the many factors involved in the caregiver experience, Ory et al. (1999) found that, compared to caregivers of family members without dementia, caregivers of family members with AD show more negative impact from this process.

They suggest that the behavioral problems often associated with AD may account for the increased burden. In fact, the link between behavioral problems in people suffering from AD and increases in caregiver stress is well documented (e.g., Arai, Kumamoto, Wahio,

Ueda, Miura, & Kudo, 2004; Black & Almeida, 2004; Mourik, Rosso, Niermeijer, Duivenvoorden, Van Swieten, & Tibben, 2004). More caregiver burden has also been found in AD caregivers when compared with caregivers of people with diseases that present with little or no behavioral problems, such as cancer (Clipp & George, 1993). This lends credence to the idea that behavioral problems associated with AD account for the increased stress among caregivers of family members with AD.

In general, the literature indicates that caregiving has both positive and negative aspects. The negative aspects of caregiving, such as behavioral problems and time restrictions tend to increase the burden of caregiving (e.g., Kramer, 1997a; Stephens & Kinney, 1989). A robust link has been reported by several researchers of the negative health effects resulting from increased caregiver burden (e.g., Covinsky, Newcomer, Fox, Wood, Sands, Dane et al., 2003; Stueve, Vine, & Struening, 1997). Recent studies have also looked at the positive aspects of caregiving (PAC) as a way to better understand the caregiving experience; these may include factors such as the satisfaction that comes from providing care for someone else and companionship (Cohen, Colantonio, & Vernich, 2002; Tarlow, Wisniewski, Belle, Rubert, Ory, Gallagher-Thompson, 2004). There is also some evidence that indicates the negative effects of caregiving can be in part mitigated by PAC (e.g., Tarlow et al., 2004). Recent research has found that the negative and positive aspects of the caregiver experience are also influenced by another factor, culture.

Much of the research on caregiving has been limited to the Anglo-American population (Connell & Gibson, 1997). Research that has focused on the cultural

differences in the caregiving experience has found strong evidence to suggest that culture is an important factor in how caregiving is experienced (Arean, & Gallagher-Thompson, 1996; Harwood, Barker, Ownby, Bravo, Aguero, & Duara, 2000; Martin, 2000); thus, culture may be a factor that influences the effectiveness of the programs developed to reduce caregiver burden (Gallagher-Thompson, Haley, Guy, Rubert, Arguellas, Zeiss et al., 2003). Adams, Aranda, Kemp, and Takagi (2002), for example, found that African-Americans tend to report more PAC than Anglo-Americans or Mexican-Americans, and that Mexican-Americans and Japanese-Americans tend to react to caregiver burden with higher levels of depression than Anglo-Americans or African-Americans. Furthermore, the literature suggests that even among similar cultures, such as different Spanish-speaking cultures (e.g., Mexican vs. Cuban) there is a significant difference in how caregiving is experienced (Gallagher-Thompson, Coon, Solano, Ambler, Rabinowitz, & Thompson, 2003; Harwood et al., 2000).

The U.S. Census (1996) projects that by the year 2050, 24.4% of the U.S. population will be Hispanic. Most of the Hispanic population in the U.S. today consists of people of Mexican descent. Unfortunately, the research that focuses on the caregiver experience in this growing segment of the population is lacking.

In summary, the nature of AD has made caregivers a key component in the treatment of this disease. The caregiver experience has been found to include both positive and negative factors. Most of the research in this area has focused on the Anglo-American population, but cross-cultural variations have been found to influence the caregiver experience, as well. The growing number of Hispanics in the U.S., particularly

Mexican-Americans, has made the development of theory and measures to better understand this population crucial.

Purpose of Study

The aim of this study is to better understand the cultural influence on the Mexican-American caregiver experience. The focus will be on two factors: 1) caregiver burden and, 2) positive aspects of caregiving (PAC).

CHAPTER II - REVIEW OF THE LITERATURE Overview

Due to the irreversible and incapacitating nature of AD, it has become particularly important to focus on the caregiver as a part of the treatment for AD; however, there is woefully little research attempting to understand the caregiver experience in the Mexican-American culture and develop programs to enhance caregiving tailored to this population. The following literature review will present a brief description of AD and its consequences, developments in the understanding of the caregiver experience in the mainstream U.S. culture, and how these developments have been applied to the understanding of caregiving in the Mexican-American population.

What is Dementia?

According to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV: American Psychiatric Association, 2000), dementia is the development of cognitive deficits including memory impairments and other cognitive impairments such as aphasia, apraxia, agnosia, or disturbances in executive functioning (e.g., planning, organizing, sequencing, and abstracting). There are several causes of dementia, the most common being dementia due to Alzheimer's disease.

The cognitive decline in Alzheimer's disease is caused by the loss of a large number of neurons or brain cells. This disease presents with many behavioral symptoms; however, the diagnosis is confirmed by the presence of amyloid plaques and neurofibrillary tangles. Only an autopsy can reveal the presence of these two factors. It

is thought that the presence of amyloid plaques in the brain is in some way toxic to the cells. The neurons also form neurofibrillary tangles, which affects proper distribution of nutrients within the cell and leads to the death of the cell. In *early-onset* Alzheimer's, a subset of Alzheimer's which can develop when the person is in his or her thirties, the development of amyloid plaques is caused by a gene mutation. In the more common *late-onset* Alzheimer's, which develops in people over sixty, the etiology of amyloid plaques and neurofibrillary tangles is not entirely clear.

On average, people with Alzheimer's disease live from eight to ten years after the initial diagnosis (Department of Health and Human Services, 2004). Four distinct stages of dementia due to Alzheimer's have been identified, the early stage, the intermediate stage, the severe stage, and the end stage. In the early stage the person shows a loss in recent memory, starts to show a decline in the ability to learn new information, has word finding problems, mood swings, and some personality changes. In this stage, the person may find that he or she gets lost or forgets appointments or names of people he/she recently met. The *intermediate stage* is thought to be the most demanding for caregivers of those suffering from Alzheimer's (Rolland, 1984). In this stage, the person with Alzheimer's loses the ability to learn new information and the disease starts to affect the person's remote memory. The person might require help with the basic activities of daily living, such as bathing, eating, dressing, or toileting. The person might also become more aggressive and uncooperative. The increased dependence on the caregiver combined with the increase of problem behaviors is thought to contribute significantly to the stress of the caregiver. The caregivers are also emotionally burdened because the

person with Alzheimer's loses the ability to recognize significant others. Ironically, problem behaviors decrease in the next stage, the *severe stage* of Alzheimer's. In this stage, the person is usually completely dependent on a caregiver to carry out basic activities of daily living. By this stage, the person might lose the ability to swallow, speak, and walk. There is also a severe loss of the person's ability to fight off infections; consequently, he/she is susceptible to a number of them. The decline of the person's physical abilities reduces the problem behaviors that contribute to the caregiver's burden, and the severity of symptoms usually require that the person be cared for in a long-term care facility. In the final stage of Alzheimer's, the *end stage*, the person falls into a coma and dies.

Other causes of dementia such as vascular dementia, Binswanger's dementia, or dementia due to Parkinson's disease differ in the progression and rate of deterioration.

These types of non-Alzheimer's dementia can occur suddenly. While they might present similarly to Alzheimer's dementia, the non-Alzheimer's dementias do not necessarily progress. It is this inability to stop the progression of Alzheimer's that makes it the focus of many studies.

The fact that this disease affects the person's ability to realize he/she are suffering from AD spares the person from the loss of cherished memories and relationships; however, for significant others, this loss of a person's ability to recognize them or recall fond interactions might be more distressing. Little has been found to reverse the effects of AD; therefore, much of the therapy involves improving the quality of life for the individual with AD. Due to the increase of reliance on others, the quality of life for the

person with AD is largely dependent on the caregivers. Valle (1998) points out that the "disease not only ravages the individual but has a devastating impact on the caregiving network." [p.19]. It is therefore important to understand the experience of caregiving and what factors contribute to this experience.

Caregiver Burden

Caregiver burden has been investigated and commented upon as early as the 1950s. The early understanding of caregiver burden extended only to the additional financial burdens and physical work involved with caregiving (Parson & Fox, 1952; Yarrow, Shwarts, Murphy, & Deasy, 1955). The understanding of caregiver burden now extends to include the subjective reaction of the caregiver to not only the additional financial and physical burden, but also to the emotional toll, negative health consequences, and time constraints of caregiving (Poulshock & Deimling, 1984).

Grad and Sainsbury (1968) were the first to introduce the concept of "family burden" in relation to caregiving. Grad and Sainsbury's (1968) study of how mental illness affects the family was prompted by a change in England's health system that advocated home health care. They described how this change affected the patient and their family. They concluded the burden of caregivers could be compounded by the health, economic situation, and attitude of the caregiver. They also found that caregivers were more burdened by things like violent behavior and socially embarrassing behavior, and not the actual mental illness itself. This finding was important because it hinted at the idea that caregiver burden was not a uni-dimensional construct.

Hoenig and Hamilton (1966) first proposed the idea that caregiver burden was multi-dimensional. Their research led them to believe that caregiver burden had objective and subjective dimensions. They defined objective burdens as those burdens that disrupt family life, such as financial burdens, burden of supervision, and abnormal behaviors that are likely to disturb others. Subjective burdens were defined as those burdens created by how the caregiver responded to the situation, that is, how much the caregiver was bothered by the objective burden. They found that objective burden was greater than subjective burden, as reported by the family. They also found that caregiver burden was found across socio-economic status (SES), racial groups, and gender groups. Another finding of interest was that the quantity or quality of the objective burden did not affect quality or quantity of subjective burden. This was more evidence that the two burdens had to be considered independently.

This idea was further developed by Thompson and Doll (1982), who attempted to delineate dimensions that make up the construct of subjective caregiver burden. There were three major conclusions in this study. The first conclusion was that subjective burdens are a large part of the burden that caretakers feel. The second was that of the "universality" of the emotional burden across SES, racial groups, and gender groups, confirming a finding first reported by Hoenig and Hamilton (1966). The third conclusion was that objective and subjective burdens are caused by two different factors. A significant association between the two was observed (Tau=.26; p<.001); however, it was also reported that objective burden accounted for less than 10% of the variation in subjective burden reported. This indicated that objective burden did not necessarily lead

to subjective burden. Again, this also supported the findings of Hoenig and Hamilton (1966).

