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Latino Alzheimer's Caregiving: Neither a Burden nor a Carga[1]

Latin Alzheimer Hastasına Bakım Verme: Ne Yük ne de "Carga"

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Editöre not / Note to Editor: This manuscript reports only on the experience of bilingual caregivers. The data analysis on monolingual Spanish speakers was excluded for this manuscript.

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ABSTRACT

Introduction: Caregivers provide care for relatives with Alzheimer's disease at an emotional and physical cost to themselves. Language and cultural factors influence how caregivers are impacted by their role, yet the role that culture and language play on a person's perception of caregiving has not been adequately explored. Not having a Spanish equivalent for the expression "caregiver burden." raises concern when this concept is translated to the word carga and used to describe Latino caregiving.
Aim: To describe the perceptions of the caregiving experience of bilingual Latino/Hispanic family caregivers of relatives living with Alzheimer's disease, and explore the language used in their narratives.
Method: Data collection and analyses followed a modified Spradley ethnographic methodology. Semi-structured interviews were conducted, and prolonged participant observation and artifacts provided rich data.
Results: All caregivers described their experience as difficult, but not as a burden or *carga*. Caregiving was described as an honorable opportunity to accomplish two culturally prescribed goals: caregiver satisfaction, and caregiver duty fulfillment. Three overarching themes were elucidated: caregiving has consequences, caregiving fulfills a duty, and caregiving is satisfying. The main consequences were: caregiving is physically challenging, caregiving is emotionally draining, and caregiving is financially detrimental. Caregiving fulfills a duty had two main components: Caregiving is my duty, and caregiving is learned. Caregiving is satisfying had three components: Caregiving is my opportunity to give back, knowing that I am doing my best, and a sacrifice.
Conclusion: Data support the formulation of a conceptual orientation of the Latino caregiving experience.

Keywords: Alzheimer's; caregiving; dementia; ethnomethodology.

ÖZ

Giriş: Alzheimer hastalığı olan akrabalarına bakım verenlerin verdikleri bu bakım, kendileri için duygusal ve fiziksel bir maliyet doğurur. Bakım verenlerin rollerinden nasıl etkilendiklerini belirlemede dil ve kültürel faktörler önemlidir, ancak kültür ve dilin bir kişinin bakım algısı üzerinde oynadığı rol yeterince araştırılmamıştır. "Bakım/Bakım veren yükü" ifadesinin İspanyolca birebir karşılığı bulunmamaktadır. Bununla birlikte Latin toplumu için bu kavramı tanımlamada giderek daha fazla carga kelimesinin kullanılması endişe uyandırmaktadır.
Amaç: Alzheimer hastalığı olan yakınlarına bakım veren Latino/Hispanik aile bakıcılarının bakıcılık deneyimine ilişkin algılarını tanımlamak ve anlatılarında kullanılan dili araştırmak.
Yöntem: Kalitatif bir araştırmadır. Veri toplama ve analizinde değiştirilmiş bir Spradley etnografik metodolojisi takip edilmiştir. Yarı yapılandırılmış görüşmeler gerçekleştirilmiş ve katılımcılar uzun süreli gözlenerek zengin veriler sağlanmıştır.
Bulgular: Tüm bakım verenler deneyimlerinin zor olduğunu ifade etmiş, ancak yük ya da carga olarak tanımlamamışlardır. Bakım verme, kültürel olarak bakıcı memnuniyeti ve bakıcı görevinin yerine getirilmesi şeklinde belirlenmiş iki hedefe ulaşmada onurlu bir fırsat olarak tanımlanmıştır. Bakımın sonuçları vardır, bakım verme ile bir görev yerine getirilir ve bakım verme tatmin edicidir şeklinde üç ana tema ortaya çıkmıştır. Bakımın sonuçları temasında bakım, fiziksel olarak zordur, bakım, duygusal olarak tüketir ve bakım, maddi olarak külfetlidir; bakım verme ile bir görev yerine getirilir temasında, bakım verme benim görevimdir ve bakım verme öğrenilir ve son olarak bakım verme tatmin edicidir ana temasında, elimden gelenin en iyisini yaptığımı bilerek geri verme fırsatım ve bir fedakarlıktır ifadeleri vurgulanmıştır.
Sonuç: Bulgular, Latino kültüründe bakım deneyiminin kavramsal yöneliminin formülasyonunu desteklemektedir.

