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CAREGIVER BURDEN IN THE LATINO FAMILY

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Yvonne Arellanes-Amador

December 2006

CAREGIVER BURDEN IN THE LATINO FAMILY

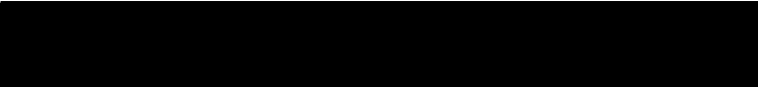
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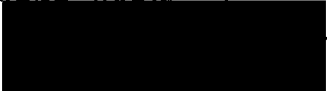
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ABSTRACT

The goal of this research was to provide a view of caregiving from the lens of Latino family caregivers. The research covers many areas of the family caregiving experience. It investigated unmet needs, levels of stress and burden, formal service utilization and the responsibilities involved when taking care of a mentally, physically, or cognitively impaired loved one. It also revealed some personal views of the caretakers, including the use of alternative coping skills, levels of familism, beliefs about what the positives in the role of caretaker, and what advice these caregivers would give to others faced with the task of caring for a loved one. Latino caregivers from both Los Angeles and San Bernardino counties were interviewed and or surveyed. This study sought to answer the question, "Does the use of formal supports decrease the stress and burden of Latino caregivers?" The null hypothesis was that Latino caregivers who utilized formal support services would be less stressed and burdened than those who did not. Results indicated a positive correlation between levels of familism, unmet needs, and caregiver strain.

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DEDICATION

This project is dedicated to my family.

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CHAPTER ONE

INTRODUCTION

The study focuses on the attitudes and beliefs regarding perceived and actual burden experienced by Latino caregivers and their use of formal support services. The study also looks at the needs of Latino caregivers and explores their beliefs about why they take on the caregiver role, the responsibilities the role entails, and coping skills used by these caregivers. This chapter will discuss the problem statement, the purpose of the study and the significance of the project for social work.

Problem Statement

Many caregivers experience stress when they become fulltime caregivers of a sick family member (Burack-Weiss, 1995). Categories such as sex, age, ethnicity, illness, and relationships may all play a causal factor to the level of caregiver stress. Providing full-time caregiver to a loved one can become overwhelming when the caregiver does not have enough support or coping skills to deal with such work. Does social work intervention help this group alleviate stress

and burnout? There have been many studies of the relationship between care giving and stress, strain and burden (McCallion et al., 2004). This study will attempt to find out if there is less stress by those who access community resources, how familism affects their stress, and ways caregivers cope.

Persons caring for family members with cognitive or physical impairments are under a great amount of emotional, physical, and financial burden. Knight et al., stated that providing care for persons with dementia and other chronic diseases such as stroke, Alzheimer's Disease (AD) and Parkinson's Disease has been documented as a major stressor for over twenty years (2002). The problems associated with caregiving someone with AD, for example, can include higher rates of depression, illness, use of psychotropic medication, an increase of social isolation, a decrease in quality of life and problems sleeping (Aranda et al., 2003).

Over the last twenty years Alzheimer's disease and other dementias have gained public attention and are now recognized as a major public health problem affecting millions of Americans and their families. All members of society should be aware that the burden of taking care of

a family member affected by this or any other debilitating disease is a likely possibility. The social work field, the medical community, policy makers, and the government have all studied caregiver distress and burden.

The population with Alzheimer's disease and other dementias is growing and the need for caregivers' support will expand. Over the next thirty years the population of elderly, those who are at most risk of needing care giving assistance is estimated to reach 25% of the American population, increasing the need for research, policy, and advocacy to identify the special needs of both caregivers and receivers (Riggs, 2001). The need for specialized senior services and support will be determined by market factors and insurance policy, making it difficult for care recipients to have other options besides informal family or friend caregivers (Riggs, 2001).

Riggs found that Alzheimer's Disease (AD) costs the United States about \$70 billion each year. In addition, Medicare spends 70% more on people with dementia than other people on Medicare. Persons taking time off from work to take care of their elderly friend or relative

cost businesses in America \$3 billion each year (Riggs, 2001).

Aranda et al. report that as the population of elderly persons grow, between 2.4 and 3.1 million estimated spouses, partners, relatives, and friends at one point or another will be taking care of a person afflicted with AD or any other debilitating illness, and this number will likely to increase as the population of older persons grows (2003). Some research argues that informal or relative caregivers are the backbone of the service provided to surviving stroke patients, but of course this is not without consequences to the care provider (Bugge & Hagen, 1999). Time and time again studies show that caregivers complain of stress and burden due to the many complex problems with which this role comes.

Like other minorities Latinos typically take care of their elders at home, so it is especially important for social workers to understand their predicaments.

Theoretical literature suggests that Latinos may view institutionalization more negatively and may be less likely to terminate the caregiver role than other ethnic groups. Latinos seem to prefer familial support over

formal support (Mausbach et al., 2004). Latinos also perceive their role as caregivers differently than other groups as they are more willing to accept caregiving responsibilities regardless of their perceived burden level. Latina daughters, for example, delay institutionalization significantly longer than do Caucasian daughters and perhaps this is a way of protecting their aging parents (Mausbach et al., 2004). Levkoff et al., reported that Latino caregivers have both a language barrier to care and a lack of culturally competent services (1999).

The strong cultural value of family responsibility is a strength in Latinos, however care giving for a person with AD or another debilitating illness inflicts a high burden on these families. Studies have suggested that a high sense of filial responsibility for elders, and a high acceptance of cognitive impairment and dementia as a normal part of aging that is to be managed by the family, are contributors to the disproportionate share of family members in the Latino community providing care for their elderly relatives. Latinos are less likely to be living in long-term care facilities and less likely to use formal supportive services (Novak & Riggs, 2004).

Although this can be viewed as a positive in the Latino family, caregivers need support, information, and ways to help manage their stress and burden and resources to help them maintain their desired roles as caregivers. Latino caregivers need culturally competent services and information that reinforce family values and help to assure that the elderly care recipient gets the medical and social services he or she needs (Novak & Riggs, 2004).

Purpose of the Study

Research shows that the use of formal support services alleviates strain on caregivers. For example, one study showed that providing caregivers with training and support decreases their burden and improves psychosocial outcomes in both patients and caregivers (Patel et al., 2004). Other studies focused on increasing the use of formal services as a means to decrease burden (Mc Callion et al., 2004).

Since most studies on both caregiver stress and burn out and utilization of services have been conducted with Caucasian participants it is important to also gain knowledge of these problems in the Latino community to

see how they are different and in what way research can help Latino caregivers.

Significance of the Project for Social Work

Social work is committed, among other important issues, to enhancing the well-being of people and to cultural competence. The National Association of Social Work's (NASW) preamble states the following: "The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty. An historic and defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living" (NASW, n.d.). Because of what is known about the marginalization of Latinos and what the literature review suggests about the dilemmas Hispanic families face when having to take on the responsibility of caring for an elderly relative the role of social work is crucial in helping empower this group.

Another key role for the social work profession in looking at this problem is the concept of cultural competence. The NASW code of ethics has three dimensions that are supported by this study. The following is from NASW's Code of Ethic's section on competence: "(1) Social workers should understand culture and its function in human behavior and society, recognizing the strengths that exist in all cultures. (2) Social workers should have a knowledge base of their clients' cultures and be able to demonstrate competence in the provision of services that are sensitive to clients' cultures and to differences among people and cultural groups. (3) Social workers should obtain education about and seek to understand the nature of social diversity and oppression with respect to race, ethnicity, national origin, color, sex, sexual orientation, age, marital status, political belief, religion, and mental or physical disability" (NASW, n.d.). Social workers helping Hispanic caregivers should note the importance of these responsibilities. This study aims to facilitate the methods of the generalist social work model in the engagement, assessment, planning, intervention, and termination stages of the practice process. Misunderstandings, bias,

and ignorance of the Latino caregiver's culture and perceived role may negatively impact the outcomes for both the practitioner and the client. Gaining knowledge and an awareness of Latino caregivers beliefs and experiences in regards to caregiver burden and stress as well as cultural beliefs, family values and attitudes toward both the elderly and formal service usage from this study can help with all phases of the generalist model. Emphasis on social justice, cultural competence, and practice with members of oppressed groups are concepts that are addressed for the generalist practitioner. Gerontological social work, family practice, group practice, medical social work, community organizations, caregiver resources centers, adult day health care centers, and policy workers should all benefit from the information obtained from this study.

CHAPTER TWO
LITERATURE REVIEW

Introduction

This section of the paper will consist of relevant literature that supports the purpose of the study. A substantial amount of research has been completed regarding caregiver burden. The research has been divided into the following subsections: Family Caregiving, Female and Male Caregivers, Latino Caregivers, and Theories Guiding Conceptualization.

Family Caregiving

The burden of care giving is well documented. While care giving is taxing and often difficult for both formal and informal caregivers, some individuals in both groups manage to handle the chronic stress better than others. Why are some caregivers experiencing burnout, while others appear to take the difficulties in stride?

It is important to note that most care giving is provided by family members and not formal support services. Family members provide care in their home for approximately 75% of all Alzheimer's disease patients in the US (Donaldson & Burns, 1999; Atienza et al., 2001).

Yoon (2003) found that functional impairment had both indirect and direct effects on relative caregiver's depression, and direct effects on impact of schedule, impact on health and sense of entrapment. Duration of care had an impact on finances, feelings of abandonment and impact on health through emotional support. Yoon also found that caregivers who experienced greater impact on finances and impact on health were at higher risks of depression as well.

Relative caregivers face many complex problems which can include negative emotional responses to providing care, reactions to the care recipient's behavior and being generally overwhelmed by the never-ending tasks involved in providing care for their loved ones. These problems can be physically straining such as those involved with physically laborious tasks like moving or carrying a loved one (Gallagher-Thompson et al., 2000; Wackerbarth, 1999), while others can be emotionally straining such as deciding when a relative needs out of home placement and giving up the care giving role (Penrod & Dellasega, 1989; Wackerbarth, 1999). Albinson & Strang found that relative caregivers spent more time doing care giving tasks, were more physically and psychologically

burdened and were more often forced to devote less time to other tasks, compared to non-relative caregivers (Albinson & Strang, 2003).