Poulshock and Deimling (1984) also recognized that caregiver burden was multidimensional. They argued, however, that Thompson and Doll (1982) did not go far enough to clearly define the factors that affect caregiver burden. They proposed that burden is, "...based on...highly personal and individualized responses to specific caregiving contexts" (p. 231). These contexts are defined by the types of impairment the care recipient has, including physical and/or mental impairment. So in their model, level of burden depended on the caregiver's responses to the impairment of the care recipients. They further argue that the subjective impact the impairment had on the caregiver weighed heavily on the burden felt.

The literature suggests that caregiver burden is highly correlated with behavioral problems of the patient; however, it also suggests that other factors contributed to increased burden. Other studies found that burden was highly correlated with factors such as depression (Covinsky et al., 2003), family conflict (Semple, 1992; Almberg, Jansson, Grafstrom, & Winblad, 1998), and even gender (Adams et al., 2002; Almberg et al., 1998; Barusch & Spaid, 1989). This suggests that caregiver burden is composed of many different factors; however, the overall caregiver experience is more than just burden. Kramer (1997b) points out that research has been more likely to focus on what is going wrong while ignoring what is going right.

Positive Aspects of Caregiving

Currently there is a trend to consider the positive aspects of caregiving (PAC) to understand the caregiver experience more fully. Several researchers have called for a closer examination of the role of PAC (Cohen, Gold, Shulman, & Zucchero, 1994; Kramer, 1997b; Ryff, 1989a; 1989b). Kramer (1997b) cites four reasons to study PAC: 1) it is an aspect of caregiving reported by many caregivers, and one that they want to talk about, 2) understanding PAC will help in giving better service to the caregiver, 3) understanding PAC might be important in determining the quality of care provided to older adults, and 4) improving the understanding of PAC will help in constructing better theories of caregiving adaptations.

The concept of PAC was first proposed in 1989 (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). Since then, evidence of PAC has been found in caregivers of those suffering from a variety of illnesses, such as AIDS (Ferrari, McCown, & Pantano, 1993) and schizophrenia (Bulger, Wandersman, & Goldman, 1993). Cohen, Colantonio, & Vernich, (2002) found that PAC includes such things as companionship, a sense of being fulfilled, a sense of duty, and in some cases just simply the sense of enjoyment from giving care to another.

PAC is not the opposite or simply the absence of caregiver burden. The literature suggests that PAC is correlated with things such as religiosity (Farran, Miller, Kaufman, & Davis, 1997), caregiver demographics (Cohen, et al., 1994), and even racial groups (Connell & Gibson, 1997); however, the reported association that PAC has with burden has been inconsistent. Some have found only a low level of correlation with caregiver

burden (Lawton et al., 1989) while others report a significant relationship between the two factors (Cohen et al., 2002). Caregiver burden, on the other hand, has consistently been found to correlate strongly with such things as behavioral problems of the patient (Black & Almeida, 2004; Grafstrom & Winblad, 1995). This seems to suggest that PAC is a different factor altogether from caregiver burden, and, as such, affects the overall caregiver experience differently.

Enhancing Caregiving

Understanding the caregiver experience has led to the development of interventions designed to reduce caregiver burden. One of the largest studies exploring the specific programs to reduce caregiver burden is the *Resources for Enhancing Alzheimer's Caregiver Health* (REACH) project (Wisniewski, Belle, Coon, Marcus, Ory, Burgio et al., 2003).

The purpose of the REACH project was to test the efficacy of several interventions design to enhance caregiving for persons with dementia. A total of 1222 (56% Caucasian, 24% Black, and 19% Hispanic) participants were used to test nine different interventions at six different sites located around the U.S. Several important results were reported from this large study, among these were: 1) the intervention programs tested significantly enhanced caregiver experience, 2) caregiver's SES level affected how caregiving was experienced and which intervention program was more effective, and 3) caregiver's ethnicity was also an important determinant in how caregiving was experienced and which intervention program was more effective.

The results of the REACH project suggest that effective programs to reduce caregiver burden are possible and it highlighted the importance of tailoring these interventions to the target population. The results of this project also suggest that more understanding of caregiver experience within the various ethnic groups is needed.

General Caregiver Experience in the Anglo-American Culture

The studies of PAC and caregiver burden suggest that these two factors must be taken into account when attempting to understand the overall caregiver experience.

Caregiver burden has consistently demonstrated strong correlation to problem behaviors, but has had inconsistent correlations with PAC. Caregiver burden has also been found to have a strong relationship to depression, gender, and age (Covinsky et al., 2003). Some research has even found an increase in PAC and decrease in burden with lower SES levels, contrary to what one would expect (Roff, Burgio, Gitlin, Nichols, Chaplin, & Hardin, 2004). As mentioned before, to best understand the overall caregiver experience, one must take into account the effects of both burden and PAC, as well as cultural differences.

Cross Cultural Aspects of the Caregiver Experience in the U.S.

Most studies exploring caregiver experience have been based on an Anglo-American sample, but there is strong evidence in the literature to suggest that caregiver experience is different between racial groups in the U.S. Most of the studies exploring the cross-cultural aspect of caregiving looked at the African-American population; however, there are an increasing number of studies exploring caregiver experience in other racial groups.

Studies looking at PAC in African-Americans have found that this group reports higher levels of PAC than do Anglo-Americans (Foley, Tung, & Mutran, 2002; Lawton, Rajagopal, Brody, & Kleban, 1992; White, Townsend, & Stephens, 2000; Rapp & Chao, 2000). This difference has also been found in the level of caregiver burden that African-Americans report compared to Anglo-Americans (Covinsky et al., 2003).

Several explanations for these differences have been offered; for example,
Lawton et al., (1992), and Foley et al., (2002) suggest that being a caregiver is a deeply
ingrained norm in the African-American culture and therefore is accepted with more
ease. Dilworth-Anderson and Anderson (1994) and Haley, Roth, Coleton, Ford, West,
Collins et al. (1996) found that, in fact, caregiving was more normative in the AfricanAmerican culture. Others have suggested that the higher PAC in the African-American
culture is due to the higher religiosity found in this culture compared to the AngloAmerican culture (Connell & Gibson, 1997; Farran et al., 1997; Segall & Wykle, 19881989; Wykle & Segall, 1991). These findings, however, are not conclusive; other studies
found no differences in levels of religiosity in African-Americans (Haley et al., 1996) or
PAC (Cox, 1999).

Adams et al. (2002) compared the level of stress reported by a sample of Japanese-American, Anglo-American, African-American, and Mexican-American caregivers of persons with dementia. This study used a sample of 202 people who were providing care to spouses suffering from dementia. The sample included 41 Japanese-

Americans, 67 Anglo-Americans, 49 African-Americans, and 45 Mexican-Americans. Measures of the caregiver were taken to assess appraisal of caregiving, coping styles, social support, religiousness, psychiatric distress, and depression. Measures of the patient were also taken to assess psychiatric symptoms, cognitive status, and ADLs.

Adams et al. (2002) found that ethnicity of the caregiver was related to caregiver appraisal, coping styles and social support received. They concluded that these factors contribute to the overall elevation of depression, such as the tendency of the Mexican-American caregiver compared to the other ethnic groups to use escape-avoidance as a coping mechanism. They found that Japanese- and Mexican-American caregivers reported significantly more psychiatric distress than did Anglo- and African-Americans. Kinoshita and Gallagher-Thompson (2004) point out that in Japanese culture, dementia carries more of a stigma than in other cultures because it is seen as a mental illness and as such is thought to reflect badly, not just on the person suffering from dementia, but on the entire family. This might make Japanese-American caregivers more susceptible to caregiver stress.

It is clear that culture has some impacts on the caregiver experience, yet research looking at the impact of caregiving in Hispanic cultures remains unclear (Gallagher-Thompson, Coon et al., 2003). One of the possibilities for this might be the fact that Hispanics are treated as a homogeneous group, while in reality Hispanics consist of many different groups.

Some studies using various Hispanic groups have found they differ from Anglo-American groups in a unitary way (Mausbach, Coon, Depp, Rabinowitz, Wilson-Arias, Kraemer et al., 2004). Other studies looking at caregiver burden in specific Hispanic groups, however, suggest that caregiver experience differs between Hispanic groups. For example, studies comparing caregiver experience of Cuban-Americans with Anglo-Americans found that both of these groups report similar levels of depression (Harwood et al. 2000). Studies comparing Mexican-American caregivers with Anglo-American caregivers found significantly higher levels of depression in the Mexican-American group (Adams et al., 2002).

Caregiver Experience in the Mexican-American Culture

Traditionally, there has been little effort to distinguish among the different

Hispanic groups when describing caregiver experience, which might have led to

conflicting results in studies attempting to understand the caregiver experience in the

Hispanic culture. Most studies that focused on the Mexican-American caregiver

experience are not systematic in including only Mexican-Americans; thus, less is known about this group.

In the Coon, Rubert, Solano, Mausbach, Kraemer, Arguëlles et al. (2004) study, the sample of Hispanics was not limited to Mexican-Americans, although most were Mexican-American. The sample included both English and Spanish speaking Hispanics. The study explored the caregiver experience of Hispanics and Anglo-American females. The study looked at the interaction of well-being, appraisal, religiosity, ethnicity, and acculturation in the experience of dementia caregivers. The data used in this study were taken from a larger multi-site study whose main focus was assessing the effectiveness of

several programs used to improve family caregiving of those suffering from Alzheimer's or related diseases (Wisniewski, Belle, Coon, Marcus, Ory, Burgio et al., 2003). Caregivers participating in this study had to be at least 21, family members of the care recipient, and living with the care recipient. They also needed to have been providing care for at least six months and for at least four hours each day. The researchers attempted to include males in the study; however, they could not find an equal number of male participants in the different sites, so they decided to use only the information collected from the female participants. Total sample size was 420, including the Hispanic (n = 191) and Caucasian (n = 229) participants. The study concluded that Hispanics reported lower appraisals of stress, more PAC, and more use of religion to cope than Anglo-American caregivers did.