Anahtar Kelimeler: Alzheimer; bakım verme; demans; etnometodoloji.

Introduction

Worldwide, 50 million people are living with dementia in 2018, and this number will more than triple to 152 million by 2050 (Alzheimer's Disease International, 2018a). Every three seconds someone in the world develops dementia, costing the global economy over US$ 1 trillion in 2018, straining health systems worldwide (Alzheimer's Disease International, 2018b). The Alzheimer's Association (2018) estimates that there are now 5.7 million people of all ages living with Alzheimer's disease (AD) in the United States, including approximately 5.5 million people age 65 and older, and 200,000 persons who have younger-onset (below 65) Alzheimer's. One out of 10 people (10%) age 65 and older has Alzheimer's and nearly half of people 85 and older have it (Alzheimer's Association, 2018).

In 2010, Latinos/Hispanics[1] were the largest ethnic minority in the United States (Unites States Census Bureau, 2010) and proportionally more likely than older whites to have AD (Alzheimer's Association, 2004). The number of Latino elders affected by AD could increase more than six-fold, from fewer than 200,000 in 2004 to more than 1.3 million by 2050 (Alzheimer's Association, 2004). Regardless of race or ethnicity, the opportunity for a person living with AD to live at home depends on the availability of support provided by family caregivers. Therefore, understanding cultural values and norms that influence the caregiving experience of Latinos is of paramount importance to design programs aimed at improving the quality of life of the caregiver and patient.

Review of the Literature

Latino Alzheimer's Caregivers

The number of studies on Latino AD caregivers is relatively small. The paucity of information is primarily due to the historical lack of Latino and Latino subgroups identifiers in major data sets including the census (National Alliance for Hispanic Health, 2001). Currently in the United States, family members provide some type of care to at least 70% of persons with dementia who live at home (National Alliance for Caregiving and American Association of Retired Persons, 2004). More than 27% of Latino households provide informal caregiving to an impaired friend or family member (Talamantes et al., 2006). Caregivers are mainly women around 40 years of age in the sandwich generation providing care for their children under 18, while also caring for older relatives in the caregiver's home (Ayalon & Huyck, 2002; Connel & Gibson, 1997; National Alliance for Caregiving and Evercare, 2008; Talamantes & Aranda, 2004).

Numerous studies pertinent to caregiving and caregiver burden found in the literature do not report specific data relevant to Latino. For instance, in a review and analysis of racial, ethnic, and cultural differences in dementia caregiving (Connell & Gibson, 1997), only two studies, Cox and Monk (1990) and Mintzer et al. (1992), included Latino subjects. Few studies have attempted to capture cultural differences in caregivers. Mintzer et al. (1992) attempted to explore whether ethnicity made a difference among daughters' caregiving for Latino and non-Latino patients with AD. The comparison was made between 13 Cuban-American Latino and 15 white daughter primary caregivers. Cox and Monk (1990) compared 31 Black and 19 Latino caregivers. Two- thirds were dementia caregivers. The two groups were similar in burden scores and the acknowledgment of strong feelings of family obligation. These findings were corroborated by Cox and Monk (1996) in a comparison of 76 African-American caregivers and 86 Latino caregivers of AD elders in New York and Baltimore. Latino caregivers reported significantly higher personal strain and role strain than African-Americans. Later, Aranda and Knight (1997) found that Latino caregivers reported a level of emotional burden or depression similar to or higher than that of white caregivers. Aranda and Knight also concluded that Latinos were more likely than whites to feel bothered or upset by specific caregiving tasks such as instrumental support with activities of daily living and by care recipients' problem behaviors.