Family relationships and roles should also be examined. At least one study shows that siblings use collaboration to take care of their elderly parents. Findings discuss that siblings distributed caregiving responsibilities by taking turns and dividing the load amongst themselves according to their expertise or caregiver tasks (Ingersoll-Dayton et al., 2003). It is also reported that elders are most likely to be cared for by their adult children, followed by their spouses (e.g., Cohen-Mansfield et al., 1994).

Because Latinos delay institutionalization and are less likely to seek formal support earlier on in the care of their ill relative the literature seems to point out that they may be at greater risk for many negative outcomes related to caregiver burden.

Female and Male Caregivers

Gender appears to be an important factor when studying caregiver stress. According to Donaldson and Burns, the relationship of gender and kinship deserve

more research attention even though a substantial number of studies have examined the extent to which the cognitive and non-cognitive problems of the impaired patient influence the amount of burden of experienced by family caregivers (1999). According to the Family Caregiver Alliance National Center on Caregiving (2003) estimates of the percentage of family or informal caregivers who are women range from 59% to 75%. They also go on to mention that the average caregiver's age is 46, married and working outside the home earning an income of \$35,000 per year. Their research provides that although men are also care providers women spend as much as 50% more time than men providing care for the recipient.

In the Hispanic family the responsibility of care giving usually falls on the matriarch of the family or on the female children of the care recipients. Latino cultural values and positive views of the caregiving role are important factors for the Latino caregiver. The likelihood of Latinos to delay institutionalization places them at a higher risk for experiencing more stress and burden (Mausbach et al., 2004).

According to the Alzheimer's Association, Latino families, particularly daughters, provide a

disproportionate share of Alzheimer care, for both longer periods of time and at higher rates of impairment. They also state that previous research has indicated that Latina caregivers participate and benefit the most from services designed to meet their very specific needs (Novak & Riggs, 2004). The following paragraphs report more on gender differences in care giving.

Atienza et al. (2001) found that female dementia caregivers had increased blood pressure reactivity to care giving strain than their male counterparts. Simply being a female caregiver was found to be a significant risk factor for psychological morbidity by Donaldson et al. (1998.) Similarly, Bedard et al., found that female family caregivers usually experience more burden than male relative caregivers.

About 30 percent of in-home caregivers are men, mostly being elderly spousal caregivers (Kaye & Applegate, 1990; Kramer, 2002; Olson, 1994). It seems that studies on male caregivers, however, are lacking. Kramer explains that "their experiences continue to be neglected and marginalized" (Kramer, 2002). In addition, many researchers found that the male caregivers' experiences were only used as a "contrast in comparison

to women caregivers" (DeVries, Hamilton, Lovett, & Gallagher-Thompson, 1997; Horowitz, 1985; Miller, 1987; Zarit, Todd, & Zarit, 1986). Carpenter and Miller (2002) found less than 20 small studies on men caregivers between 1988 and 1999, irregardless of increase of male caregiving.

Gender may also be indicative of whether a caregiver seeks outside support. Russell found that the likelihood of men caregivers seeking outside social support has been investigated in a few studies, but the results are sometimes conflicted (2004). Some studies (Stone et al., 1987; Kosloski, Montgomery, & Kramer, 1999) found that husbands are more likely to seek respite and receive outside support than wives, yet other studies (Miller, 1990; Montenko, 1998; Vinick, 1984) found husbands less likely to seek assistance. Coe and Neufeld (1999) argue that husbands sought outside support only when all else failed, and explained that men saw outside support as dishonorable, shameful and an invasion of their family's privacy.

Some men feel that their work is unappreciated in the absence of support systems (Archer & MacLean, 1993), and Parson concludes that this sometimes results in

increased family conflict (Parson, 1997). The impact on men's psychological health has been found to be both negative and positive when social support networks are formed (Carpenter & Miller, 2002). Braithwaite (1996) found that according to some studies, men were able to protect themselves successfully from caregiver depression, stress and burnout. Harris (1995) and Harris and Long (1999) found that male caregivers were more willing to explore the possibility of using social supports as care tasks grew and that many men reported decreasing levels of stress and burden when supports were made accessible.

It has also been reported that caregivers who are female fair poorly and are more susceptible to strain compared to males (e.g., Horowitz, 1985; Kosberg et al., 1990; Stoller, 1983). Some studies argue that this may be because female caregivers spend a significant amount more time caring for older relatives and are responsible for a many more care giving tasks than male caregivers (Dwyer & Coward, 1991; Neal, Ingersoll-Dayton, & Starrels, 1997). In addition, Doty, Jackson, and Crown (1998) argue that women are more likely to assume to a caregiver role when they are employed. Many women caregivers must devote time

to their own children, grandchildren and their elderly parents.

Because the likelihood that the caregivers in this study will be female, focusing on gender differences and gathering information from both genders is important to the study.

Latino Caregivers

This study attempted to determine if in fact there are differences in the way Latino caregivers perceive their stress and how and why they use formal supports. Some studies suggest that there are ethnic differences.

It is understood that Latino caregivers are less likely to seek out formal support. For example, the Alzheimer's Association concluded in their paper, "Hispanic/Latinos and Alzheimer's Disease" (2004) that there is a substantial body of evidence that Latino's with dementia are low users of formal services and that they are less likely than non-Hispanic groups to see a physician and much less likely to use services by other health professionals. The paper also talks about the barriers that Hispanics may have when it comes to treating or getting diagnosed with AD or other related

dementias. Firstly, the Latino elder population is far more likely to have limited English skills, making it difficult to access healthcare. Secondly, cultural bias in cognitive testing and inadequate translation of diagnostic tools along with a lack of culturally competent, bilingual healthcare professionals may skew diagnosis and treatment. Finally older Hispanics have less health insurance than non-Hispanics. The dilemmas that face the elderly Hispanic fall on their families who are the primary caregivers. Does this population experience the burden of care giving in the same way as other examined groups? Does the use of formal support services such as support groups and social work intervention help this group alleviate stress and burnout?

A study presented at the Ninth International Conference on Alzheimer 's Disease and Related Disorder's (ADRA) explained that AD symptoms, on average begin almost seven years earlier in Latinos than in other non-Hispanic whites. The researchers attributed high rates of vascular disease, low schooling, and less likelihood of using medical services or having medical insurance than other Americans to the acceleration or

increase of the risks of AD (Alzheimer's Association, 2004).

According to the Alzheimer's Association (AA), Latinos face a high risk of Alzheimer's disease (AD) and other dementias. The AA's findings suggest that Hispanics may have a greater risk of developing dementia than any other ethnic or racial groups. The greatest risk factor of AD is age. The Hispanic's life expectancy is expected to increase to age 87 by 2050 surpassing all ethnic groups in the U.S. By this time the Hispanic population is expected to make up sixteen percent of the total elderly population from five percent presently (Novak & Riggs, 2004).

Another factor that puts elderly Latinos at risk for AD, according to the AA, is lower education. Latinos have the lowest education level of any group in the U.S. Finally, the AA's research discusses how vascular disease, including diabetes may also put elderly Latinos at higher risk for AD and other dementias (Novak & Riggs, 2004).

Other researchers have studied varying ethnic group to find differences in caregivers' needs and service use.

Chow et al. found that in Asian communities, Asians under-enrolled by fifty percent compared to Caucasian in the utilization of Alzheimer's disease clinics. However this did not stand true at one clinic where all the staff was bilingual. This study suggests that Asians may not utilize services as much as Caucasians due to language. This study also found that referrals for financial help were given significantly more to Asians than to Caucasians, which again suggests that Asians underutilize services because of a language barrier and perhaps due to ignorance of services in the community (Chow et al., 2000).

One study focused their attention on familism values in studying caregivers and seeing if cultural values versus western individualism helped caregivers reduce burden and distress. This study put attention on cultural values in finding how this would influence the stress and coping process of people caring for elders with dementia. The articles examined Latinos, Korean and Korean-Americans, Japanese-Americans, and African-Americans. For Latino caregivers, familism was significantly associated with lower Anglo and higher Latino cultural identifications, lesser burden, but not

depressive symptoms. Latinos are the only group in the study that had high familism with low burden. For Korean and Korean-American caregivers this study discovered that they reported a higher level of anxiety, depression, and burden than Anglo caregivers even though they were much higher in familism than White American caregivers. This may be due to very low emotional and instrumental supports. They reported that because in the Korean culture it is the eldest son's wife that is responsible for care giving perhaps it is done out of obligation and not affection, leading to high results in anxiety and depression. Japanese and African-American caregivers reported a relatively low level of depression and anxiety. Japanese-Americans were also the most acculturated of the groups. In studying Japanese Americans it was surprisingly found that Asian cultural values were highly associated with familism and caregiver burden, especially with patient's dependency. It was found that familism and values in this sample were associated with higher depression scores. African-American caregivers scored relatively low on reporting feeling depressed or anxious and the study supports other research that suggests that

African-American caregivers score relatively low on caregiver burden (Knight et al., 2002).

Since the literature suggests that Latino caregivers do have significant ethnic difference that may directly impact their role, burden and use of formal support services to help them with the task of caring for an elderly or sick relative looking at ethnic differences is important to this study.