Jolicoeur and Madden (2002) used primarily qualitative data to explore the impact of acculturation on the Mexican-American caregiver. All the participants for this study were Mexican-American. They also had to be caregivers of an elderly person that required assistance with at least one ADL. Social service agencies identified potential participants, and of 72 potential participants, 39 were used in the study. Measures of acculturation were taken as well as information used to determine the SES level of the individual. Structured and open-ended interview questions were used to collect information from the caregivers about the caregiver experience, including: burden and stress, physical and emotional stress, emotional toil of watching the decline of the care recipient, role expectations, and caregiver satisfaction. The sample of caregivers used in this study was not limited to caregivers of family members with Alzheimer's; however,

they did find that some aspects of caregiving were similar across acculturation levels. These included the strong beliefs about the role of elders in the family and the significant amount of burden associated with caregiving, while other factors were significantly influenced by acculturation. A surprising finding was that Mexican-American caregivers with less acculturation reported significantly higher levels of burden, perhaps due to the significantly more time spent in the role of caregiver, compared to more acculturated Mexican-Americans. Lower acculturated Mexican-Americans also reported significantly less satisfaction with the role of caregiver.

Jolicoeur and Madden (2002) had some interesting conclusions; however, the study used mostly qualitative data making it difficult to gauge the significance of the conclusions and how well they generalized to the Mexican-American culture at large. Other studies, however, have also report surprising findings regarding Mexican-American caregivers.

Adams et al. (2002), mentioned previously, found that Mexican-Americans reported less social support than African-Americans, Japanese-Americans, and even Anglo-Americans. They did not take acculturation into account and so it is unclear how, or if, this factor would have affected the results. This finding is surprising because traditionally, Hispanics have reported higher levels of social support from family (Lubben & Becerra, 1987; Markides & Mindel, 1987). It is possible that the surprising results found by Adams et al. (2002) were due to variations of family support across acculturation levels in the Mexican-American sample. Aranda and Knight (1997), suggest that less acculturated Mexican-Americans might have less social support than

more acculturated Mexican-Americans. The suggestion is based on an earlier study (Valle & Bensussen, 1985) that found that Mexican-Americans with more time in the U.S. have more kin available to them, while new immigrants have less family in the U.S. Aranda and Knight (1997) suggested that this lack of family availability leads to more stress. Lower acculturated Mexican-Americans tend to have less time in the U.S., so it is possible that they have less social support to count on, increasing their caregiver burden. The more acculturated Mexican-Americans would have had more time in the U.S. which would give them more time to establish family connections nearby, thereby having more access to family support. The increased family support would lessen the caregiver burden.

In general, Hispanic caregivers tend to be different from caregivers in other ethnic groups. Within the Hispanic population, the various subgroups also have important distinctions that must be considered in order to fully understand the caregiver experience. The Mexican-American culture is of particular importance because of its large presence in the U.S.

The Mexican-American Culture

The terms Hispanic and Latino refer to any person who comes from Latin

America or other Spanish speaking countries. The group called Mexican-American

consists of people who either came from Mexico or are descended from people who came

from Mexico and now live in the U.S. The Mexican-American culture is not, as some

would believe, a replication of the Mexican culture. It has components of both the

Mexican culture and the Anglo-American culture, but it is not just an amalgamation of the two cultures. The Mexican-American culture has elements that are distinct from both the Anglo-American culture and the Mexican culture (Mendoza, 1989). A full exploration of the distinctions of the Mexican-American culture is beyond the scope of this literature review, but it is important to establish characteristics of this culture that are relevant to the caregiver experience.

Perhaps one of the more important characteristics of the Mexican-American culture relevant to caregiving is the concept of familism or familialism (Marin, 1993; Vega, 1995). Chun & Akustu (2003) describe familialism as "a cultural commitment to Latino family life and consists of strong identification with and attachment to members of the nuclear and extended family as well as strong feelings of loyalty, reciprocity, and solidarity toward members of the family" [p. 104]. Familialism is thought to have both positive and negative effects in the caregiver experience. In some instances, familialism leads Mexican-American families to be more reluctant to seek medical help for family members who are ill (Hough, Landsverk, Karno, Burnam, 1987) and less willing to seek respite care (Gallagher-Thompson, Leary, Ossinalde, Romero, Wald, & Fernandez-Gamarra, 1997). It has been suggested that the adherence to the cultural norm of familialism demands that individuals take on the role of caregivers to ill family members. Seeking respite care would mean admitting that one cannot take care of a family member, thus failing in their role of caregiver (Gallagher-Thompson, Talamantes, Ramirez, & Valverde, 1996). From a positive standpoint, familialism also results in a strong family support unit (Mannino & Shore, 1976; Valle & Bensussen, 1985). Problems of family

members are openly discussed within the family, consequently the individual might feel less isolated and have help in resolving issues.

Other characteristics prevalent in the Mexican-American culture could also be responsible for the reluctance to seek help, or at least the under use of medical services. It has been suggested that this reluctance could be associated with language differences, lack of knowledge of available services, fear of discrimination, and a general sense of alienation from the dominant society (Sanchez, 1986).

The Mexican-American culture is constantly in flux, changed both by influences from the U.S. and from Mexico, and also by changes evolving within the culture itself. These factors make the culture complex, which makes establishing suitable services difficult. Further complicating the understanding of cultural factors is the influence of acculturation. This factor is extremely important because it affects how much influence the beliefs, such as familialism, have on the individual.

Acculturation

The term acculturation was first used in 1936 (Redfield, Linton, & Herskovits, 1936) to describe the changes a culture undergoes when exposed to another culture. The definition of acculturation has changed since it was first introduced; however, effects of acculturation have consistently been found important to understanding the physical health, mental health, and behavioral patterns of those affected by acculturation (Berry, 1997). What has been less consistent in the literature is agreement on how to conceptualize and measure acculturation.

Some major elements of the first definition of acculturation (Redfield, Linton, & Herskovits, 1939) are still part of today's generally accepted understanding of this construct, namely the idea that acculturation is the changes a culture undergoes when it is exposed to another culture. A major change to the definition of this construct happened in 1957 (Social Science Research Council). The earlier definition presented acculturation as a process that ended with assimilation of one culture into another culture (Spindler & Spindler, 1958). It also assumed that acculturation happened only with long-term exposure and that the changes to the culture were irreversible (Trimble, 2003). The new definition allowed for the possibility of other outcomes of acculturation besides assimilation (Chun & Akutsu, 2003), such as integration (Berry, 2003) where the individual successfully combines elements of both cultures; or separation (Mendoza & Martinez, 1981), where the individual chooses to reject all aspects of the new culture. Another possible outcome of acculturation includes marginalization (Stonequist, 1937), where the individual does not clearly identify with the new culture or the old culture and thus feels out of place in both cultures. Cultural transmutation (Mendoza, 1989) is yet another possible outcome of acculturation. In this scenario, the individual reacts to acculturation by establishing a new cultural group which claims elements of both the original groups, but identifies itself as separate and distinct from them.

Recent studies have found that the process of acculturation is not linear, irreversible, or continuous (Richman, Gaviria, Flaherty, Birz, & Wintrob, 1987; Suarez-Orozco, 2001; Trimble, 2003) and that there are several facets of acculturation (Trimble, 2003). As mentioned before, the literature is rich in studies on the effects of

acculturation in many aspects of life. Evidence suggests that acculturation is a factor in several health areas, such as cardiovascular health (Sundquist & Winkleby, 1999; Winkleby & Ahn, 1998), low birth weight and infant mortality (Zambrana, Scrimshaw, Collins, & Dunkel-Schetter, 1997), drug use (Pumariega, Swanson, Holzer, Linskey, & Quintero-Salinas, 1992; Vega, Kolody, Anugilar- Gaxiola, Catalano, & Caraveo-Anduaga, 1998) depression, (Burnam, Hough, Karno, Escobar, & Telles, 1987; Swanson, Linskey, Quintero-Salinas, Pumariega, & Holzer, 1992) and other mental disorders (Burnam et al., 1987; Escobar, Waitzkin, Silver, Gara, & Holman, 1998; Vega et al. 1998,). What is less clearly understood is the conceptual basis of acculturation, such as what factors influence acculturation and to what extent. It is also difficult to decipher how to best measure these influences.

Perhaps the most prominent model conceptualizing acculturation in use today is Berry's Model of Acculturation (Berry & Annis, 1974). This model proposes that acculturation begins when two cultures influence each other (directly or indirectly), triggering a change or reaction in both of the cultures. The change in the cultures then elicits a reaction in the individual. In short, changes within the entire culture influence changes at the individual psychological level. In order to understand acculturation as presented by this model, Berry (2003) says that one must measure the process of change at both the cultural and individual level. In order to understand the cultural and psychological changes, one must first have a firm understanding of the major components of the culture and individuals in the culture before they were exposed to the other culture.

Mendoza and Martinez (1981) proposed that these major components of the group

and individual can be broken down into cognitive, affective, and behavioral changes. The cognitive component refers to the individual's "problem-solving propensities on two dimensions, information gathering and information evaluations" [p. 77]. The affective component refers to the individual's beliefs and the behavioral component refers to the individual's manner of doing things, including food preferences, dress habits, aesthetic preferences, and child-rearing practices. The instrument used to measure acculturation in the current study, the Acculturation Rating Scale for Mexican-Americans version II (ARSMA-II; Cuellar, Arnold, & Maldonado, 1995) uses the suggestions of Mendoza and Martinez (1991) as bases to measure acculturation in Mexican-Americans (a complete review of the ARSMA-II is presented in the methods section).