Studies about Latino caregivers have increased in recent years (Baker, 2006). Most current research, however, has used nonprobability-sampling methods and a large number of measures of psychological well-being that often cannot be compared (Aranda & Knight, 1997; Dilworth-Anderson et al., 2002; Talamantes & Aranda, 2004). Generalizability was lacking in the studies conducted with Latino caregivers prior to findings from the Resources for Enhancing Alzheimer's Caregivers Health (REACH) project. This project initiated a new standard in studying dementia caregiving because it achieved probability sampling of separate Latino subgroups such as Cuban Americans in Florida, Mexican-Americans in California, and others. In their recent review of interventions for Latino caregivers of patients with dementia, Llanque and Enriquez (2012) conclude that intervention studies focused on the needs of Latino caregivers of people living dementia are scant, and that values endorsed by Latino caregivers as well as language and communication, should be considered when presenting information, developing interventions, and conducting future research.

Caregiver Burden

Providing primary care for a relative with AD can become overly demanding, especially as the disease progresses. Caregiving stress can have many causes, particularly the need to provide constant supervision and dealing with communication and behavior problems. Lee and Cameron (2005) reported that the primary sources of strain to caregivers of people with dementia are behavioral problems and incontinence. The stress of caregiving can increase because of a perceived lack of family and friends' support, lack of supportive responses from local health and social services, and perceived criticism from family, among other factors (Shaji, Smitha, Lal, & Prince, 2003). Ory et al. (2000) reported that caregivers of dementia patients experience more role stress, psychological distress, emotional strain, family conflict, and interference with other activities, than caregivers of frail elder relatives without dementia.

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

Acton and Kang (2001) suggested that burden might be an outcome too global to be affected consistently by intervention, and that better and more precise measurements are needed to evaluate the outcomes of interventions for caregivers. The recognition that burden may not be the best outcome to evaluate the effectiveness of the interventions implies that other types of measurements are needed. Focusing on the degree to which caregivers experience positive aspects of caregiving might be a better way to evaluate interventions. Murphy (2005) found strong evidence that caregivers of patients with AD were able to describe positive motives, rewards, and coping strategies to deal with the stresses of caregiving. The presence or absence of positive aspects of caregiving could provide a better indication of the effectiveness of interventions designed to reduce stress in the caregivers.

For Latino caregivers the use of burden scales to measure the outcomes of interventions is questionable. Considering that the English word *burden* does not accurately translate to

Table 1. Spradley's Developmental Research Sequence

The 12 Steps	Sample Tasks
1. Locating an informant	Identify the best possible informants
2. Interviewing an informant	Practice interviewing skills
3. Making an ethnographic record	Set up a field notes book, begin making entries, arrange the first interview
4. Asking descriptive questions	Ask grand tour and mini tour questions, ask native language questions
5. Analyzing ethnographic interviews	Make a preliminary domain analysis, list tentative cover terms
6. Making a domain analysis	Conduct a thorough domain analysis, make a list of hypothesized domains
7. Asking structural questions	Conduct interviews using structural questions for each type of domain
8. Making a taxonomic analysis	Analyze the internal structure of domains, identify subsets within the domain
9. Asking contrast questions	Ask different types of contrast questions to understand cultural meaning
10. Making a component analysis	Identify the components of meaning for folk terms
11. Discovering cultural themes	Discover conceptual themes used to connect the domains
12. Writing an ethnography	Generate cross-cultural statements, write the ethnography

a word in Spanish with the same contextual meaning and that cultural differences have not been taken into consideration, the use of the word and burden scales appears inappropriate with this population (Arévalo-Flechas & Lewis, 2006).