Theories Guiding This Study

For this study three theories will be employed to examine the phenomenon of caregiver burden in Latinos. Role theory contends that although people learn by their own trial and error they also perform much learning by watching other people. It is, after all, safer to let others make the mistakes. When the behavior makes sense, we go through it in our minds then try it for ourselves. When we succeed, we become more confident (self-efficacy). As we interact with our environment, it becomes a two-way process: as we change it, it changes us (reciprocal determinism). When one takes on the role of caretaker and does not quite fit or has difficulties distress may occur following levels of anxiety, stress,

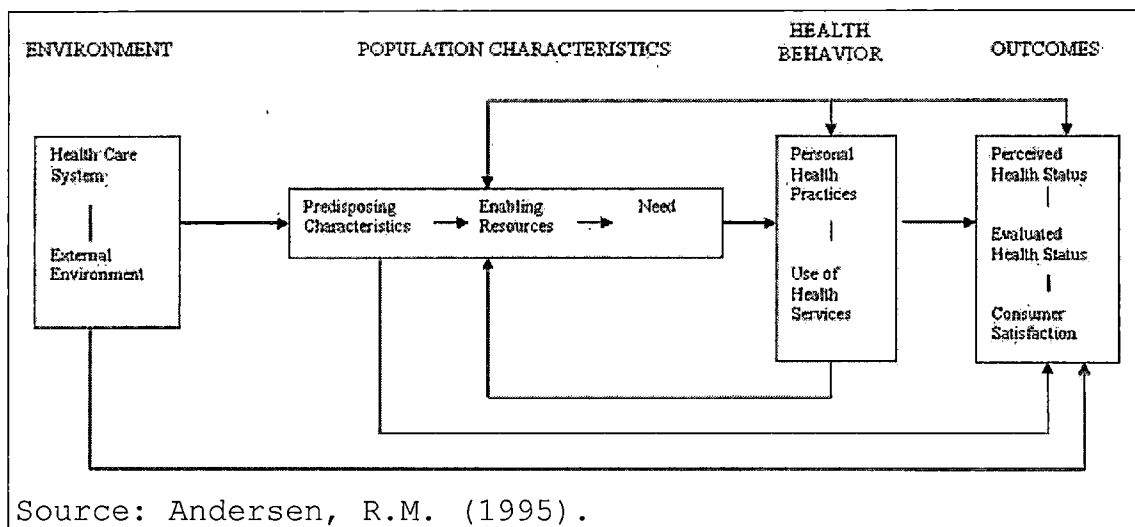
and dissatisfaction. In the case of children taking care of parents the role may be especially burdensome as they are not accustomed to taking care of their parents whose role was to take care of them. Since Latino's report such a high satisfaction with their caregiver role it is important to look at this theory for guidance.

Aranda's and Knight's socio-cultural stress and coping model argues that ethnicity implies specific cultural differences that will directly affect the appraisal of care giving as stressful, and that will change mediating variables such as ability to cope. For example, ethnicity could be described as a positive to depict low burden or ethnicity could be described as a negative to explain constant worry (Knight et al., 2002). Since the literature has described ethnic and cultural differences in burden as well as in care giving satisfaction this theory is also an important one for this study.

Anderson's framework of health service utilization is used to understand people's health seeking behavior. The rationale of this framework is to determine circumstances that either ease or hinder utilization. The objective being, to develop a behavioral model that

provides measures of access to medical care. An individual's access to, and use of, health services is considered to be a function of three characteristics: Predisposing Factors, Enabling Factors, and Need Factors. Predisposing factors are the socio-cultural characteristics of individuals that exist prior to their illness. These include: social structure; such as education, occupation and ethnicity; health beliefs such as attitudes, values, and individual knowledge about and towards the health care system; and demographics, which include variables such as age and gender. Enabling factors are the logistical aspects of obtaining care. These include: personal and family characteristics; such as the ability and knowledge of accessing health services, income, insurance coverage, genetic and psychological characteristics, and quality of social relationships and community factors which include available health personnel, facilities and wait times. The third characteristic is the needs factor and it is considered to be the most immediate cause of health service use, from functional and health problems that generate the need for health care services. Need factors are divided into two classifications, perceived need and

evaluated need. Perceived need is how people view their own general health and functional condition regarding health, pain and worries, etc. Evaluated need represents a "professional" judgment about a person's health and need for medical care. "Perceived need will better help to understand care-seeking and adherence to a medical regimen, while evaluated need will be more closely related to the kind and amount of treatment that will be provided after a patient has presented to a medical care provider" (Andersen, 1995). Figure 1 illustrates this model. This framework is important because Latino's help seeking behavior may be influenced by all the factors in this model.



Source: Andersen, R.M. (1995).

Figure 1. Anderson's Framework of Health Service

Utilization

Summary

The literature important to the project was presented in Chapter Two. The literature review went over the strain and burdens that family caregivers have in their lives. It also examined difference between male and female caregivers and specific ethnic differences that will be pertinent to the study of Latino caregivers and their perceived and real burden. Finally, the literature review described the kinds of theories that are relevant to the issue of caregiver burden, specifically, role theory, Aranda's and Knight's socio-cultural stress and coping model and Anderson's framework of health service utilization.

CHAPTER THREE

METHODS

Study Design

The purpose of this study was to build on previous descriptive research on caregiver burden, familism, and utilization of services in the Hispanic family. The author used a mixed approach, with both interviews and quantitative questionnaires. The goal of this project was to identify the services that Latino caregivers have used the level of stress and burden they have, the coping mechanisms they use, their levels of familism, the types and kind of care they provide for their loved ones and the extent to which their role as caregivers affects their lives. The purpose of utilizing both a qualitative and quantitative approach was to be able to obtain caregivers' opinions and feelings that otherwise might not have been attained. Since care giving is a very personal and familial experience gathering qualitative data was essential to be able to more fully understand the Latino family caregiving experience.

Sampling

The data were obtained from a sample of caregivers who were caring for their cognitively, physically, or mentally ill relatives. The participants were obtained from two Alzheimer's caregiver support groups in the East Los Angeles area, and adult day health care center in the high desert area of San Bernardino. The participants were all related through blood or marriage and were all of Hispanic heritage. Some participants were monolingual, either in Spanish or English and some were fluent in both English and Spanish.

This sample was chosen to expand on previous research that did not explore fully reasons why Latino caregivers under utilize formal services, and to understand what resources they currently do use. Furthermore, this sample was chosen to yield data from the viewpoints of Latino caregivers to further the knowledge of the care giving experience in the areas of levels of stress and burden, familism, and how caretaking affects their health, mental, social, financial, and family areas. Finally the sample was chosen to find out what the caregiver role entails and how caregivers cope with the demands of this role.

Data Collection and Instruments

Data on caregivers were obtained using a mixed design of closed and open-ended questions. Closed ended questions were based largely on the "Caring for Persons with Alzheimer's 2004 National Study" (Alzheimer's Association & National Alliance for Caregiving, 2004). The interview /questionnaire also included the Caregiver Strain Index (Robinson, 1983) and the Heller Familism scale (Heller, 1976). The researcher allowed the interview participants to expand upon any question in the survey. The interview asked for information including, sex, ethnicity, marital status, work status, income, level of education, and religious preference. The interview also asked for information about the care recipient including age, relationship to caregiver, medical conditions, where the care recipient lives, whether they are sick, disabled, or elderly and the biggest problem the caregiver believes the care recipient has. The interview included questions on burden by asking about the number of hours caretakers spent helping their relatives, the number activities of daily living, and instrumental activities of daily living they helped with

and the length of time the caregivers had provided care to their loved ones.

The caregiver strain index (CSI) is an instrument designed to measure objective caregiver burden, and has been used as a predictor of psychological distress and health of caregivers (Robinson, 1983). It has thirteen questions which measure the five major domains that can be affected by caregiver burden. These items cover employment, financial, physical, social, and time. The instrument is dichotomous and the participants answer simply yes or no to each item. The instrument includes at least one question for each of the five domains. The overall score is achieved by summing up the number of "yes" answers. A score of seven yes answers or higher is indicative of a high level of stress, although any yes answer could be a sign of required intervention in that section. The internal consistency of this index was measured by Cronbach's Alpha. The alpha level was high at .86, representative of good internal consistency. Since the questions are designed for and about caregiving the reliability of the constructs measured by the CSI are excellent to measure subjective caregiver strain. The

items are short and easy to answer for example, "It is a financial strain" (Robinson, 1983) (See Table 9).

Coping strategies were explored by providing a list of common coping strategies and also asking caregivers to tell about other coping strategies they have used in their roles as caregivers. Caregivers were asked whether or not they used the coping skills listed.

Perceived emotional stress and physical strain of caregiving was measured by asking scaling questions, where one was none at all and five was high. Objective emotional stress and physical strain were measure by asking about coping strategies, use of formal supports and perceived impacts on health of the caregiver.

Although the researcher allowed the interview participants to expand on the closed ended questions at anytime, several open-ended qualitative questions were included in the interview to further explore meaning and reasons that the caregiver took on the role of caring for their loved ones and also as discussed later in this section, to obtain information on familism. The questions were meant to provide further insight into the experiences and lives of Latino caregivers to gather information on attitudes and beliefs about caregiving,

coping, perceived positives about caregiving and advice caregivers would give to other family caregivers. These questions were, "Please tell me any other coping strategies you have used in your role as caregiver," "Briefly explain why you are the caregiver and not someone else," "When you do have free time how do you spend it," "If you were to become disabled who would most likely take care of you?" "Please mention any things you like or enjoy about being the caregiver" and "If you could give potential caregivers some kind of advice what would it be?"

Familism was examined in two ways. First, by using the 13 items from the Heller Familism scale (see Table 8) developed in 1975. These items included questions such as "a married person should be willing to share his home with brothers and sisters of their husband or wife," and "married children should live close to their parents so they can help each other" (Heller, 1976). The items were dichotomous, with either an "agree" or "disagree" response. "Agree" responses were summed to reveal level of familism. Higher scores indicated higher levels of familism. Familism was also examined by seeking familial themes in the responses to several open ended questions

such as "Please mention any things you enjoy or like about being the caregiver." and "Briefly explain as best you can why you are the caregiver and not another relative?"

The interviews were conducted in either English or Spanish and the questions were read to participants by the researcher. The questionnaire was self administered in the language of the participant's choice.

The strengths of the instrument are that it addresses caregiver issues in several domains, including service use, coping mechanisms, demographics, both subjective and objective stress and strain and allowed for qualitative responses to further expand on information from caregivers.

The limitations on the instrument were that it was developed by using English version adaptations that were not originally made for a Latino population. This could result in semantic, content, or technical problems. The researcher translated the interview questions and read them to participants in either English or Spanish, offering any clarification as needed. This avoided potential problems with reading the questions. Participants were instructed to stop the interview if

they needed clarification and the researcher would further explain the questions so that the participant would get the clarification and be able to answer the questions.

Procedures

The data were gathered by soliciting participation at the adult day health care center when caregivers came to the center for information or services for their loved ones. Similarly, participation was solicited before the start of the two- caregiver support groups. Caregivers were given the option of filling out the questionnaire on their own time and returning it to the author or participating in a more in-depth interview which was recorded if the caregiver allowed. Interviews were held at the caregivers' home, the adult day health care, or via telephone. Interviews were set up at the convenience of the caregiver. The data were collected by the author.