The current understanding of acculturation suggests that cultural changes happen in all groups that are exposed to each other. These changes occur in both directions and happen to the groups as a whole. The individual reacts to these changes in various ways, involving the person's thinking, beliefs, and manner of doing things. Acculturation, therefore, is an important factor when attempting to understand an individual's experiences and developing effective therapies.

Summary of Literature Review

Alzheimer's dementia is an incurable disease with symptoms that include cognitive deterioration and problem behaviors. These specific symptoms tend to cause more stress in caregivers than the stress experienced by caregivers of individuals who do not have dementia. Issues for all caregivers, such as caregiver burden, are understood to

be universal and multi-dimensional. Problem behaviors are the biggest factor contributing to the level of burden, but subjective and objective perceptions of the caregiver also contribute to it. Caregiving also has positive aspects, but positive aspects of caregiving are not simply polar opposites of caregiver burden; they may be influenced by other caregiver characteristics. In the Anglo-American culture, caregiver burden is highly correlated with problem behaviors, but has an inconsistent correlation with positive aspects of caregiving. However, little is known about the caregiver experience in various Hispanic cultures. Familialism is a factor that may have an effect on the caregiving experience within the Mexican-American culture. Degree of acculturation also may be another factor affecting the caregiving experience in the Mexican-American culture. Cross-cultural differences in the caregiver experience have been found, and research with interventions that may reduce caregiver burden has revealed that the effectiveness of the programs varies with ethnicity. Examining the factors involved in the caregiver experience in the Mexican-American culture may help in understanding the experience and in constructing more effective caregiver interventions.

The Present Study

This study will explore the effects of acculturation, within a Mexican-American sample, on three dependent variables: caregiver burden, problem behaviors, and PAC.

Research Goals

The goals of this investigation are to:

- 1. Measure caregiver burden, positive aspects of caregiving, and problem behaviors of family member with dementia in a sample of Mexican-Americans.
- 2. Analyze how caregiver burden, positive aspects of caregiving, and problem behaviors relate to each other, in order to determine if these variables relate in a Mexican-American population as they do in the Anglo-American population.
- 3. Analyze the effects of acculturation on levels of caregiver burden, positive aspects of caregiving, and problem behaviors.
- 4. Analyze the effects of acculturation on the relationship between caregiver burden, positive aspects of caregiving, and problem behaviors.

Hypotheses:

Hypothesis 1

The correlational pattern found between the three dependent variables in the Mexican-American group as a whole will be similar to the correlational pattern of Anglo-Americans as suggested by the literature. Using the entire sample, there will be:

- A. A significant positive correlation between caregiver burden and problem behaviors.
- B. No significant correlation between caregiver burden and PAC.
- C. No significant correlation between PAC and problem behaviors.

This hypothesis is based on the correlation patterns suggested by past studies involving Anglo-American caregivers. The literature suggests that the dependent variables interact in similar ways across various demographic constructs, such as gender, SES, and ethnicity. The correlation between caregiver burden and problem behaviors in Anglo-American samples is well documented (Arai, Kumamoto, Wahio, Ueda, Miura, & Kudo, 2004; Black & Almeida, 2004; Mourik, Rosso, Niermeijer, Duivenvoorden, Van Swieten, & Tibben, 2004). This correlation has also been found in samples of other ethnic groups such as African-Americans, Japanese-Americans, and various Hispanic groups (Adams et al., 2002). Past studies exploring the correlation between PAC and caregiver burden and the correlation between PAC and problem behaviors have reported an inconsistent relationship between these factors (Cohen, Colantonio, & Vernich, 2002; Lawton et al., 1989). Some mitigating effects of caregiver burden produced by PAC

have been reported, however (Tarlow et al., 2004). It is therefore hypothesized that there will be no significant correlation between these constructs.

Hypothesis 2

Group differences will be found between the Highly Acculturated (HA) group and the Lower Acculturated (LA) group for levels of the three dependent variables. Specifically:

- A. Significantly less PAC will be found in the HA group compared with the LA group.
- B. Significantly more caregiver burden will be found in the LA group compared with the HA group.
- C. No significant difference will be found between the groups in the level of problem behaviors.

Hypothesis 2-A is based on past studies that suggest that characteristics associated with less acculturated Mexican-Americans correlate positively with PAC in other groups. Religiosity, which has been reported to be higher in lower acculturated Mexican-Americans (Hood & Hall, 1977), for example, has been reported to correlate positively with PAC (Farren et al. 1997). Lower acculturated Mexican-Americans also tend to have lower SES compared to more acculturated Mexican-Americans, and lower SES has also been found to correlate positively with PAC in samples of African-Americans (Roff et al. 2004). It should be mentioned, however, that at least one study found less PAC in lower acculturated Mexican-Americans (Jolicoeur and Madden, 2002).

Hypothesis 2-B is also based on past studies that suggest that characteristics associated with less acculturated Mexican-Americans correlate positively with more caregiver burden in other groups. Adams et al. (2002), for example, report a significant negative correlation between social support and caregiver burden. For Mexican-Americans, social support is mostly provided by the family (Jolicoeur & Madden, 2002). Aranda and Knight (1997) point out that less acculturated Mexican-Americans have less access to their family because most of their family members are not in the U.S. This serves to remove the most important mechanism used by Mexican-Americans to relieve caregiver burden. Another characteristic that would increase caregiver burden in lower acculturated Mexican-Americans is the under-use of formal care services such as respite services (Gallagher-Thompson, Leary et al. 1997). The use of respite care correlates negatively with caregiver burden (Ham, 1999; Kosloski & Montgomery, 1993). Due to various factors (see section on Mexican-Americans), less acculturated Mexican-Americans are more reluctant to use these services, and therefore they are more likely to experience increased levels of caregiver burden.

Hypothesis 2-C is based on the fact that no studies were found to suggest a difference in levels of behavioral problems in people suffering from Alzheimer's between racial, SES, or gender groups. On the other hand, no published study looked directly at this issue.

Acculturation will not affect the correlational pattern between the three dependent variables; however, the relationship between caregiver burden and problem behaviors will be significantly stronger in the LA group. The relationship between caregiver burden and PAC, and the relationship between PAC and problem behaviors will not be significantly different in the one group compared with the other group. Specifically, there will be:

- A. A significantly stronger correlation between caregiver burden and problem behaviors in the LA group compared to the HA group.
- B. No significant difference between the HA group and LA group for the correlation of caregiver burden and PAC.
- C. No significant difference between the HA group and LA group for the correlation of PAC and problem behaviors.

Hypothesis 3-B and 3-C are based on the lack of evidence suggesting that demographical or acculturation factors have an effect on the interaction between caregiver burden and PAC, and between PAC and problem behaviors. Hypothesis 3-A is based on a past study that found that lower acculturated Mexican-Americans report having more caregiver burden compared to more acculturated Mexican-Americans despite the fact that problem behaviors are not different (Jolicoeur and Madden, 2002). This suggests that the same level of problem behaviors would cause more adverse effects in less acculturated Mexican-American than the more acculturated group. It is still

possible that a significant correlation might be found between problem behaviors and caregiver burden in both groups; however, it is hypothesized that the correlation between these two factors in the lower acculturated group would be significantly stronger than in the highly acculturated group.

CHAPTER III METHODS

Participants

There will be two types of participants used in this study, 1) the person suffering from dementia; he/she will be referred to as the patient and 2) the caregiver of the patient, who will be referred to as the caregiver. Patients and caregivers will be recruited from the Parkland Geriatric Clinic (PGC). The PGC is a primary care clinic located in Dallas, Texas, which accepts any patient age 60 and above. The clinic does not keep a database of the demographic characteristics of the population they serve; however, they estimate that most of the patients they serve are lower income, and about 50% of the patients are Hispanic. It is likely that the population in this clinic is not representative of the ethnic makeup of the city of Dallas; according to the 2000 U.S. Census, 35.6% of the population of Dallas is Hispanic (U.S. Census Bureau, 2001).

Criteria for Inclusion of Participants

In order to be included in this study, caregivers must be Mexican-American and be the primary caregiver. Care recipients must have a diagnosis of dementia or be suspected of having dementia of the Alzheimer's type based on DSM-IV criteria or a Mini Mental Status Examination score of less than 23. Care recipients also must be identified as being in the intermediate stage of dementia by their primary healthcare provider and be Mexican-American. A sample of 100 Mexican-American participants will be selected based on a first-come-first-served basis.

Recruitment of Participants

Primary health care personnel at the Parkland Geriatric Clinic will identify possible participants. The caregivers will be asked by the clinic personnel if they have interest in learning more about the study and perhaps participating. If they have interest in the study, the caregiver will be introduced to the investigator. The investigator will explain the study in more detail and invite him/her to participate.

Measures

Caregivers will complete the following four measures, in their language of preference: the Revised Memory & Behavior Problems Checklist (RMBPC), the Zarit Burden Interview (ZBI), the Positive Aspects of Caregiving (PAC) scale, and Acculturation Rating Scale for Mexicans (ARSMA-II).

The Revised Memory & Behavior Problems Checklist (RMBPC)

The RMBPC (Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992) will be used to assess the behavioral problems reported by caregivers. This is a 24-item, self-administered measure that assesses three domains of problematic behaviors in people with dementia: memory-related problems, depression problems, and disruption problems. The items ask the caregiver about the frequency of problem behaviors, from (0), *never occurs* to (4), *occurs daily or more often;* scores are then summed and yield a frequency subtotal score, which can range from 0 to 96. The scale also has the caregiver rate how much he/she is bothered by the problem behavior; however, in the current study only the

subtotal of the frequency scores will be used. Time to complete the RMBPC is approximately 10 minutes. Reliability analysis revealed good internal consistency (*Cronbach's alpha* .84). A copy of the RMBPC can be found in the Appendix.