Methods Design

The investigation followed ethnographic methodology using an adapted developmental research sequence (Table 1) as proposed by Spradley (1979). After obtaining Institutional Review Board (IRB) approval from The University of Texas Health Science Center at San Antonio, informants were recruited from a geriatric medicine clinic, and from the pool of caregivers taking part in a National Institutes of Health (NIH) funded program for AD caregivers in South Texas. The caregivers were recruited personally over a period of 22 months. Once informed consent was obtained, the caregivers were interviewed at a mutually agreed time in their home or in a soundproof room located in the facilities used by the NIH caregiver's program study staff.

Sample

The purposive sample yielded 14 self-reported Latino bilingual family caregivers of a relative (care-receiver) living with AD who had been providing care for at least one year. Eight participants were Mexican-American, 3 Mexican, 2 Puerto Rican, and 1 Peruvian. 5 caregivers were daughters, 6 were wives, 2 were husbands, and 1 was an ex-daughter in law. The caregivers' ages ranged between 33 and 75 years with a mean age of 54. Educational level ranged from some grade school to college graduate. Only one of the caregivers was able to work full-time, all others had retired, taken early retirement or become unemployed to assume caregiving duties. The care-receivers' ages ranged from 55 to 89 years with a mean age of 72. They were 9 men and 5 women who had been living with a diagnosis of AD for an average of 7 years.

The author conducted all semi-structured interviews in the language of choice of participants (Spanish, English or both). The author was born and raised in Colombia where Spanish is the official language. The author immigrated to the United States at the age of 20 and received her professional education in English. The author is proficient in reading, writing, and speaking both languages. At the time of the study, the author had lived in South Texas for 19 years and a total of 23 years in the United States.

Data Collection

The data included participant observations, artifacts, demographic data, and audio tape-recorded semi-structured ethnographic interviews that included descriptive, structural, and contrast questions. Artifacts included personal letters, diaries and journal materials volunteered by the caregivers and the draft of a book written by one of the caregivers on the experience of caring for her mother. Data saturation was achieved with 14 face-to-face interviews. The first eight provided an opportunity to test questions derived from the literature and observation of participants during support programs, and the remaining six were in-depth. Member checking was ongoing during the interviews as the author asked for clarification, meaning, and verification of the participants' answers.

The interviews were recorded in either English or Spanish, or both, as requested by the participants. The participants were not asked to refrain from code switching (the practice of changing languages or borrowing words from the other language). After removing identifying information, the interviews were transcribed verbatim in the source language and double-checked for accuracy. The verbatim transcripts of the interviews in their source language were used for analysis.

Data Analysis

The author used Spradley's (1979) sequence of ethnographic data analysis (Table 1). A domain search was conducted after the first five interviews were completed. For each of the identified domains, structural questions were generated. A list of hypothesized domains was formulated to isolate the fundamental units of cultural knowledge (domains) into which the participants organized what they knew. Then structural questions were generated to verify the domains and elicit folk terminology included in the domains. For instance, verification was needed that the impact of caregiving as described by the caregivers was organized by three domains: physical, emotional, and financial. Taxonomic analysis followed to find the relationship among all the folk terms in a domain (Spradley, 1979), looking at the internal structure of each identified cultural domain. The substitution frame had the format "________ (is a kind of) _______." Once the substitution frame was identified, the author searched for possible subsets among the terms in the taxonomy and formulated more structural questions to verify the taxonomic relationships that had been identified. For instance, stress, isolation, sadness, and loneliness were identified as kinds of emotional consequences.

Then contrast questions were created to facilitate the discovery of meaning. An example of a contrast question was: Are there positive or negative aspects of caregiving? This question sought to clarify under what theme the domains *sacrifice, duty*, and *satisfaction* needed to be assigned. A componential analysis of the interviews was then completed using contrast sets. This analysis searched for the attributes that signaled differences among symbols in a cultural domain (Spradley, 1979). More contrast questions such as: "Are duty and obligation the same?" were created to fill any gaps that appeared in the data.