Protection of Human Subjects

Each participant was provided an informed consent (see Appendix B), explained in detail, before the interviews were conducted. The names of the participants were not reported or disclosed at any time. All notes and

taped recording were locked in a file and destroyed upon completion of the project. After completing the survey/interview, caregivers were provided with a debriefing statement which further explained the purpose of the study (see Appendix C).

Data Analysis

Statistics for this study were generated by using SPSS Graduate Pack 13 for Windows.

Interviews were recorded than transcribed verbatim. Spanish data was translated into English and back translated into Spanish. Quantitative answer to open-ended questions were listed and catalogued, to identify themes and constructs related to caregiver burden, familism and unmet needs.

Bivariate correlations were tested between services used, unmet needs, caregiver strain, and familism to ascertain whether or not associations among these variables existed. Interpretive associations, i.e., lesser services use having a positive association with more unmet needs, were analyzed. CSI scores, Familism scale score, number of unmet needs and number of services

used were transformed into single variables and bivariate analysis was done to find if correlations existed.

Summary

The previous paragraphs outlined the descriptions of the sample, how data was collected, the procedures involved in gathering the data, and analyzing it, and how the author protected the subjects that participated.

CHAPTER FOUR

RESULTS

Introduction

This chapter reveals the results obtained from the questionnaires/ interviews. The first section will describe caregivers, their responsibilities, their levels of stress, where they obtain assistance and their unmet needs. The next section will focus on describing the characteristics of the care receivers. Types of diseases, age, and assistance they need will be included. The final section will discuss the caregivers' levels of familism, caregiver strain index results, and other levels of burden.

Presentation of the Findings

The sample was made up of twenty-five Latinos caring for their cognitively, mentally, or physically ill family member. Most of the caregivers were female (92%), married (60%) and described themselves as homemakers (40%). The educational status varied with 32% having less than high school, 28 % having completed high school and 32% having had some college but no degree. 66.7 % of the caregivers had an income of less than \$30,000 last year. Most

caregivers were Catholic (68%). 52% of the caregivers had been caretaking their loved ones for one to four years and 40% had been caretaking for five years or more.. Caregivers described their health as poor 44% of the time. 72 % of the caregivers were 50 years or older. The mean caregiver age was 55.52 years old with the youngest caregiver being 34 and the oldest being 85. See Table One for more detailed findings on the characteristics of the sample.

Table 1. Latino Family Caregiver Characteristics

Variable	Frequency	Percent
N = 25		
Gender		
Female	23	92
Male	2	8
Marital status		
Married	15	60
Single	2	8
Divorced	3	12
Widowed	4	16
Employment status		
Fulltime	7	28
Part time	2	8
Retired	6	24
Homemaker	10	40

Variable	Frequency	Percent
N = 25		
Education		
< High school	8	32
High school	7	28
Some college	8	32
Bachelor degree	1	4
Master degree	1	4
Religion		
Catholic	17	68
Christian	7	28
Jehovah 's Witness	1	4
Health status		
Excellent	1	4
Very good	6	24
Fair	7	28
Poor	11	44
How long caregiving		
5 or more years	10	40
1-4 years	13	52
Less than 1 year	2	8
Income last year		
Missing/declined	1	4
Less than 30k	16	66.7 valid percent
30k-49k	5	20.8
50-99k	2	8.3
Over 100k		

Most of the caregivers were taking care of their mothers (32%) or spouses (28%) (see Table 2).

Table 2. What Relationship is the Person You Care for to You?

Relationship N = 25	Frequency	Percent
Mother	8	32
Father	3	12
Spouse	7	28
Grandparent	1	4
Grandparent of Spouse	2	8
Sibling	3	12
Child	1	4

The care recipients had many needs and caregivers in this sample provided help in many areas. Caregivers helped with a number of activities of daily living (ADLs) and instrumental activities of daily living (IADLS). The most common ADLs were: "helping with dressing" (88%) and helping bathe or shower (80%) (see Table 3). Table 4 shows that the most common IADLS caregivers helped with were; "helping with medications," "preparing meals," and "housework."

Table 3. Activities of Daily Living

The following is a list of kinds of help, which might be provided to a person, if the person cannot do it themselves. For each, please indicate if you provided this kind of help.		
<i>Variable Answered Yes</i>	<i>Frequency</i>	<i>Percent</i>
Getting in and out of beds and chairs	17	68
Getting dressed	22	88
Helping bathe or shower	20	80
Getting to and from the toilet	13	53
Dealing with incontinence or diapers	19	76
Feeding care recipient	13	76
Reminding the person to eat, shower, etc.	9	36

Table 4. Instrumental Activities of Daily Living

Do/did you help the care recipient with:			
<i>Answered Yes N = 25 Missing = 1</i>	<i>Frequency</i>	<i>Percent</i>	<i>Valid percent</i>
Transportation	20	80	83.3
Grocery shopping	20	80	83.3
Housework	22	88	91.7
Managing finances	21	84	87.5
Preparing meals	22	88	91.7
Helping with medications	22	88	91.7
Managing services	20	80	83.3

The average age of the care recipients was 76.24 years old. The oldest was 95 and the youngest was 36. Care recipients lived with their caregivers (88%) or within twenty minutes from the caregiver's home (12%). Caregivers described their loved ones as sick (68%), frail (64%) or disabled (68%). Only one caregiver stated that these did not describe the care receiver. 96% of the care receivers took medicines prescribed by a physician and 84% needed assistance by the caregiver to take them. Caregivers stated that they provided care for these individuals twenty-one or more hours per week (96%). The care recipients main medical conditions were Alzheimer's disease (n = 20), mental illness (n = 3), Parkinson's Disease (n = 1) and epilepsy (n = 1). The most common co-morbid conditions were diabetes (n = 10) and stroke (n = 6) .52% of the care recipients had three or more co-morbid conditions.

Caregivers coped with their stress in varying ways. Praying was the most common form of coping (100%). When asked what ways caregivers coped qualitative answers included, "taking time out, going outside just for five minutes to breathe fresh air," "asking my daughters for help," "asking my neighbors to help me," "sharing at

support groups," " going on 48 hour caregiver retreats," "dedicating myself to church," "reminding myself that this is my obligation and duty and I am not going to give up," "talking about my problems with other caregivers," "walking away and ignoring the behaviors," and "talking to social workers." Table 5 shows quantitative results of caregivers coping skills.

Table 5. Ways Caregivers Cope

<i>Variable N = 25</i>	<i>Frequency</i>	<i>Percent</i>
Praying	25	100
Talking with or seeking advice from friends or relatives	16	64
Reading about caregiving	15	60
Exercising or working out	5	20
Going on the internet to find information	5	20
Talking to a professional or spiritual counselor	11	44
Taking medication	3	12
Attended a caregiver support group	12	48

Caregivers reported that they would go to Social Workers (76%) most often if they had questions regarding some aspect of caregiving. Table 6 shows results.

Table 6. Information about Some Aspect of Helping

If you were looking for information about some aspect of helping take care of your (care recipient), where would you turn?		
<i>Variable</i> <i>N = 25</i>	<i>Frequency</i>	<i>Percent</i>
Internet	3	12
Doctor	12	48
other health professionals	12	48
Social Worker	19	76
family or friend	10	40
books, magazines ,library	5	20
senior center	6	24
Government agency	8	32
Aging association/groups/organizations	14	32

Caregivers reported low use of formal support services. During one interview, a woman stated that she finally received respite care when her husband was referred to hospice services. Her frustration was both sad and indicative of Latino caregivers' experiences with formal supportive services. "The only one on the hospice team that spoke Spanish was the social worker but I rarely saw her. I used to be able to get away from home when the aide came over to help my husband, but I never felt comfortable leaving him with someone that didn't speak Spanish. I never understood why they brought my

husband home from the hospital when he was so sick and ready to pass away." This caregiver, who had taken care of her husband through his battle with cancer and Alzheimer's disease never got an explanation of what hospice was. The most common formal support service used was enrolling the care recipient in adult day health care (52%). Table 7 shows other support services used or requested.

Table 7. In Your Experience as a Caregiver, Have You Ever...

<i>Variable N = 25 Answered Yes</i>	<i>Frequency</i>	<i>Percent</i>
Requested info about financial help	12	48
Obtained formal training	12	48
Used transportation services	7	28
Used services such as meals on wheels	4	16
Enrolled recipient in recreation camp	1	4
Enrolled participant in Adult Day health care	13	52
Used respite service	2	8
Attended a caregiver support group	12	48

Caregivers reported a number of unmet needs. Of the thirteen items listed on the questionnaire, the three most common unmet needs were "managing my emotional and

physical stress" (68%), "balancing my work and family responsibilities (52%), and "moving or lifting the person I care for" (52%) (see Table 8).

Table 8. Unmet Needs

As a caregiver on which of the following do you need more help or information:		
<i>Variable Answered Yes</i>	<i>Frequency</i>	<i>Percent</i>
Finding time for myself	8	32
Keeping the person safe at home	8	32
Balancing my work and family responsibilities	13	52
Managing my emotional and physical stress	17	68
Easy activities I can do with the person I care for	10	40
How to talk with doctors	6	24
Making end of life decisions	11	44
Moving or lifting the person I care for	13	52
Managing challenging behaviors such as wandering	10	40
Choosing or finding a home health agency	3	12
Choosing an assisted living facility	4	16
Managing incontinence or toileting problems	6	24
Choosing a nursing home	4	16
Finding non-English educational materials	7	28

As expected, the sample reported high levels of familism. When the familism scale items were transformed into one variable the mean for the scale was 6.96 with a standard deviation of 2.76104. The maximum was 13. A revealing aspect of the caregivers surveyed was that 96% of the caregivers believed that, "Family members should be able to turn to other family members, before anyone else, for support, when met with a financial, emotional, or medical crisis". 68% of the sample believed "Married children should live close to their parents so they can help each other," and 64% believed "It is the responsibility of married children to be with their parents in time of of serious illness even if the children have moved some distance away from the parents." Table 9 shows more details on the results of the Heller Familism Scale.