Spanish Revised Memory & Behavior Problems Checklist (SRMBPC)

The Spanish Revised Memory & Behavior Problems Checklist (SRMBPC) is a translation of the RMBPC (Coon et al., 2004). As with the English RMBPC, the SRMBPC also asks the caregiver to report the frequency of problem behaviors, from (0), never occurs to (4), occurs daily or more often; scores are then summed and yield a frequency subtotal score, with scores ranging from 0 to 96. The translation of this instrument was done in three parts. First, a number of instruments measuring behavioral problems were pilot-tested with Spanish speaking caregivers to find the one that conceptually translated the best. The instruments selected from this pilot-testing were then translated again by a professional team of translators. The measures were then back translated to English again to insure that meaning, intent, and understanding was not lost. Another team then reviewed the translations and selected the instrument best suited for the study. The end result was the Spanish Revised Memory & Behavior Problems Checklist (SRMBPC). No psychometric information was reported on the translated measure. It is recognized that this may make the results derived from the SRMBPC questionable; unfortunately this scale is the only one found that has been translated or developed into Spanish. A copy of the SRMBPC can be found in the Appendix.

The Zarit Burden Interview (ZBI; Zarit, Orr, & Zarit, 1985) will be used to measure caregiver burden. The ZBI is a 22 item self-report inventory that was developed based on an earlier version of this measure (Zarit, Reever, & Bach-Peterson, 1980). Items in the inventory were chosen to tap into areas frequently reported by caregivers to be problems, as found by the authors' experience and past studies (e.g. Lowenthal, Berkman, & Associates, 1967). The caregiver responds to each item on a 5-point scale, ranging from (0) *never* to (4) *nearly always*. Scores can range from 0 to 88. A copy of the ZBI can be found in the Appendix.

The original study that developed the 22-item ZBI (Zarit, Orr et al., 1985) did not report any reliability testing; however, Majerovitz (1997) and Zarit, Antony, & Boutselis (1987) reported high internal consistency of the ZBI (*alpha*= .83 and *alpha*= .89), and good test-retest reliability (*alpha*= .71). Later authors also found that the ZBI had good construct validity when controlling for age and gender (Vitaliano, Young, & Russo, 1991).

The validity of the original ZBI was tested by comparing it to concurrent measures. The authors of the study expected that behavioral problems would correlate with caregiver burden, as suggested by Sainsbury and Grad de Alarcon (1970).

Behavioral problems were measured using the Memory and Behavior Problem Checklist. It was also expected that the extent of cognitive impairment (measured with a mental status exam) and functional impairment, as measured by Lawton's (1971) Instrumental and Physical Activity of Daily Living scales (IADL & PADL) would correlate with

caregiver burden. The study, however, did not find significant correlations with any of these concurrent measures, although later studies did find significant correlations when controlling for gender and age (Fitting, Rabins, Lucas, & Eastham, 1986; Pratt, Schmall, & Wright, 1986).

The Spanish version of the ZBI

Manuel Martin et al., (1996) translated the ZBI into Spanish, and as with the English ZBI, the Spanish ZBI asks caregivers to rate the frequency of burden causing events on a 5-point scale, ranging from (1) *never* to (5) *nearly always*, scores can range from 22 to 110. The translation of the Zarit 22-item Burden Interview was done using procedures suggested by Karno, Burnam, Escobar, Hough, & Eaton (1983) and Brislin (1980), which involved three steps. The first step was the translation of the scale by a bilingual person. The second step involved taking the translated scale and translating it back into English by three separate people, without having seen the original English version. The third step in the process involved comparing all three translations to the original version, for any difference. If it was found that there were major differences, the process would be repeated until an accurately translated version was found.

Four steps were used to evaluate validity and reliability of the final translation. The first step involved a test-retest method with a three month interval (r = 0.86). Secondly, a factor analysis was then used with varimax rotation. This analysis revealed that three factors accounted for 53.8% of the variance. The three factors included the subjective feelings of burden placed on the lives of the caregivers, the feelings of

rejection of the patients, and items related to the caregiver's evaluation of his/her ability to care for the patient. The third step involved using a Cronbach coefficient alpha to analyze the internal consistency reliability. It revealed good internal consistency reliability (*Cronbach coefficient alpha* = 0.91). In the final step, validity of the measure was evaluated by comparing it to concurrent measures; it was found to have a good correlation with two more established measures, the Lobo (1986) 28-item General Health Questionnaire (r = 0.63, p < 0.05) and Katz's (1976) Index of ADLs (r = .045, p < 0.05). The authors also reported the translated measure had a strong correlation with reports of memory/orientation problems (r = 44, p < .05) and behavioral problems (r = 0.55, p < 0.05). A copy of the Spanish ZBI can be found in the Appendix.

Positive Aspects of Caregiving (PAC) scale

The Positive Aspects of Caregiving scale, developed by Tarlow, et al. (2004), is a nine-item, self-administered scale that looks at caregiver's self-affirmations and outlook on life. Authors of this scale report a good overall reliability (*Cronbach's Alpha* .89). Scale validity was measured by comparing it to concurrent instruments; it was found to have correlations with them. The measure asks caregivers to rate how much they agree with proposed positive experiences (e.g., *Providing help to (CR) has made me feel more useful)* on a scale from (1), *disagree a lot* to (5), *agree a lot*. Scores can range from 9 to 45. Caregivers also have the option of refusing to answer the item or answering as *unknown*. This scale was developed in both Spanish and English in a similar process described for the translation of the SRMBPC (Coon et al., 2004). Unlike the SRMBPC,

the Spanish PAC (SPAC) scale was not chosen from several instruments measuring the positive aspects of caregiving, but was translated from the English PAC scale. The English PAC was developed as a revision of an earlier scale (Lawton, et al., 1989; Beach, Schulz, Yee, and Jackson, 2000). A copy of both the English and Spanish versions of the PAC scale can be found in the Appendix.

Acculturation Rating Scale for Mexican-Americans-II (ARSMA-II)

The Acculturation Rating Scale for Mexican-Americans-II (ARSMA-II) will be used to measure acculturation. The ARSMA-II (Cuellar et al., 1995) is a 30-item self-report scale which assesses four areas: 1) language use and preference, 2) ethnic identity and classification, 3) cultural heritage and ethnic behaviors, and 4) ethnic interactions. This scale is written in both English and Spanish. The ARSMA-II also includes a second experimental scale that measures cultural marginality; however, for the purposes of this study only the first scale will be administered.

The ARSMA-II was found to correlate highly with the original ARSMA scale (r = .89). Cuellar et al. (1995), also reported good internal reliability of each of the two subscales that are a part of this instrument (Cronbach's Alpha = .89 for the Anglo Orientation Subscale and .88 for the Mexican Orientation Subscale).

For each of the 30 items of the ARSMA-II the person is asked to rate him or herself on a 5-point Likert scale, from (1) *not at all* to (5) *almost always*.

In order to calculate the acculturation score, the average rating of items 2, 4, 7, 9, 10, 13, 15, 16, 19, 23, 25, 27, and 30 is derived; the average rating of this set of items is called

the Anglo Orientation Subscore (AOS). Then the average rating of items 1, 3, 5, 6, 8, 11, 12, 14, 17, 18, 20, 21, 22, 24, 26, 28, and 29 is calculated; the average rating of this set of items is called the Mexican Orientation Subscore (MOS). The AOS is then subtracted from the MOS and the remainder is the acculturation score, which will be used in this study. Scores can range from -4, very Mexican oriented to 4, very assimilated or Anglicized.

The authors of this scale divided acculturation level into five groups, depending on what generational level they were. For example, first generation people were born in Mexico and had parents born in Mexico. Second generation people were those born in the U.S. but had parents who were both born in Mexico, and so on. The mean acculturation score was then found for each of the five groups. High correlation was reported between acculturation group and generational status (.61, p< .001). A significant difference was also reported between the means of the five groups (F (4, 346) =54.195, p< .001). The study was based on a sample of 379 subjects.

In the current study, the five acculturation groups suggested by Cuellar et al. (1995) will be collapsed into two groups. The two least acculturated groups (Level I and II) will be collapsed into the Low Acculturated (LA). The two most acculturated groups (Level IV and V) are collapsed into the High Acculturated (HA) group. Those subjects within level III will not be used in the study. A copy of the ARSMA-II can be found in the Appendix.

Procedure

Once the caregiver has been identified and has agreed to take part in the study, informed consent will be obtained and confidentiality issues explained. Caregivers will be asked to read and sign all required forms, including forms with information about the study and their rights as a participant. The investigator will assist caregivers to fill out the measures described previously and a demographic information sheet.

It is estimated that the caregivers will take approximately 45 minutes to complete the measures. After the data have been collected, both the caregiver and the family member with dementia will be thanked and any questions they have about the study will be addressed. All rating forms and test protocols will be identified with only a number; all other identifying information will be removed.

CHAPTER IV DATA ANALYSIS

The information collected will be analyzed using the Statistical Package for the Social Sciences 13.0 (SPSS). The following statistical analyses will be performed in order to test the stated hypotheses.

For Hypothesis 1:

Correlational analysis will be performed to determine the relationship between the three variables within the entire sample:

- A. Correlation between caregiver burden (CB) and problem behaviors (PB),
- B. Correlation between CB and PAC, and
- C. Correlation between PAC and PB.

For Hypotheses 2:

The sample will be divided into two groups based on the level of acculturation:

- A. Highly Acculturated (HA) Group defined by Acculturation Score (AS) >1.19
- B. Lower Acculturated (LA) Group defined by AS <-.07

In order to maximize the ability to detect differences in acculturation, potential participants whose acculturation score falls within -.07 to 1.19 will not be used in the remaining statistical procedures.

A MANOVA will then be used to determine if there are significant differences between the HA group and the LA group in terms of levels of:

A. CB,

B. PAC, and

C. PB.

If the MANOVA detects a significant difference between the groups, post hoc analysis will be performed to determine which of the dependent variable pairs reflect a significant group difference.

For Hypotheses 3:

A correlational analysis will then be performed to determine the relationship between the three variable pairs for each of the two acculturation groups separately. This will yield three sets of correlation coefficients (see Table 1).