Cultural themes were then identified. It was anticipated that emic descriptions of the caregiving experience for Latinos would be identified from this thematic analysis. Peer debriefing was accomplished with three experienced researchers, a bilingual psychologist (Spanish native speaker born in El Salvador), a white non-Hispanic nurse whose area of expertise was dementia caregiving, and a white non-Hispanic nurse who had lived most of her life in South Texas and had expertise in qualitative analysis. These researchers and the author reached agreement for each of the themes and subthemes identified.

Results

Caregiving has consequences, caregiving fulfills a duty, and caregiving is satisfying are the three major themes identified from the description of emotional, physical, and financial aspects of caregiving.

Caregiving has consequences

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

Caregiving is physically challenging. The caregivers without exception described a feeling of being constantly tired or having no energy. A feeling of exhaustion, fatigue, being worn out, and about to fall apart were some of the descriptors used by caregivers to illustrate how they felt physically. Caregivers attributed feelings of exhaustion to the actual physical effort required to care for the care-receiver.

Caregiving is emotionally draining. Caregivers reported feeling emotionally drained or empty, a feeling of being unable to or having difficulty giving or nurturing others. Caregivers described how assuming responsibility for major life decisions for the care-receiver and, in several instances for the entire family, was often one of the most emotionally charged duties they were experiencing. Caregivers who had been designated by the care-receivers or other family members as the caregivers and who had power of attorney for either health care or financial decisions explained that a great deal of their emotional energy was invested in "keeping peace" with their relatives. They shared they received ongoing criticism, rather than support, and in some cases had to deal with the resentment of other family members who were not designated as the decision makers. A major cause of the emotional stress was dealing with change in roles and in their ability to socialize. Four domains emerged related to change: loss of companionship, relinquishing social activities, and feeling isolated, and always thinking about the care-receiver.

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

Relinquishing social activities. The inability to leave home to socialize with friends and acquaintances, work, attend church, engage in volunteering, or interact with other people was referred to by the caregivers as a major emotionally draining change. As the disease progressed and the caregivers came to the realization that public places were no longer an option for their relative, the caregivers relinquished engaging in socialization.

Feeling isolated. This feeling of isolation appeared to be the result of the loss of companionship and the loss of opportunities to socialize. The lack of social contact outside the home and the inability to maintain a coherent, logical conversation with their relative lead the caregivers to live in what a caregiver described as "the world of Alzheimer's."

Always on my mind. All caregivers mentioned that their relative was always on their mind. The caregivers related how this was different from the time before the AD diagnosis. The ability to engage in other activities without worrying about their relative appeared to have been lost. Regardless of the reassurance offered by formal caregivers, family members, or friends, the caregivers were in a constant state of worry about the care-receiver's welfare.

Caregiving is financially detrimental. Regardless of socioeconomic status, caregivers faced long-term detrimental consequences, including loss of income, loss of time required in the work force for pension or retirement, loss of health insurance benefits, and depletion of family leave time. All caregivers who were no longer employed or had retired stated that their financial security had been compromised.

Caregivers must reduce number of work hours. Caregivers who were employed at the time their relative was diagnosed with AD tried to stay employed as long as possible. Gradually they were forced to reduce the number of work hours causing a decrease in income, and a loss of benefits. These benefits included health care insurance, prescription medication coverage, paid time off, and, in every case, less income set aside for retirement.

Giving up work altogether. Remaining employed was impossible. Caregivers who had worked invariably took leaves of absence, worked only part-time, and eventually quit working. Caregiving duties and work became overwhelming and impossible to juggle.

Being hired as a caregiver by family members. Two of the caregivers received a fixed amount of income for their caregiving duties. They were children caring for one of their parents. This arrangement appeared to be feasible because in their families there were 4 or more children working. The financial arrangement was proposed by the other siblings or by the caregiver.