Table 9. Heller Familism Scale

<i>Answered Agree N = 25</i>	<i>Frequency</i>	<i>Percent</i>
A Married person should be willing to share his home with brothers and sisters of his husband or wife	14	56
Married children should live close to their parents so they can help each other	17	32
If a person of the family is insulted or injured you should feel more strongly about it than if the person were not a member of the family	11	44
It is the responsibility of married children to be with their parents in time of serious illness even if the children have moved some distance away from the parents	16	64
Children owe to their parents to put their own family interests above their own personal interests.	10	56
If a family group has strong political and moral views a member should not be influenced by outsiders to change these views.	9	36
As many activities as possible should be shared by married children and their parents.	10	40
Marriage should be viewed as keeping families going rather than starting a new family.	10	40
Children of elderly parents have as much responsibility for the welfare of their parents as they do for their own children.	14	56
Whenever possible a person should talk about important life decisions with family members before taking action.	16	64
When choosing a life partner it is important that a person choose someone whose moral or political views align with the family's.	8	32
If a person's father has a medical bill of \$1500 which he cannot afford to pay, the son or daughter is morally obligated to pay debt?	15	60
Family members should be able to turn to other family members, before anyone else, for support, when met with a financial, emotional, or medical crisis.	24	96
Mean Heller Familism Scale: 6.9600 Standard Dev: 2.76104		

Caregivers revealed to be under a great amount of strain which affected different areas of their lives. A score of 7 or more on the caregiver strain index (CSI) indicates a high level of stress (Robinson, 1983). The sample scored a mean of 8.72 with a standard deviation of 3.61156, indicating a high level of stress (See Table 10). The two most common difficulties reported from the CSI were: "having other demands on there time," (84%) and reporting that their "sleep was disturbed" (80%) (see Table 10).

Table 10. Caregiver Strain Index

<i>Variable Answered Yes</i>	Frequency	Percent
Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around all night)	20	80
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)	13	52
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)	18	72
It is confining (e.g., helping restricts free time or cannot go visiting)	18	72
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)	17	68
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)	17	68
There have been other demands on my time (e.g., from other family members)	21	84
There have been emotional adjustments (e.g., because of severe arguments)	18	72

<i>Variable Answered Yes</i>	Frequency	Percent
Some behavior is upsetting (e.g., because of incontinence; has trouble remembering things; or accuses people of stealing things)	16	64
It is upsetting to find__ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)	15	60
There have been work adjustments (e.g., because of having to take time off)	.15	60
It is a financial strain	16	64
Feeling completely overwhelmed (e.g., because of worry about ; concerns about how you will manage)	15	64
Mean CSI = 8.72 Standard Dev = 3.61156		

Bivariate correlations were conducted on three variables to see if positive or negative correlations were presented. Familism, Unmet Needs, and Caregiver Strain Index results were correlated. A positive correlation existed between familism and caregiver strain (.609 significance). This result showed that the higher the amount of familism the high amount of caregiver stress and strain. This is somewhat surprising since Familism is usually associated as a positive aspect of family life. These results are unlike Knight et al.'s report that familism was significantly associated with lesser burden but not lesser depressive symptoms (2002). Perhaps higher levels of familism place extra weight on the caregiver making them feel more responsible for their

loved ones well being and less likely to go outside of the family for help. Caregiver strain index results were also positively associated with unmet needs (.402 significance). This result is easily understandable since the caregivers who have more unmet needs would be more likely to feel more strain (see Table 11 & 12).

Table 11. Frequencies

	Familism	Unmet Needs	CSI
N			
Valid	25	25	25
Missing	0	0	0
Mean	6.9600	5.4800	8.7200
Std. Deviation	2.76104	3.28024	3.61156
Range	11.00	13.00	13.00
Minimum	2.00	1.00	.00
Maximum	13.00	14.00	13.00

Table 12. Bivariate Correlations

		CSI	Familism	Unmet needs
CSI	Pearson	1	.609 (**)	.402 (*)
	Correlation		.001	.046
	Sig. (2-tailed)	25	25	25
Familism	Pearson	.609 (**)	1	.389
	Correlation	.001		.055
	Sig. (2-tailed)	25	25	25
Unmet needs	Pearson	.402 (*)	.389	1
	Correlation	.046	.055	
	Sig. (2-tailed)	25	25	25

So why do caregivers continue their roles regardless of such high levels of stress and strain? Some caregivers felt trapped, i.e. "there's no one else that can take her...my sisters... They.. no. they just um..It is much too much for them, no room or whatever and they work." And "I am the only one who can take care of her, my mother is constantly in pain so she can't help" and "Nobody else will help me even though he has four other daughters." Others simply stated that they were the care providers because they were the wife, the son or the daughter. More optimistic views on taking on the caregiver role included: "She is my sister and I love her, I will always taker care of her," "My mother was the sweetest and most caring person you could ever meet, she

always took care of people, she helped me with my kids and she always took people into her home. She taught me so much and now that she is elderly and sick I am not just going to throw her away," and finally a wife taking care of her husband stated, "My husband was so good to me, he was always there for us and he always sang to me, these beautiful love songs, I will always take care of him, no matter how bad he gets."

Summary

The preceding paragraphs offered a view of the caregiving experience from the Latino family caregiver's perspective. The responsibilities and barriers are many. High beliefs about responsibility to the family and low levels of services use may contribute to the stress and strain that these caregivers feel.

CHAPTER FIVE

DISCUSSION

Introduction

The following paragraphs offer discussion on the results of the study, limitations and recommendations for social work practice, policy and research

Discussion

As the results showed, caregivers expend a great deal of time, energy and personal sacrifice providing numerous hours of care to their loved ones. Even though, high levels of stress and burden were reported it is highly unlikely that these caregivers would consider placing their loved ones in residential facilities or institutions given their high levels of familism. Correspondingly, only two out of the twenty-five respondents had used respite care. Although 52% had used adult day health care, and 48% had attended support groups these numbers could certainly increase given that these services are available in most communities. The findings suggest that Latino caregivers have been providing a significant amount of care without the help of sufficient formal services. Several explanations can

account for the low service use of Latino family caregivers. Not enough services, lack of information, and feelings of filial responsibility and distrust of social services may account for some of the under use of services. A lack of culturally appropriate and Spanish speaking services may be another factor.

Limitations

There were several limitations worth noting in this study. The main limitation to this study was the external validity or generalizability of the study due to the low number of Latino caregivers surveyed in the project. Because only twenty-five caregivers participated results may not be indicative of all or most Latino family caregivers. Another limitation was that the study did not ask about acculturation, years in the U.S. or citizenship status. Since people with more years in the U.S. may be more aware of programs versus people who recently immigrated who may be ignorant to programs and services this would have been important information to assess whether this was a factor in under use of services. Finally, participants in this study were already using or had inquired about using caregiver support groups or

adult day health care, indicating some knowledge of services available to them. Self-selection to participate in this study may also be a limitation in regards to validity.

Recommendations for Social Work Practice, Policy and Research

Since caregivers stated that they would most often go to social workers when faced with problems associated with caregiving (76%), social workers should make an immediate effort to engage family caregivers and provide referrals, information and therapeutic interventions. Caregivers also used doctors (48%) and other health professionals (48%) to get help for caregiving issues. Social workers should develop systems to be able to get information to these professionals and inform them of the need for referrals for programs and services that would help these caregivers.

Social workers should also make it best practice to assess for caregiver stress and strain when family members come in for services for their loved ones. Social Workers should remember that although the caregivers are not the "identified client" they still need services and support to remain in their desired caregiver role. Social

workers also need to remember that stress and burden can lead to depression and poor health, so assessing these in caregivers are very important so that they can get the assistance they need.

As the study indicated there was an association between levels of familism and caregiver strain. Social workers should use care not to place a higher value on familism and instead look for the best treatment for the client whether that be at home or in a nursing facility. Although client self-determination is important, safety and health concerns are equally important. Social workers can still honor cultural traditions and values and at the same time educate caregivers on treatment issues, counsel them when they are feeling stressed and sad and make sure that there is a continuum of culturally and linguistically appropriate programs and support systems in place.

The In-Home Support Services Program (IHSS) currently will help pay for services provided to seniors and disabled person so that they can remain safely in their own home. To be eligible, individuals must be over 65 years of age, or disabled, or blind. IHSS is considered an alternative to out-of-home care, such as

nursing homes or board and care facilities. The types of services which can be authorized through IHSS are housecleaning, meal preparation, laundry, grocery shopping, personal care services, taking individuals to medical appointments, and supervision for the mentally impaired (California Department of Social Services, 2006). Since most of the caregivers surveyed in this study are providing these services already, described financial burden and want alternatives to out of home placement this program perfectly coincides with their needs. The IHSS program staff, social workers and other people involved with caregivers should make concerted efforts to let the public know about this program and assist caregivers in applying and obtaining payment for the work they do. Policy makers should choose to keep programs like this going and make demands for more funding.

Future research should focus on programs that offer caregivers ways of lowering caregiver burden and finding ways to assist caregivers cope with the demands of caregiving. Future research should also focus on the positive aspects of caregiving and degrees of familism to help make people aware of the importance of family

responsibility and the rewards caregiving has. Future research may also focus on the upsides of using culturally and linguistically appropriate programming for caregivers to see if this would increase service use, decrease unmet needs and yield better overall outcomes for caregivers and their loved ones.

Conclusions

As this study confirmed, caregivers are under a great amount of emotional and physical stress and strain. They provide numerous types of help for many hours each day to their loved ones. Although the study had limitations, it did yield important information about the sacrifices Latino caregivers make when taking care of their loved ones and it offered a glimpse of what the experience of providing care entails. Social workers should assess caregivers for stress and strain and provide appropriate interventions. Culturally appropriate programs and services should always be available. Policy makers must make concerted efforts to keep financial programs such as IHSS going so that caregivers get paid for the actual work they do. Future research should focus

on ways to reduce caregiver burden and ways to increase service use in the Latino family.