The procedure developed by Fisher (1921) will be used to compare the three pairs of correlation coefficients. This is a three step procedure:

First, each of the correlation coefficients are transformed:

$$r' = (0.5)\log_e \left| \frac{1+r}{1-r} \right|$$

Then, the *z* is obtained in the following way:

$$z = \frac{r_1' - r_2'}{\sqrt{\frac{1}{n_1 - 3} + \frac{1}{n_2 - 3}}}$$

In the final step a p value is found for the computed z.

CHAPTER V IMPLICATIONS

The analyses of the data could yield several possibilities. Each of the hypotheses proposed attempts to predict a perspective of the Mexican-American caregiver experience suggested by the literature. The study was set up so that a contribution to the understanding of Mexican-American caregiver experience would be gained, regardless of the results of hypothesis testing. The implications of finding support for each of the hypotheses will be explored first.

Support for the first hypothesis would indicate that the Mexican-American caregiving experience is very similar to that of Anglo-Americans in terms of the interaction of the three dependent variables (i.e., caregiver burden, problem behaviors, and PAC). This first hypothesis does not control for acculturation, so acculturation could still have an effect on the interaction of the dependent variables; however, because the sample consists of all acculturation levels, the effects of acculturation could be obscured or cancelled out.

The second hypothesis looks specifically at the effects of acculturation on the level of three dependent variables. Support for this hypothesis would suggest that acculturation, or some aspect of acculturation, affects caregiver experience in both positive and negative manners. Mexican-Americans who are more acculturated would experience less burden, but also less positives from caregiving. Mexican-Americans with less acculturation would experience more PAC, but also more caregiver burden. Support for this hypothesis does not indicate that the dependent variables interact any differently

in the two levels of acculturation, but only that the participants report different levels of the burden and positive experiences. It would suggest, however, that the strength in the relationship between variables, in particular between caregiver burden and problem behaviors, could be stronger in the LA group.

The third hypothesis looks at the relationship among the three dependent variables and takes acculturation into account. Support for this hypothesis would indicate that the three dependent variables relate in similar ways regardless of acculturation level, with respect to PAC and problem behaviors, and PAC and caregiver burden, but not caregiver burden and problem behaviors. It would suggest that the LA group is more affected by problem behaviors than is the HA group.

As mentioned previously, valuable information could also be gained even if the data did not support the hypotheses or supported only part of any one of the hypotheses. The failure of support for the first hypothesis could have several potential explanations. It is possible that there is a high degree of variability within the Mexican-American population due to acculturation that skews the results. In this case, effects of the variability would also be detected in the third hypothesis. Another possibility is that there is a true difference in how the three dependent variables interact in the Mexican-American sample compared to Anglo-American samples.

There could also be support for only part of the first hypothesis. A significant correlation could be found between caregiver burden and problem behaviors, but not between caregiver burden and PAC or PAC and problem behaviors. A situation in which only part of the hypothesis was supported would indicate that these variables are not

interacting in this sample as was found in samples of Anglo-Americans. Such a result would be unexpected, as much of the literature indicates that caregiver burden, PAC, and problem behaviors are at least moderately connected; however, if such results were obtained they would warrant further investigation.

The lack of support for the second hypothesis would indicate that acculturation has little effect on levels of positive and negative experiences in caregiving. A more unusual finding would be a significant difference in levels of problem behaviors between the HA and LA groups. It would suggest that the severity of dementia symptoms change as does acculturation level. This type of result would be highly suspect, because little support can be found in the literature indicating that acculturation affects the severity of neuropsychiatric symptoms. There are some studies indicating a difference in the expression of neuropsychiatric symptoms between racial groups, but these differences were stable across acculturation levels in the same racial group (Cohen & Magi, 1999). It is possible that other factors affected by demographic characteristics have a bearing on levels of problem behaviors. It has been reported that Hispanics react to stress with more depression (Adams et al. 2002; Covinsky et al., 2003; Hinton, Haan, Geller, & Mungas, 2003). Elevated levels of irritation and anger are symptoms of depression. It is possible that Hispanics who are suffering from dementia react with more depression than do other racial groups, which could lead to more anger and less cooperation. This could lead to increased problem behaviors.

As with the first hypothesis, the data could also support only part of the second hypothesis. This would suggest that some of the variables are affected by acculturation,

while others are not. Partial support for the second hypothesis could imply that the dependent variables are not as closely related in Mexican-American caregivers as suggested in the literature. If, for example, the data showed no significant differences in caregiver burden between the HA and LA groups, but showed significantly more behavioral problems in one group, this would suggest that acculturation affects caregiver burden in ways that mitigate the negative effects of problem behaviors. It could indicate that, unlike in other ethnic groups, behavioral problems are not a chief contributor of caregiver burden in Mexican-Americans. It would also indicate that there could be another factor common to both HA and LA Mexican-Americans that contributes to caregiver burden. Support for this implication would also likely be found in the partial support of the first hypothesis and the third hypothesis.

Lack of support for the third hypothesis could indicate that acculturation has no effect on how problem behaviors and caregiver burden interact, yet have an effect on the interactions of PAC and caregiver burden, or PAC and problem behaviors. The lack of support for hypothesis 3-B and 3-C would, as mentioned before, be surprising because much of the literature suggests that these variables interact in the manner hypothesized. Hypothesis 3-A is based on sound past research (see Methods section) that indicates that certain factors correlate to caregiver burden, such as social support (see Methods section); however, it is possible that other factors that are not accounted for might affect the hypothesized interaction.

Limitations of the Study

One of the major weaknesses of this study concerns the translated instruments used. The SRMBPC, for example has no reported psychometric testing, and acculturation effects on the validity of translated versions of the RMBPC, the PAC scale, and the ZBI have not been thoroughly examined. It is possible that the validity of these instruments is compromised by acculturation level. Unfortunately, a thorough search of the literature did not reveal better measures. This again emphasizes the importance of research such as the one proposed here, which seeks to better understand the Mexican-American population.

Another possible confound in this study is the failure to account for SES. SES will not be directly measured in the current study because SES level is often strongly associated with acculturation level (Cuellar et al., 1995).

Strengths of the Study

The current study is similar to past studies; however, it is unique and thus valuable in several ways. This study looks exclusively at Mexican-Americans. Unlike the Coon et al. (2004) study, the restriction in this sample makes it more likely that the unique characteristics of the Mexican-American culture are captured. This study also uses a sample consisting of both males and females. This is important because several studies have reported differences in caregiver experience between genders (Adams et al., 2002; Almberg et al., 1998; Barush & Spaid, 1989).

Conclusions

The aim of this study is to increase understanding of caregiver experience in the Mexican-American population and in doing so provide information to improve programs developed to support caregivers. Large studies, such as the REACH study, have found that support programs for caregivers significantly improve the quality of life for both the caregiver and care recipient, and that these programs are significantly more effective when tailored to the particular target ethnic group (Gallagher-Thompson, Haley et al., 2003). In programs developed to relieve caregiver burden, for example, it was found that some programs were more effective in helping Anglo-American caregivers and others more effective in helping African-American caregivers (Burgio, Stevens, Guy, Roth, & Haley, 2003). Knowing how similar the Anglo-American and Mexican-American caregiver experience is will help in tailoring services to this population.

The proposed study directly examines those factors deemed important to understanding caregiver experience in Mexican-American culture. It will also provide a base to develop more effective support programs, if those already developed prove to be ineffective.

This study also increases the general knowledge of the Mexican-American experience which provides the basis to develop theory, measures, and clinical methods to better serve this population. It also furthers the information available to help service providers of the Mexican-American population to increase their cultural competence, as prescribed by the APA guidelines on providing services to a multicultural population (American Psychiatric Association, 2002).

Finally, apart from increasing knowledge of the Mexican-American culture, the proposed study could also reveal other areas to explore. This would be particularly true if unexpected results, such as those discussed in the implications section, were found. The Mexican-American culture is a population in cultural flux, and as such is influenced by a myriad of factors, such as the actual immigration experience of first generation Mexican-Americans or perceived SES. Unexpected results have often led to previously unexamined factors in the understanding of various areas of study. The design of this study allows for valuable insight regardless of outcome.

Table 1

	HA Group	LA Group
CGB X PB	R	R
PAC X PB	R	R
CGB X PAC	R	R

APPENDIX

Acculturation Rating Scale for Mexican Americans

Instruction: Please read the each of the following and indicate how much you agree with each one by indicating on the scale below. There are no right or wrong answers.

1. I speak Spanish

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

2. I speak English

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

3. I enjoy speaking Spanish

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

4. I associate with Anglos

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

5. I associate with Mexican and/or Mexican Americans

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

6. I enjoy listening to Spanish language music.

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

7. I enjoy listening to English language music.

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

8. I enjoy Spanish language TV.

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

9. I enjoy English language TV.

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

10. I enjoy English language movies.

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

11. I enjoy Spanish language movies.

Not at al	l Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

12. I enjoy reading (e.g., books in Spanish)

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

13. I enjoy reading (e.g., books in English)

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

14. I write (e.g., letters in Spanish).

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

15. I write (e.g., letters in Spanish).

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

16. My thinking is done in the English language.

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

17. My thinking is done in the Spanish language.

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

18. My contact with Mexico has been

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

19. My contact with the USA has been

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

20. My father identifies or identified himself as "Mexicano"

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

21. My mother identifies or identified herself as "Mexicana"

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

22. My friends, while I was growing up, were of Mexican origin.

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

23. My friends, while I was growing u were of Anglo origin

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

24. My family cooks Mexican foods

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

25. My friends now are of Anglo origin

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

26. My friends now are of Mexican origin

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

27. I like to identify myself as an Anglo American

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

28. I like to identify my self as a Mexican American

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

29. I like to identify my self as a Mexican

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

30. I like to identify myself as an American

Not at all	Very little or not very often	Moderately,	Much or Very often	Extremely often or Almost always
1()	2()	3()	4()	5()

Spanish Acculturation Rating Scale for Mexican Americans

INSTRUCCIONES: Después de leer cada frase, por favor, indique qué tanto Usted está de acuerdo o en desacuerdo con cada una de las frases. No existen respuestas correctas o incorrectas.