Caregiving Fulfills a Duty

This overarching theme was identified in every interview. Caregivers voiced a strong sense of duty to family members, especially to elders. Caregivers emphasized the difference between having to do something and wanting to do something.

Caregiving is my duty. Caregivers described a strong sense of duty to their care-receiver and expressed that the responsibility for the well-being of their relative with AD was theirs and no one else's. Wives caring for their husbands described a sense of duty to their spouses, regardless of the quality of their marital relationship prior to the diagnosis of AD. Several of the care-receivers were described as loving, caring, and devoted husbands. These attributes, in the words of their caregiver wives, strengthened their sense of duty, and they had the conviction that what they were doing was the right thing to do. Having received love and nurturing from their husbands made caregiving for them a natural decision. The two husbands caring for their wives also described this strong sense of duty. With almost identical words, they stated that caregiving was a duty of love, and they were sure that their wives would have done the same for them. Daughters described the feeling of duty to their parents and stated it was a privilege and an honor to have the opportunity to care for their parents.

Duty to family. Most caregivers described a sense of pride in belonging to a strong family unit. Caregivers emphasized their descriptions of close-knit family units in which family obligations were clearly acknowledged and met. The family was honored through hard work and by placing family members and the needs of the family before any other wants or needs, especially if they were individual needs. Every caregiver mentioned expressions such as "mom had to be first," and "family comes first." These expressions were the caregivers' way to explain why they had become caregivers to their relative with AD. A daughter who stated that as a child she had been neglected by her mother now living with AD stated: "Family comes first." Crying, she elaborated: "Regardless of what she has done to me in the past, she is my mother, she is my blood, and she is my family. I would never abandon her." Several caregivers engaged in descriptions that denoted pride in how crises were handled by the family.

Caregivers living with their adult children said they were very proud of the manner in which their children and their families had chosen to remain close, take the caregiver and care-receiver in, and provide financial and emotional support. Caregivers brought up the topic of nursing homes, or homes specialized in the care of patients with AD when they were asked why they had become caregivers. Caregivers were emphatic in their comments about placement. Nursing homes were simply the last option, regardless of the financial abilities of the family. Caring for their relatives at home was a family duty to be fulfilled. None of the caregivers spoke positively about nursing home placement. Caregivers described institutionalization as a failure to meet a family duty.

Respeto. Central to the caregiver narratives was the value of respect (*respeto*). Respect was one of the reasons listed to become caregivers. Children caregivers spoke about the treatment they owed their parents, not only because they were their parents because they were older. The elderly deserved to be treated with the utmost respect and not taking care of them was the equivalent to being disrespectful. Older people according to caregivers were to be loved, respected, and cared for. Institutionalizing a loved one was seeing as a valid reason to lose the respect of family members and other people. The daughter who described her relationship to her mother as not close, or not ideal, placed special emphasis on caregiving, more as a sign of respect than a sign of love.

Distribution of responsibilities among siblings. Children caregivers who had siblings and were caring for a parent described the dynamics of decision-making as complicated, especially if they had a large family. The greater the number of siblings, the more intricate the dynamics. Caregivers talked openly about intrafamilial conflict.

Caregiving is learned. Caregivers emphasized that their families had instilled in children the importance of family and respect for authority and the elderly. The vast majority had recollections of parents taking care of grandparents and placing the needs of the older person before their own needs. Childhood was the time during which they believed they had learned about caring for family. A daughter eloquently summarized: "No one taught us what caregiving was, no one told us how to do it. We lived it! Every day, that is why it is part of who we are."

Caregiving is Satisfying

This third overarching theme was described as a deep sense of satisfaction in being able to fulfill a duty to a relative. Regardless of the difficulties they faced, caregivers described this sense of satisfaction as something positive and enriching in their lives. A daughter stated that although caregiving was very difficult and she resented a few things from her siblings, she felt privileged and honored to be able to care for her father.