APPENDIX A
QUESTIONNAIRE ENGLISH

QUESTIONNAIRE ENGLISH

1. How old are you? _____
2. What is your gender?
 - a. Male
 - b. Female
3. Are you
 - a. Married
 - b. Single
 - c. Divorced
 - d. Widowed
4. Are you presently
 - a. working full time
 - b. working part time
 - c. retired
 - d. homemaker
5. In regards to education you have
 - a. less than high school
 - b. finished high school
 - c. some college
 - d. bachelors degree
 - e. masters degree
6. What is your religion _____
7. What is you ethnicity _____
8. What was your family's total income before taxes last year?
 - a. Less than \$30,000
 - b. \$30,000-49,000
 - c. \$50,000-99,000
 - d. Over \$100,000
9. What relation is the person you care for to you
 - a. Mother
 - b. Grandparent
 - c. Father
 - d. Spouse
 - e. Mother or Father-in-law
 - f. Sibling
 - g. Child
 - h. Other _____

10. Please list all the medical conditions the person you care for has (for example, dementia, cancer, lung disease, stroke, schizophrenia, etc.)

11. How old is the person you care for, give your best estimate.

12. The person you care for lives

- a. in the same house as you
- b. 20 minutes or less from you
- c. between 20 minutes to an hour away
- d. from 1-2 hours away
- e. more than 2 hours away

13. The person you care for

- a. Lives in the same home as you
- b. Lives alone
- c. Lives with his/her spouse
- d. Lives in someone else's home
- e. Lives in a nursing home
- f. Lives in their own home with someone else
- g. Lives in an assisted living facility
- h. Lives in a retirement home or skilled nursing facility

14. In your opinion, what is the biggest problem the person you care for has:

- a. Alzheimer's disease
- b. Memory problems
- c. Old age
- d. Heart disease
- e. Stroke
- f. Mental illness
- g. Mobility
- h. Arthritis
- i. Cancer
- j. Diabetes
- k. Blindness/ vision problems
- l. Other

15. Is/ was your (care recipient):

- a. Frail
- b. Sick
- c. Disabled or
- d. none of these

16. Does the person you care(d)for take prescription medications?
 - a. Yes
 - b. No

17. If they do, do they
 - a. Need help from you to take them
 - b. Manage their own medications without help
 - c. N/A

18. The following is a list of kinds of help, which might be provided to a person, if the person cannot do it themselves. For each, please indicate if you provided this kind of help.
 - a. Getting in and out of beds and chairs
 - b. Getting dressed
 - c. Helping bathe or shower
 - d. Getting to and from the toilet
 - e. Dealing with incontinence or diapers
 - f. Feeding care recipient
 - g. Reminding them to shower, eat, etc.

19. Do/did you help the care recipient with
 - a. Transportation
 - b. Grocery shopping
 - c. Housework
 - d. Managing finances
 - f. Preparing meals
 - g. Helping with medications
 - h. Managing services

20. If not in the household, on average how many times do you visit the care recipient?
 - a. Lives with care recipient
 - b. Once a week
 - c. Few times a month
 - d. Once a month
 - e. Few times a year
 - f. Less often

21. Thinking about all the help you give the care recipient, how many average hours per week do you spend?
 - a. 40 or more
 - b. 21-39
 - c. 9-20
 - d. 8 or less

22. If you receive IHSS how many hours are you actually paid for per month? _____
23. For how long have you been providing the help?
- 5 or more years
 - 1-4 years
 - less than 1 year
 - Occasionally
24. Have you done or had to obtain or make any changes to your home to make it easier for the care recipient? (i.e., obtained a bathing bench, magnifying lenses for reading, or other helpful devices or installed ramps or alarm systems)
- Obtained assistive devices
 - Made home modifications
25. Has anyone else provided unpaid help for this person?
- Yes
 - No
26. If yes who would you say provides the most help?
- You
 - Someone else
27. Has anyone else provided unpaid help to the care recipient during the last 12 months? If yes, who? Indicate all that apply.
- Care recipient's daughters
 - Care recipient's sons
 - Grandchild
 - Spouse
 - Non-relatives
28. If not in a nursing home did the care recipient receive any of the following paid services regardless of who paid for it?
- Aid or nurse through an agency
 - Hired housekeeper
 - Aide or nurse independent of an agency
 - Other help
29. How would you describe your own health?
- Excellent
 - Very good
 - Fair
 - Poor

30. How would you say taking care of your loved one has affected your health?
- Made health better
 - Not affected
 - Made health worse
31. Using a scale from 1 to 5 where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say caring for your loved is for you? _____
32. Using a scale from 1 to 5 where 1 is not a strain at all and 5 is very much a strain how much of a physical strain would you say caring for your loved one is for you? _____
33. There may have been other ways in which caring for a loved one has affected your life. As a caregiver...
- Less time for friends or family
 - Give up vacations, hobbies or social activities
 - Get less exercise than before
34. If working while a caregiver: in your experience as both a caregiver and a worker, did you ever...
- have to go in late, leave early or take time off
 - have to go from working full time to part-time
 - have to give up work entirely
 - lose any of your job benefits
 - have to turn down a promotion
 - choose early retirement
35. Using the same scale from 1 to 5 where 1 is no hardship and 5 is a great deal of hardship how much would you say of a financial burden is caring for your loved? _____
36. The following is a list of ways that caregivers such as yourself have coped with the demands of caregiving. For each one please indicate whether you have used any of these. Did you ever try coping with stress by...
- Praying
 - Talking with or seeking advice from friends or relatives
 - Reading about caregiving
 - Exercising or working out
 - Going on the internet to find information
 - Talking to a professional or spiritual counselor
 - Taking medication
 - Attended a caregiver support group

37. Please tell me any other coping strategies you have used in your role as caregiver...

38. In your experience as a caregiver, have you ever... _____

- a. Requested info about financial help
- b. Obtained formal training
- c. Used transportation services
- d. Used services such as meals on wheels
- e. Enrolled recipient in recreation camp
- f. Enrolled participant in Adult Day health care
- g. Used respite service
- h. Attended a caregiver support group

39. As a caregiver on which of the following do you need more help or information:

- a. Finding time for myself
- b. Keeping the person safe at home
- c. Balancing my work and family responsibilities
- d. Managing my emotional and physical stress
- e. Easy activities I can do with the person I care for
- f. How to talk with doctors
- g. Making end of life decisions
- h. Moving or lifting the person I care for
- i. Managing challenging behaviors such as wandering
- j. Choosing an assisted living facility
- k. Choosing a home health agency
- l. Managing incontinence or toileting problems
- m. Choosing a nursing home
- n. Finding non-English educational materials

40. If you were looking for information about some aspect of helping take care of your (care recipient), where would you turn. Please choose all that apply

- a. internet
- b. doctor
- c. other health professionals
- d. Social Worker
- e. family or friend
- f. books, magazines ,library
- g. senior center
- h. Government agency
- i. Aging association/groups/organizations

41. For the following questions please indicate whether yes or no they apply to you as caregiver.
- a. Sleep is disturbed _____
 - b. It is inconvenient _____
 - c. It is a physical strain _____
 - d. It is confining _____
 - e. There have been family adjustments _____
 - f. there have been changes in personal plans _____
 - g. there have been demands on my time _____
 - h. there have been emotional adjustments _____
 - i. some behavior is upsetting _____
 - j. it is upsetting to find that _____ has changed so much from the person they used to be _____
 - k. there have been work adjustments _____
 - l. it is a financial strain _____
 - m. Feeling completely overwhelmed (e.g., because of worry about _____, or concerns about how I will manage) _____
42. Briefly explain as best you can why you are the caregiver and not another relative? _____
43. When you do have free time how do you spend it?

44. If you were to become disabled who would most likely care for you?
45. Please mention any things you enjoy or like about being the caregiver...

46. For the following list of statements about families please indicate with a check mark if you agree with the statements. Leave blank if you do not agree.
- a. A Married person should be willing to share his home with brothers and sisters of his husband or wife ____
 - b. Married children should live close to their parents so they can help each other ____
 - c. If a person of the family is insulted or injured you should feel more strongly about it than if the person were not a member of the family ____
 - d. It is the responsibility of married children to be with their parents in time of serious illness even if the children have moved some distance away from the parents ____
 - e. Children owe to their parents to put their own family interests above their own personal interests. ____
 - f. If a family group has strong political and moral views a member should not be influenced by outsiders to change these views. ____
 - g. As many activities as possible should be shared by married children and their parents. ____
 - h. Marriage should be viewed as keeping families going rather than starting a new family. ____
 - i. Children of elderly parents have as much responsibility for the welfare of their parents as they do for their own children. ____
 - j. Whenever possible a person should talk about important life decisions with family members before taking action. ____
 - k. When choosing a life partner it is important that a person choose someone whose moral or political views align with the family's. ____
 - l. If a person's father has a medical bill of \$1500 which he cannot afford to pay, the son or daughter is morally obligated to pay the debt? ____
 - m. Family members should be able to turn to other family members, before anyone else, for support, when met with a financial, emotional, or medical crisis. ____
47. If you could give potential relative caregivers some kind of advice what would it be?

SPANISH QUESTIONNAIRE

Fecha _____

1. Cuantos anos tiene usted?
2. Cual es su sexo?
 - a. Hombre
 - b. Mujer
3. Su estado civil es:
 - a. Casada(o)
 - b. Soltera(o)
 - c. Divorciada(o)
 - d. Viuda(o)
4. Esta usted presentemente:
 - a. Trabajando tiempo completo
 - b. Trabajando medio tiempo (part time)
 - c. Retirado o pensionado
 - d. Ama (o) de casa
5. Cual es su nivel de educación?
 - a. Menos de preparatoria
 - b. Termino preparatoria
 - c. Algunas clases de colegio pero no termino
 - d. Termino la universidad
 - e. Maestría o mas
6. Cual es su religión _____
7. Cual es su etnicidad (raza) _____
8. El ano pasado cuales eran sus ingresos anuales para la familia antes de impuestos?
 - a. Menos de \$30,000
 - b. De \$30,000 hasta \$49,000
 - c. De \$50,000 hasta \$99,000
 - d. \$100,000 o mas