1. Yo hablo Español

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

2. Yo hablo Inglés

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

3. Me gusta hablar en Español

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

4. Me asocio con Anglos

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

5. Me asocio con Mexicanos o con Norte Americanos

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

6. Me gusta la música Mexicana (música en idioma Español)

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

7. Me gusta la música de idioma Inglés

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

8. Me gusta ver programas en la televisión que sean en Español

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

9. Me gusta ver programas en la televisión que sean en Inglés

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

10. Me gusta ver películas en Inglés

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

11. Me gusta ver películas en Español

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

12. Me gusta leer (e.g., libros en Español)

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

13. Me gusta leer (e.g., libros en Inglés)

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

14. Escribo (e.g., cartas en Español)

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

15. Escribo (e.g., cartas en Inglés)

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

16. Mis pensamientos ocurren en el idioma Español

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

17. Mis pensamientos ocurren en el idioma Inglés

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

18. Mi contacto con México ha sido

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

19. Mi contacto con los Estados Unidos Americanos ha sido

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

20. Me padre se identifica (o se identificaba) como Mexicano

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

21. Me madre se identifica (o se identificaba) como Mexicana

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

22. Mis amigos(as) de mí niñez eran de origen Mexicano

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

23. Mis amigos(as) de mí niñez eran de origen Anglo Americano

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

24. Mí familia cocina comidas mexicanas

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

25. Mis amigos recientes son Anglo Americanos

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

26. Mis amigos recientes son Mexicanos

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

27. Me gusta identificarme como Anglo Americano

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

28. Me gusta identificarme como Norte Americano (México-Americano)

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

29. Me gusta identificarme como Mexicano

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

30. Me gusta identificarme como un(a) Americano(a)

Nada	Un Pocito o A veces	Moderato	Mucho o Muy Frecuenté	Muchísimo o Casi Todo el Tiempo
1()	2()	3()	4()	5()

Positive Aspects of Caregiving Scale

Instructions: Some caregivers say that in spite of all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experience too. The following are a few of the good things reported by some caregivers. Please rate how much you agree or disagree with these statements. If none of these options match exactly how you feel, choose the closest one.

1. Providin	g help has made me fe	eel more useful:		
		Neither agree nor disagree ()	Agree a little	Agree a lot
()	,	()	()	()
		eel good about myself:	A 1101	A 1.
	Disagree a little ()	Neither agree nor disagree ()	Agree a little	Agree a lot
	g help has made me for Disagree a little	eel needed: Neither agree nor disagree	Agree a little	Agree a lot
()	()	()	()	()
4. Providin	g help to has made me	e feel appreciated:		
Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
()	()	()	()	()
5. Providin	g help has made me fo	eel important:		
Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
()	()	()	()	()
6. Providin	g help has made me fe	eel strong and confident:		
Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
()	()	()	()	()
7. Providin	g help has given more	meaning to my life.		
Disagrae a lot	Dicagraa a littla	Neither agree nor disagree	A grae a little	Agrae a lot
()	()	()	Agree a nuic	()
8. Providir	ng help has enabled m	e to learn new skills.		
Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
()	()	()	()	()

9. Providing	g help has enabled me	e to appreciate life more:		
•	Disagree a little	Neither agree nor disagree	Agree a little	Agree a lot
10. Providing	g help has enabled me	to develop a more positive attitue	de toward life:	
-	Disagree a little	Neither agree nor disagree ()	Agree a little	Agree a lot
11. Providing	g help has strengthene	ed my relationship with others:		
Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a little ()	Agree a lot

Escala de Aspectos Positivos Cuidados

INSTRUCCIONES: Algunas personas que cuidan a un familiar con problemas de la memoria o de salud dicen que pueden sacar algo bueno de ello a pesar de ser una experiencia difícil. Ahora, me gestaría hacer una serie de preguntas sobre como Usted mismo(a) se ha sentido en relación a la atención y al cuidado que Usted brinda para ayudar a su familiar con problemas de la memoria o de salud. Por favor, indique qué tanto Usted está de acuerdo o en desacuerdo con cada una de las siguientes frases.

1. Brindar	r ayuda a su fami	liar, ¿le hace a Usted sentirse	más útil?	
Muy en Desacuerdo	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()
2. Brindar	r ayuda a su fami	liar, ¿le hace a Usted sentirse	bien con Usted	mismo(a)?
Muy en Desacuerdo	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()
3. Brindar	r ayuda a su fami	liar, ¿le hace a Usted sentirse	necesitado(a)?	
Muy en Desacuerdo	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()
4. Brindar	r ayuda a su fami	liar, ¿le hace a Usted sentirse	apreciado(a)?	
Muy en Desacuerdo	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()
5. Brindaı	r ayuda a su fami	liar, ¿le hace a Usted sentirse	importante?	
Muy en Desacuerdo	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()

6. Brindar ayuda a su familiar, ¿le hace a Usted sentirse fuerte y con confianza?							
Muy en Desacuerdo ()	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo	Muy de Acuerdo			
7 Brinda signific	•	iar, ¿le hace a Usted sentir qu	e su vida tiene 1	más			
Muy en Desacuerdo ()	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()			
	r ayuda a su famil er nuevas habilida	iar, ¿le hace a Usted tener o a des?	dquirir la capac	idad para			
Muy en Desacuerdo ()	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()			
	r ayuda a su famil ar más la vida?	iar, ¿le hace a Usted tener o a	dquirir la capac	idad de			
Muy en Desacuerdo ()	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo	Muy de Acuerdo ()			
		iar, ¿le hace a Usted tener o a ás positiva hacia la vida?	dquirir la capcio	lad para			
Muy en Desacuerdo ()	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()			
11. Brinda demás		iar, ¿le hace a Usted fortalece	er sus relaciones	con los			
Muy en Desacuerdo ()	Un poco en Desacuerdo ()	Ni en acuerdo o Desacuerdo	Un poco de Acuerdo ()	Muy de Acuerdo ()			

Revised Memory and Behavioral Problem Checklist

Instructions: Some caregivers report difficulties involved in giving care to a family member with memory or health problems. The following are some of the problems you may have encountered while caregiving. Please rate frequency of your experience with these problems. If none of these options match exactly how you feel, choose the closest one.

1. Within	the past week, t	he person I care for	has been asking the s	same question o	ver and over?		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		
	the past week, t ewspaper or on		r has had trouble reme	mbering recent	events (e.g., items		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		
3. Within	the past week, t	he person I care for	r has had trouble reme	mbering signifi	cant past events?		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		
4. Within	the past week, t	he person I care for	r has been losing or m	isplacing things	?		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		
5. Within	the past week, t	he person I care for	has been forgetting v	what day it is?			
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		
6. Within the past week, the person I care for has been starting but not finishing things?							
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		

7. Within the past week, the person I care for has had difficulty concentrating on a task?							
Never occurs	Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Don't know/not Applicable		
0()	1()	2()	3()	4()	5()		
8. Withir	the past week, t	he person I care for	r has been destroying	property?			
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		
()	,	、 ,	· · ·	`,	()		
9. Within	the past week, t	he person I care for	r has been doing thing	s that embarras	s you?		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2()	3 to 6 times in the past week 3()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		
0()	1()	2()	3()	4()	3()		
10. Within night?	the past week, t	he person I care for	r has been waking you	or other family	y members up at		
Never occurs	Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Don't know/not Applicable		
0()	1()	2()	3()	4()	5()		
11. Within	the past week, t	he person I care for	r has been talking loud	dly and rapidly	?		
Never occurs	Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Don't know/not Applicable		
0()	1()	2()	3()	4()	5()		
12. Within	the past week, t	he person I care for	r has appeared anxiou	s or worried?			
Never occurs	Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Don't know/not Applicable		
0()	1()	2()	3()	4()	5()		
	the past week, to the past week, the past wee		r has been engaging in	n behavior that i	is potentially		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()		

14 Within	the past week, t	he person I care for	r has threatened to hur	t him/herself?	70	
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4()	Don't know/not Applicable 5 ()	
15 Within	the past week, t	he person I care for	r has threatened to hur	rt others?		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()	
16. Within	the past week, t	he person I care for	r has been aggressive	to others verbal	lly?	
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()	
17. Within the p	ast week, the pe	erson I care for has	appeared sad or depre	ssed?		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()	
			r has been expressing while ever happens",			
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()	
19. Within	the past week, t	he person I care for	r has been crying and	tearful?		
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()	
20. Within the past week, the person I care for has been commenting about the death of him/herself or others (such as, "Life isn't worth living", or "I'd be better off dead")?						
Never occurs 0 ()	Not in the past week 1 ()	1 to 2 times in the past week 2 ()	3 to 6 times in the past week 3 ()	Daily or more often 4 ()	Don't know/not Applicable 5 ()	

21.	Within the	past week, th	ie person I	care for ha	s been	talking	about	feeling	lonely?
	TT I CLILLIA	publ Wooll, u.	ie person i	cure ror me	D CCCII	turiting.	acout	10011115	ioner, .

Never occurs	Not in the past week	1 to 2 times in the past week	3 to 6 times in the past week	Daily or more often	Don't know/not Applicable
0()	1()	2()	3()	4()	5()

Within the past week, the person I care for has made comments about feeling worthless or being a burden to others?

Never occurs	Not in the	1 to 2 times in	3 to 6 times in the	Daily or	Don't know/not
	past week	the past week	past week	more often	Applicable
0()	1()	2()	3()	4()	5()

23. Within the past week, the person I care for has made comments about feeling like a failure or about not having any worthwhile accomplishments in life?

Never occurs	Not in the	1 to 2 times in	3 to 6 times in the	Daily or	Don't know/not
	past week	the past week	past week	more often	Applicable
0()	1()	2()	3()	4()	5()

Within the past week, the person I care for has been arguing, irritable, and/or complaining?

Never occurs	Not in the	1 to 2 times in	3 to 6 times in the	Daily or	Don't know/not
	past week	the past week	past week	more often	Applicable
0()	1()	2()	3()	4()	5()

LISTA DE LOS PROBLEMAS DE MEMORIA Y COMPORTAMIENTO REVISADA (Revised Memory and Behavioral Problem Checklist)

INSTRUCCIONES: A continuación se presentan una lista de problemas qué algunas personas reportan cuando cuidan a otra persona. Después de leer cada frase, indique con qué frecuencia a tenido usted el problema indicado. No existen respuestas correctas o incorrectas.