Caregiving is my opportunity to give back. Caregivers mentioned giving back to the care-receiver for all the positive things done in the past or given to the caregiver or the entire family. Caregivers elaborated on the things they had received from the caregiver prior to the diagnosis of AD – both tangibles and intangibles.

Caregiving is knowing that I am doing my best. In general, caregivers recognized their limitations and found satisfying trying to make the best of their situations. Each caregiver faced a unique situation, but each took pride in doing what was humanly possible to do for a relative. Several caregivers described caregiving as an opportunity to bring out the best in them as human beings. Caregivers also talked about not knowing what they were capable of doing and enduring until they became caregivers.

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

Caregiving is a sacrifice. The idea of sacrificing self, time, career, money, and socializing to care for their relatives with AD was described as necessary in order to fulfill a duty to family. The majority of caregivers spoke about this sacrifice positively. Caregiving was described as something done with resignation that became an offering to God. Several caregivers described caregiving as a challenge sent by God.

Es un sacrificio, lo primero es la fe de nuestra religión que no estamos solos que aunque las cosas se miren oscuras y tristes a... tiene que uno pensar en los sacrificios que nuestro Dios hizo por nosotros, entonces lo que uno hace es simplemente cumplir con una obligación.[It is a sacrifice, first it is part of our religion that we are not alone even though things look dark and sad eh... one has to think in the sacrifices that our Lord made for us, and then what one is doing is simply to fulfill an obligation.]

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

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

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

The Language of Caregiving

Caregivers did not use the words burden or *carga* to describe their experience. The caregivers qualified their experience as difficult (*difícil*), hard (*dura*), challenging (*un reto*), frustrating (*frustrante*), sad (*triste*), lonely (*solitaria*), and stressful (*tensionante* or *estresante*). Different terminology and expressions were used when caregivers were asked to elaborate on the emotional and financial impact of caregiving.

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

Caregivers described the financial impact of caregiving as negative (*negativo*), worrisome (*preocupante*), and difficult (*difícil*). The financial situation (*situación financiera*, or, *situación económica*) was described as difficult. It was only in this context that one caregiver spontaneously used the word burden: "Taking care of my mother has created a tremendous financial burden."

None of the caregivers spontaneously used the words *burden* or *carga* except in the aforementioned example. When caregivers were asked what the word burden meant to them, they offered the following expressions: "Burden is something that you do because you have to, but not because you want to"; "Burden is having too much on your plate and you not being able to handle it anymore"; "[Burden] is something very difficult that a person has to do and that the person does not enjoy at all. It is something, eh perhaps...painful? Maybe a struggle? I really don't know how to tell you what it means"; and "Burden is something hard that you can't do."

When the caregivers were asked to translate the word burden to Spanish, they hesitated and could not offer a single word to convey the meaning. Rather the caregivers engaged in explanations and used code switching to illustrate the idea. Caregivers offered the following statements:

Burden *es como que uno no puede hacer algo, uno quiere pero no puede hacerlo porque es demasiado difícil.* [Burden is as if one cannot do something; one wants to but cannot because it is too difficult.]

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

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

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

Even though all caregivers had described the idea that they had an excess of responsibilities that were affecting them negatively, the caregivers denied experiencing burden.

Neither a burden nor a carga. With the exception of a caregiver who felt neglected as child by her mother now living with AD, none of the caregivers said they had experienced burdenor a feeling that their relative was a carga. Caregivers emphatically denied feeling burdened or that their care-receiver was a burden.