9. Cual es el parentesco o relación del paciente hacia usted?
- a. Madre
 - b. Abuela
 - c. Padre
 - d. Esposo (a)
 - e. Suegra (o)
 - f. Hermano(a)
 - g. Hijo(a)
 - h. Otro _____
 - i. No es pariente o familiar
10. Por favor ponga todas las enfermedades que tiene la persona que cuida (por ejemplo, demencia, cáncer, enfermedad de los pulmones, Alzheimer's, Schizophrenia)
- _____
- _____
11. Cuantos anos tiene o tenia el paciente (su mejor calculo)
- _____
12. La persona que usted cuida vive
- a. En mi casa
 - b. Ha 20 minutos o menos de mi casa
 - c. De 20 minutos ha una hora de mi casa
 - d. De 1 ha 2 horas de mi casa
 - e. Mas de 2 horas de mi casa
13. La persona que cuido vive:
- a. En mi casa
 - b. Solo en su casa
 - c. En su casa con su esposo (a)
 - d. En la casa de otra persona
 - e. En una casa de ansianos (nursing home)
 - f. En su propia casa con otras personas
 - g. En un casa donde le ayudan (assisted living)
 - h. En un hogar para personas retiradas o vivienda independiente (independent living or retirement)

14. En su opinión cual es o era el problema mayor de la persona que recibe su cuidado?
- a. La enfermedad del Alzheimer's
 - b. Problemas de memoria
 - c. Vejez
 - d. Enfermedad del corazón
 - e. Choque cerebral (embolia) (stroke)
 - f. Enfermedad mental
 - g. No poder moverse o problemas con movimiento
 - h. Artritis
 - i. Cáncer
 - j. Diabetes
 - k. Ceguera o problemas de visión
 - l. Otro _____
15. La persona que cuida esta (escoja todas las respuesta apropiadas)
- a. frágil
 - b. deshabilitado
 - c. enfermo
 - d. ninguna de estas respuesta lo describe
16. La persona que cuida o cuidaba toma medicina recetada por el doctor?
- a. Si
 - b. No
17. Si la persona que cuida toma medicina:
- a. Necesita ayuda tomando las
 - b. Maneja sus propias medicinas sin ayuda
 - c. No toma medicina
18. La siguiente es una lista de actividades que la persona que cuida tal vez necesita ayuda en hacer. Para cada respuesta por favor indica si usted provee este tipo de ayuda:
- a. Subiendo o bajándose de camas y sillas
 - b. Ayuda con vestir
 - c. Ayuda con bañarse
 - d. Llegando y saliendo del inodoro (baño)
 - e. Cambiando pañales o incontinencia (accidentes urinales o fecales)
 - f. Dándole comida en la boca o ayudándole a comer
 - g. No le ayudo en estos tipos de actividades

19. La siguiente es una lista de actividades que la persona que cuida tal vez necesita ayuda en hacerlas. Para cada respuesta por favor indica si usted provee este tipo de ayuda:
- Transportación
 - Comprando comida; supermercado
 - Limpiando la casa
 - Manejando finanzas (pagando su renta, abriendo cuentas de banco, etc.)
 - Preparando alimentos
 - Ayudando con medicamentos
 - Manejando servicios
20. En un promedio, cuantas veces visita la persona que cuida
- Vive en la misma casa que yo
 - Una vez por semana o mas
 - Unas cuantas veces al mes
 - Una vez al mes
 - Unas veces al año
 - Menos de esto
21. Pensando en toda la ayuda que le da a la persona cuidada, como cuantas horas por semana gasta haciendo estas cosas? _____
- Mas de 40
 - 21-39
 - 9-20
 - 8 horas o menos
22. si recibe IHSS cuantas horas le pagan pro cuidar a su ser querido? _____
23. Por cuanto tiempo le ha dado ayuda ha la persona cuidada? _____
- mas de 5 años
 - 1-4 años
 - menos de un año
 - ocasionalmente
24. Ha hecho o obtenido alguno de estos tipos de modificaciones para hacerle mas fácil la vida ha la persona que cuida
- Obtenido artículos especiales (silla para bañarse, inodoro portátil, cama de hospital)
 - Hecho modificaciones en su hogar (barra de metal para poder levantarse, puesto rampas para silla de ruedas, hecho puertas mas grandes, etc.)

25. Alguien mas le ha dado servicios de ayuda sin pagarle ha la persona que cuida?
- Si
 - No
26. Si alguien más le ayuda con el cuidado de la persona, quien diría usted, provee la mayoría de cuidado sin paga?
- Usted
 - Alguien Mas
27. Si alguien mas le ha dado cuidado sin paga al la persona que cuida cual es el parentesco al ser cuidado?
- Hijo de persona cuidada
 - Hija de persona cuidada
 - Madre o Padre de persona cuidada
 - Nieto (a)
 - Esposo (a)
 - Personas sin parentesco/ conocidos
28. Si la persona que cuida no vive en asilo de ansianos, durante el pasado ano, la persona que cuida recibió algún tipo de ayuda **pagada** – no importa quien lo pago
- Ayudante o enfermera a través de una agencia
 - Ocupo una sirvienta o persona para limpiar (housekeeper)
 - Ayudante o enfermera sin agencia
 - Otro tipo de servicio pagado
29. Como describiría su propio estado de salud?
- Excelente
 - Muy bueno
 - Bueno
 - Mas o menos
 - Mal
30. En su opinión, en cual forma el trabajo de cuidar a la persona le ha afectado su salud:
- Mi salud ha empeorado
 - No ha afectado mi salud
 - Mi salud se ha mejorado
31. Del uno al cinco, donde 1 es nada de estrés y 5 es muy estresante, que tan emocionalmente estresante diría que cuidar a la persona es para usted? _____

32. Del uno al cinco donde 1 significa nada de esfuerzo físico y 5 es muchísima esfuerzo física que tan físicamente esforzante es tener que cuidar la persona? _____
33. Cuidando una persona tal vez le ha afectado su vida en diferentes maneras. Como cuidador(a) mi vida ha sido afectado en las siguientes maneras: (indica todas las que son apropiadas)
- a. Tengo menos tiempo para mi familia e amistades
 - b. He tenido que dejar de ir a vacaciones, pasatiempos favoritos o actividades sociales
 - c. Hago menos ejercicio que antes
34. Si trabaja, en el tiempo que ha cuidado la persona, usted ha
- a. Tenido que llegar tarde, irse temprano o tomarse un día o fallar del trabajo
 - b. Tenido que tomar un plazo de ausencia del trabajo
 - c. Tenido que dejar de trabajar completamente
 - d. Perdido unos de los beneficios de mi trabajo
 - e. Tenido que decirle no ha promociones de mi trabajo
 - f. Escogido retirarse mas temprano
35. Usando la misma guílla del 1 al 5, que tanto es la dificultad financiera el cuidar la persona: _____
36. La siguiente es una lista de maneras que personas como usted enfrenten o aguantan las demandas de cuidar ha personas. Usted ha hecho alguno de estos métodos?
- a. Rezar
 - b. Hablando o pidiendo consejos de amistades o parientes
 - c. Leer información sobre como cuidar personas
 - d. Haciendo ejercicio (working out) o una rutina de ejercicio intensiva
 - e. Usando la Internet para sacar información
 - f. Hablando con un consejero profesional o espiritual
 - g. Tomando medicina
37. Por favor indica otros métodos que usa para poder aguantar las demandas de su papel como proveedora de cuidado
- a. _____
 - b. _____
 - c. _____
 - d. _____

38. En su experiencia como proveedora de cuidado alguna vez ha.....
- a. Pedido información sobre ayuda financiera
 - b. Obtenido entrenamiento formal
 - c. Usado servicio de transportación
 - d. Usado servicios como: "Meals on Wheels" (comida gratis llevadas a casa)
 - e. Inscrito la persona en un campo recreativo
 - f. Participado en grupos de apoyo
 - g. Inscrito la persona en un centro de cuidado diario de adultos (adult day health care)
 - h. Usado servicios de respito (respite-donde cuidan a la persona para que usted descanse algunos días)
39. Como cuidador(a) en cuales de los siguientes necesita mas información o ayuda: (ponga si o no)
- a. Encontrando tiempo propio para mi
 - b. Manteniendo la persona que cuido segura en casa
 - c. Balanceando mis responsabilidades de mi familia y mi trabajo
 - d. Manejando mi estrés emocional y físico
 - e. Actividades fáciles que puedo hacer con la persona que cuido
 - f. Aprendiendo como hablar con el doctor
 - g. Haciendo decisiones de fin de vida (testamento, planes de funeral, etc.)
 - h. Moviendo o levantando la persona que cuido
 - i. Ayuda con los comportamientos negativos de las persona que cuida (perdiéndose, berrinches, etc.)
 - j. Escogiendo una parte donde pueda vivir el paciente con asistencia (assisted living)
 - k. Escogiendo una agencia de cuidado del hogar (home health care agency)
 - l. Escogiendo un asilo de ancianos o hospital convaleciente (nursing home)
 - m. Manejando problemas con panales, incontinencia o accidentes urinarias o fecales
 - n. Encontrando información de educación en Español

40. Si usted estuviera buscando información acerca de algún aspecto de ayudar a cuidar su (ser querido), donde lo buscaría. Escoja por favor todas las respuestas que aplican
- Internet
 - medico
 - otros profesionales de salud
 - un trabajador social
 - familia o amigos,
 - revistas, la biblioteca o libros
 - en un centro de ancianos
 - Una agencia del gobierno
 - Asociaciones de ancianos/ Grupos o organizaciones
41. Para las siguientes preguntas por indica si o no:
- Sufro de insomnio (por ejemplo por que _____ da vueltas toda la noche o se levanta demasiadas veces de la cama.) Si O No
 - Es inconveniente (por ejemplo, por que ayudar toma demasiado de mi tiempo o tengo que manejar mucho tiempo para ayudarlo.) Si O No
 - Es un esfuerzo físico (por ejemplo, tengo que levantarlo de una silla o de una cama o esfuerzo o concentración es necesario. Si O No
 - Me limita (por ejemplo, el ayudar restringe mi tiempo libre o no puedo ir a visitar). Si O No
 - Ha habido ajustes de la familia (por ejemplo, porque ayudar ha interrumpido la rutina; no ha habido intimidad o privacidad.) Si O No
 - Ha habido cambios en planes personales (por ejemplo tuve que rechazar un trabajo: no pude ir de vacaciones) Si O No
 - Ha habido ocasiones que el tiempo no me alcanza (por ejemplo para otros miembros de la familia)
 - Ha habido cambios emocionales (por ejemplo a causa de fuertes peleas) Si O No
 - Alguna conducta molesta (por ejemplo a causa de incontinencia; se le olviden las cosas, o acusa a personas de robarle) Si O No
 - Trastorna que _____ ha cambiado tanto de como era antes (por ejemplo ahora es una persona totalmente diferente de como era antes). Si O No
 - Ha habido ajustes de trabajo (por ejemplo, tener que tomarse tiempo libre). Si O No
 - Es un esfuerzo financiero. Si O No
 - Es un sentimiento completamente agobiante, por ejemplo a causa de preocupaciones acerca de _____; preocupaciones acerca de cómo usted aguantara. Si O No

42. Por que tuvo que cuidar la persona usted y no otro pariente?

43. Cuando tiene tiempo libre a que se dedica?

44. Mencione cosas que le agraden de cuidar a la persona?

45. Si usted llega a la edad avanzada o experimenta una enfermedad deshabilitante, quien piensa que lo va cuidar ha usted?