1. Durante la semana pasada, ¿ha estado su familiar/paciente repitiendo la misma pregunta una y otra vez?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

2. Durante la semana pasada, ¿ha tenido su familiar/paciente problemas para recordar eventos recientes (ejemplo: del repitiendo la misma pregunta una y otra vez?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

3. Durante la semana pasada, ¿ha tenido su familiar/paciente problemas para recordar eventos importantes del pasado?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

4. Durante la semana pasada, ¿ha extraviado su familiar/paciente algunas cosas o las ha puesto en otro lugar?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

5. Durante la semana pasada, ¿ha olvidado su familiar/paciente qué día era?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

6. Durante la semana pasada, ¿ha empezado su familiar/paciente algunas cosas (algo), pero no las ha terminado?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

7. Durante la semana pasada, ¿ha tenido su familiar/paciente dificultades para concentrarse en una tarea?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

8. Durante la semana pasada, ¿ha estado su familiar/paciente destruyendo las cosas?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

9. Durante la semana pasada, ¿ha estado su familiar/paciente haciendo cosas que le avergonzaban a Usted?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

10. Durante la semana pasada, ¿ha estado su familiar/paciente despertándolo(a) a Usted o a los demás familiares por la noche?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

11. Durante la semana pasada, ¿ha estado su familiar/paciente hablando en voz alta y aceleradamente?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

12. Durante la semana pasada, ¿ha parecido su familiar/paciente estar ansioso(a) o preocupado(a)?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

13. Durante la semana pasada, ¿se ha comportado su familiar/paciente de una manera potencialmente peligrosa para él (ella) mismo(a) o para los demás?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

14. Durante la semana pasada, ¿ha amenazado su familiar/paciente con lastimarse o herirse a él(ella) mismo(a)?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

15. Durante la semana pasada, ¿ha amenazado su familiar/paciente con lastimar o herir a los demás?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

16. Durante la semana pasada, ¿ha estado su familiar/paciente verbalmente agresivo(a) con los demás?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

17. Durante la semana pasada, ¿ha parecido su familiar/paciente estar triste o deprimido(a)?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

18. Durante la semana pasada, ¿ha expresado su familiar/paciente algunos sentimientos de tristeza o desesperanza acerca del futuro (Ejemplo: "Nunca sucede algo bueno", "Nunca hago nada bien")?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

19. Durante la semana pasada, ¿ha estado su familiar/paciente llorando o lloroso(a)?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

20. Durante la semana pasada, ¿ha hecho su familiar/paciente algunos comentarios acerca de la muerte de él (ella) mismo(a) o de los demás (Ejemplo: "La vida no vale la pena", "Sería mejor estar muerto(a)"?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

21. Durante la semana pasada, ¿ha estado su familiar/paciente platicando [hablando] acerca de sentirse solo(a)?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

22. Durante la semana pasada, ¿ha hecho su familiar/paciente algunos comentarios acerca de sentirse que él (ella) no vale nada o que es una carga para los demás?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

23. Durante la semana pasada, ¿ha hecho su familiar/paciente algunos comentarios acerca de sentirse como un fracaso o que no había logrado nada bueno en la vida?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

24. Durante la semana pasada, ¿ha estado su familiar/paciente molesto(a), irritado(a), discutiendo y/o quejándose?

Nunca	No en la	1 a 2 veces en	3 a 6 en la	Diariamente	No se/no
	pasada	la pasada	pasada	o mas	aplica
	semana	semana	semana	frecuente	
0()	1()	2()	3()	4()	5()

ZARIT BURDEN INTERVIEW

Instructions: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way, never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers

1) Do you feel	that your relativ	ve asks for more	help then s/he needs?	
Never 0()	Rarely 1 ()	Sometimes 2 ()	Quite Frequently 3 ()	Nearly Always 4 ()
	that because of time for mysel	• •	nd with your relative,	you don't
Never 0()	Rarely 1 ()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4 ()
	stressed between		relative and trying to	meet other
Never 0()	Rarely 1 ()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4 ()
4) Do you feel	embarrassed ov	ver your relative'	s behavior?	
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4 ()
5) Do you feel	angry when yo	u are around you	r relative?	
Never 0()	Rarely 1 ()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4 ()

, ·	•	ve currently affection in a negative way	ets your relationship wi y?	th other
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()
7) Are you afra	id what the futi	ure holds for you	relative?	
Never 0()	Rarely 1()	Sometimes 2 ()	Quite Frequently 3 ()	Nearly Always 4 ()
8) Do you feel	your relative is	dependent upon	you?	
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()
9) Do you feel s	strained when y	you are around yo	our relative?	
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()
10) Do you feel relative?	your health ha	as suffered because	se of you involvement	with your
Never 0()	Rarely 1()	Sometimes 2 ()	Quite Frequently 3 ()	Nearly Always 4()
11) Do you feel of your rela		have as much pr	ivacy as you would lik	te because
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4 ()
12) Do you feel relative?	that your socia	al life has suffere	d because you are cari	ng for your
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4 ()

13) Do you feel relative?	uncomfortable	e about having fr	iends over because of	you
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()
, .	•	rive seems to expended	ect you to take care of and on?	him/her as
Never 0 ()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()
	that you don't e rest of your e		oney to care for your re	elative, in
Never 0 ()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()
16) Do you feel	that you will b	be unable to take	care of your relative m	nuch longer?
Never 0 ()	Rarely 1()	Sometimes 2 ()	Quite Frequently 3 ()	Nearly Always 4()
17) Do you feel	you have lost	control of your li	fe since your relative's	s illness?
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()
18) Do you wis	h you could jus	st leave the care of	of your relative to some	eone else?
Never 0 ()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()
19) Do you feel	uncertain abo	ut what to do abo	ut your relative?	
Never 0()	Rarely 1()	Sometimes 2()	Quite Frequently 3 ()	Nearly Always 4()

20) Do you feel you should be doing more for your relative?

Never	Rarely	Sometimes	Quite Frequently	Nearly Always
0()	1()	2()	3()	4()

21) Do you feel you could do a better job in caring for you relative?

Never	Rarely	Sometimes	Quite Frequently	Nearly Always
0()	1()	2()	3()	4()

22) Overall, how burdened do you feel in caring for your relative?

INSTRUCCIONES: A continuación se presentan una lista de frases que reflejan como se sienten algunas personas cuando cuidan a otra persona. Después de leer cada frase, indique con qué frecuencia se siente usted de esa manera, escogiendo entre NUNCA (N), CASI NUNCA (CN), A VECES (AV), FRECUENTEMENTE (F) y CASI SIEMPRE (CS). No existen respuestas correctas o incorrectas.

CON QUE FRECUENCIA (rodee con un círculo la opción elegida)

1. ¿Con que frecuencia siente usted que su familiar/paciente solicita más ayuda de la que realmente necesita?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

2. ¿Con que frecuencia siente usted que, a causa del tiempo que gasta con su familiar/paciente, ya no tiene tiempo suficiente para usted mismo?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

3. ¿Con que frecuencia se siente estresada(o) al tener que cuidar a su familiar/paciente y tener además que atender otras responsabilidades? (Ej: con su familia o en el trabajo)

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

4. ¿Con que frecuencia se siente avergonzada(o) por el comportamiento de su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

5. ¿Con que frecuencia se siente irritada(o) cuando está cerca de su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

6. ¿Con que frecuencia cree que la situación actual afecta a su relación con amigos u otros miembros de su familia de una forma negativa?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

7. ¿Con que frecuencia siente temor por el futuro que le espera a su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

8. ¿Con que frecuencia siente que su familiar/paciente depende de usted?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE

1()	2()	3()	4()	5()

9. ¿Con que frecuencia se siente agotada(o) cuando tiene que estar junto a su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

10. ¿Con que frecuencia siente usted que su salud se ha visto afectada por tener que cuidar a su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

11. ¿Con que frecuencia siente que no tiene la vida privada que desearía a causa de su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

12. ¿Con que frecuencia Siente cree que sus relaciones sociales se han visto afectadas por tener que cuidar a su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

13. SOLAMENTE SI EL ENTREVISTADO VIVE CON EL PACIENTE).

¿Con que frecuencia siente se siente incómoda(o) para invitar amigos a casa, a causa de su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

14. ¿Con que frecuencia cree que su familiar/paciente espera que usted le cuide, como si fuera la única persona con la que pudiera contar?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

15. ¿Con que frecuencia cree usted que no dispone de dinero suficiente para cuidar de su familiar/paciente, además de sus otros gastos?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

16. ¿Con que frecuencia siente que no va a ser capaz de cuidar de su familiar/paciente durante mucho más tiempo?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

17. ¿Con que frecuencia siente que ha perdido el control sobre su vida desde que la enfermedad de su familiar/paciente se manifestó?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

18. ¿Con que frecuencia desearía poder encargar el cuidado de su familiar/paciente a otra persona?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

19. ¿Con que frecuencia se siente insegura(o) acerca de lo que debe hacer con su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

20. ¿Con que frecuencia siente que debería hacer más de lo que hace por su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

21. ¿ Con que frecuencia cree que podría cuidar a su familiar/paciente mejor de lo que lo hace?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

22. En general, ¿con que frecuencia se siente muy sobrecargada(o) al tener que cuidar de su familiar/paciente?

NUNCA	CASI	A VECES	FRECUENTEMENTE	CASIE
	NUNCA			SIEMPRE
1()	2()	3()	4()	5()

Puntuación: Cada Item se puntúa de 1 (Nunca) a 5 (Casi Siempre). La puntuación mínima es por lo tanto 22, y la máxima, 110. Se han establecido los siguientes puntos de corte en población navarra:

No Sobrecarga: 22-46 Sobrecarga Leve: 47-55 Sobrecarga Intensa: 56-110

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VITAE

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