46. La siguiente es una lista de frases de familias, indique con una X si esta de acuerdo con lo que dice la frase, si no esta de acuerdo deje el espacio blanco
- a. Una persona casada debe estar dispuesto compartir su casa con los hermanos (as) de su pareja. _____
 - b. Hijos casados deben de vivir cercas de sus padres para que se puedan ayudar uno con otro. _____
 - c. Si una persona de la familia esta insultada o herido se siente más fuerte que una persona que no es de la familia. _____
 - d. Es la responsabilidad de hijos casados de estar cercas de sus padres en casos de enfermedades serias aun si se han mudado una larga distancia lejos. _____
 - e. Los hijos le deben a los padres de poner los intereses familiares a un nivel mas importante que sus intereses personales _____
 - f. Si una familia tienes fuertes opiniones acerca de morales o políticas una persona de la familia no debe dejarse ser influenciado por personas de afuera del la familia _____
 - g. Entre mas actividades compartidas entre personas casada y sus padres mejor _____
 - h. El matrimonio debe ser mirado como agradar la familia no como empezar un familia nueva _____
 - i. Los hijos tiene la misma responsabilidad de ver por el bienestar de sus padres viejitos que a cuidar sus propios hijos. _____
 - j. Cuantas veces posibles, una persona debe de hablar con sus familiares antes de tomar acción sobre una importante decisión en su vida _____
 - k. Cuando escogiendo una pareja es importante que la persona escoge alguien cuyos pensamientos morales y políticos coinciden con los de su familia _____
 - l. Si el padre de una persona tiene una cuenta de hospital de \$1500 es la obligación moral de su hija o hijo pagar esta deuda. _____
 - m. Miembros de una familia deben poder acudir a sus propios familiares antes de acudir a cualquier otra persona cuando se enfrenten una crisis financiera, emocional o medica. _____
47. Que consejo le daría ha una persona que esta pensando tomar el papel de cuidador de familia?
-

APPENDIX B
INFORMED CONSENT

INFORMED CONSENT

The study in which you are being asked to participate is designed to investigate caregiver burden and formal service use. This study is being conducted by Yvonne Arellanes-Amador (MSW student) under the supervision of Dr. Rosemary McCaslin, Professor of Social Work. This study has been approved by the Social Work Subcommittee of the Institutional Review Board, California State University, San Bernardino.

In this study you will be asked to respond to several questions regarding services for caregivers. Some of the questions ask about your view of caregiver burden and strain. Your choice to participate or not will not have any affect on any services you receive or may receive from Tender Heart Adult Day Health Care. The interview should take about 30 minutes to an hour to complete. All of your responses will be held in the strictest confidence by the researcher. Your name will not be recorded with your responses. All data will be reported in group form only. You may view the group results of this study upon completion in September 2006 at Tender Heart Adult Day Health Care or at the Pfau Library at California State University San Bernardino.

There are no foreseeable risks associated with this study and your participation in this study is totally voluntary. You are free to answer any questions and withdraw at any time during this study without penalty. When you have completed the questionnaire/ interview, you will receive a debriefing statement describing the study in more detail, and you may be eligible to enter the raffle of a gift certificate as a thank you for your participation. In order to ensure the validity of the study, we ask that you not discuss this study with other students or participants.

If you have any questions or concerns about this study, please feel free to contact Dr. Rosemary McCaslin, Professor of Social Work at (909) 537-5507.

By placing a check mark in the box below, I acknowledge that I have been informed of, and that I understand the nature and the purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Please check mark here: _____

I agree to have my interview recorded:

Yes ___ No ___ Today's date _____

CONSENTIMIENTO INFORMADO

El estudio en el que se le pide su participación esta diseñada para investigar el estrés del cuidador y uso formal de servicios. Este estudio será realizado por Yvonne Arellanes-Amador (estudiante de M.S.W. Maestría de Trabajo Social) bajo la supervisión de Dr. Rosemary McCaslin, Profesora de Trabajo Social. Este estudio ha sido aprobado por la subcomisión de Trabajo Social del Comité Institucional de la Revisión, Universidad Publica de California, San Bernardino. En este estudio, se le pedirá responder a varias preguntas con respecto a servicios para cuidadores. Algunas de las preguntas, preguntan sobre estrés físico y emocional. La participación en este estudio no afectara la elegibilidad para servicios en Tender Heart Adult Day Health Care. La entrevista del estrés del cuidador puede tomarse hasta una hora de completar. Todas sus respuestas serán estrictamente confidenciales. Su nombre no se registrara con sus respuestas. Toda información tomada será reportada en forma de grupo solamente. Usted puede ver los resultados del grupo de este estudio cuando el estudio se completa en Septiembre del 2006 en la Biblioteca de Pfau en la Universidad Pública de California San Bernardino o en Tender Heart ADHC. No hay riesgos previsibles asociados con este estudio y su participación es totalmente voluntaria. Usted es libre de retirarse en cualquier instante durante este estudio sin pena. Cuando usted termina esta entrevista y el cuestionario, usted recibirá una declaración de información que describe el estudio en mas detalle, y usted puede tener derecho a entrar a una rifa de un vale como agradecimiento por su participación. Para asegurar validez del estudio, nosotros pedimos que usted no comente nada de este estudio a otros estudiantes o participantes. Si usted tiene cualquier pregunta acerca de este estudio, por favor siéntase libre de contactar Dr. Rosemary McCaslin, la Profesora de Trabajo Social al (909) 537-5507.

Colocando un X en la línea de abajo, yo reconozco que he sido informado de, y que entiendo la naturaleza y el propósito de este estudio, y doy consentimiento libremente para participar. Reconozco también que tengo por lo menos 18 de edad.

Verifique por favor aquí ___ la Fecha Actual _____

Permito que mi entrevista sea grabada: si _____ no _____

APPENDIX C
DEBRIEFING STATEMENT

Debriefing Statement

The study you have just participated in was designed specifically to investigate caregiver stress and burden, family unity, service use and service needs by Latino family caregivers. It also sets out to explore/ expand social work knowledge in the areas of caregiver knowledge and Latino perspectives on their experiences as caregivers. Previous studies have shown that culture and family values relate to the degree of stress and burden felt by caregivers. Furthermore, studies have also shown that Latinos are less likely to use formal services.

Thank you for your participation in the Caregiver questionnaire and interview and for not discussing the contents with any other caregivers or patients. If you feel distressed in any way after participating in this study please see the attached list of resources.

Your participation in this study will add to research about social work knowledge regarding Latino caregiver burden, stress, and services usage. If you have any questions regarding this study please feel free to contact Dr. Rosemary McCaslin at (909) 537-5707. The study results will be available upon completion in September 2006 at the Pfau Library at California state university, San Bernardino. If you would like to obtain a copy of the group results of this study please contact the Tender Heart ADHC program manager at (760) 244-8776.

La Declaración de Interrogatorio

El estudio que usted acaba de tomar parte se diseño para investigar específicamente el estrés de cuidador, la unidad de la familia, el uso de servicios formales y necesidades de servicio por cuidadores latinos de familia. Trata también de explorar y expandan el conocimiento del trabajo de servicios sociales en las áreas del conocimiento de cuidador y perspectivas latinas en sus experiencias como cuidadores. Los estudios previos han mostrado valores de la cultura y la familia afecta el grado del estrés y carga sentida por cuidadores. Además, los estudios han mostrado también que latinos son menos probables de utilizar los servicios formales. Gracias por su participación en el cuestionario de Cuidador y entrevista y de no discutir el contenido con cualquier otro cuidador ni pacientes. Si usted quiere discutir cuidadores o necesita mas información sobre servicios después de haber tomado parte en este estudio por favor lea la lista conectada de recursos. Su participación en este estudio sirve para investigar acerca del conocimiento del Trabajo social con respecto a carga latina de cuidador, el estrés, y uso de servicios formales. Si usted tiene cualquier pregunta con respecto a este estudio por favor comunicarse con Dr. Rosemary McCaslin en (909) 537-5707. Los resultados del estudio estarán disponibles sobre la terminación en Septiembre 2006 en la Biblioteca de Pfau en universidad Pública de California, San Bernardino. Si usted querría obtener una copia de los resultados del grupo de este estudio contacta por favor al director del programa de Tender Heart ADHC en (760) 244-877

APPENDIX D
HELLER FAMILISM SCALE

HELLER FAMILISM SCALE

- a. A Married person should be willing to share his home with brothers and sisters of his husband or wife
- b. Married children should live close to their parents so they can help each other
- c. If a person of the family is insulted or injured you should feel more strongly about it than if the person were not a member of the family
- d. It is the responsibility of married children to be with their parents in time of serious illness even if the children have moved some distance away from the parents
- e. Children owe to their parents to put their own family interests above their own personal interests.
- f. If a family group has strong political and moral views a member should not be influenced by outsiders to change these views.
- g. As many activities as possible should be shared by married children and their parents.
- h. Marriage should be viewed as keeping families going rather than starting a new family.
- i. Children of elderly parents have as much responsibility for the welfare of their parents as they do for their own children.
- j. Whenever possible a person should talk about important life decisions with family members before taking action.
- k. When choosing a life partner it is important that a person choose someone whose moral or political views align with the family's.
- l. If a person's father has a medical bill of \$1500 which he cannot afford to pay, the son or daughter is morally obligated to pay the debt
- m. Family members should be able to turn to other family members, before anyone else, for support, when met with a financial, emotional, or medical crisis.

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