A wife shared: "No, he is my husband and I love him. He would have done the same for me. He is not a burden for me. This is hard, but he is not a burden." Two daughters did not understand the meaning of the word *carga* and thought it meant to be *encargado (a)* (to be in charge of) or *al pendiente* (to be paying attention). They both denied that caring for their fathers was a burden and reinforced that it was their duty. One of them stated "I don't see it as a burden, I am glad I can help, and I know my mother was preparing us for this in the way she raised us." A different daughter stated, "Doing what I do is not a burden; of course, there are days when it is frustrating, and I have to juggle a lot, but he is my father and I know I am doing what is right." In contrast, a wife understood the word *carga*, but asked the meaning of *burden*. She did not understand the meaning of the word *coping* either. She stated:

Nunca he pensado que él es una carga, me molesta mucho que sigue llegando a la casa con cosas que no hemos comprado, se las echa a la bolsa y no me doy cuenta cuando; y los errores que hizo con la aseguranza fueron terribles, pero nosotros hemos sido muy felices, y por alguna razón Dios permitió que fuera él y no yo la que tuviera la enfermedad. Tal vez otras personas lo vean como una carga, y si es así, entonces le digo que yo la llevo con mucho amor.

[I have never thought that he is a carga, it bothers me much that he continues getting home with things that we have not bought, he puts them in his pockets and I don't realize when; and the mistakes he made with the insurance were terrible, but we have been very happy, and for some reason God allowed that it was him and not I who would have the disease. Perhaps other people see it as a carga, and if it is that way, then I tell you that I carry it with much love.]

Despite the tremendous difficulties that caregivers faced they accepted caregiving as a family duty that had positive and negative aspects. Caregivers did not admit to experiencing burden and expressed dislike and anger for the idea that their care-receiver would be considered a burden or a carga.

Discussion

The experience of Latino family caregivers of a relative with AD and the language used to narrate their experience have been described. Three overarching themes were identified and supported by the narrative and found in the artifacts included in this study. These themes were caregiving has consequences, caregiving fulfills a duty, and caregiving is satisfying. The exploration of the themes and their components is shown in Table 2. The physical, emotional, and financial consequences of caregiving have been widely reported in the literature.

Of particular interest and not found in the literature on Latino caregivers, was the consistent manner in which financial responsibility was assumed by siblings and extended family

Table 2. Themes and Their Components

Theme	Components
Caregiving has consequences	Caregiving is physically challenging
	Caregiving is emotionally draining:
	Loss of companionship
	Relinquishing social activities
	Feeling isolated
	Always on my mind
	Caregiving is financially detrimental:
	Caregivers must reduce the number of work hours
	Giving up work altogether
	Being hired as a caregiver by family members
Caregiving fulfills a duty	Caregiving is my duty:
	Duty to family (Deber con la familia)
	Respect (Respeto)
	Distribution of responsibilities among siblings
	Caregiving is learned
Caregiving is satisfying	Caregiving is my opportunity to give back:
	Caregiving is knowing that I am doing my best
	Caregiving is a sacrifice

members (two granddaughters) to compensate the relative assuming primary responsibility for the care-receiver or to cover the care-receiver's expenses. It appeared that financial support for the care-receiver or for the sibling in the caregiver role was a top priority. This may be explained by the cultural value of *familismo*. The caregivers reported sibling involvement. Those siblings not living close to the care-receiver contributed with occasional respite time, emotional support for the caregiver, and money.

The second overarching theme was caregiving fulfills a duty. In the caregivers' descriptions about fulfilling their caregiving duties to their families, three domains emerged, duty to family, respect, and sharing responsibilities among siblings. The values of familismo and *respeto* permeated every interview. It has long been recognized in the literature that although Mexican-American families stress the importance of extended family support, nuclear family households are the norm for this Latino subgroup (Keefe & Padilla, 1987). Mexican-Americans have also been reported as tending to discourage disruptive behavior among family members (Hampson, Beavers, & Hulgus, 1990). Caregivers of Mexican descent in the study, born or not in the United States described the importance of family support. Consistent with findings reported by Sabogal et al., (1987), attitudes consistent with familismo appeared to have endured across levels of acculturation among US Latinos of four different nationalities.

Caregivers elaborated on duty to family, respect, and helping each other as values that had been acquired while growing up in their homes. Social learning theory proposes that people learn new expectations and behaviors by observing the behavior of others and the consequences of that behavior; they then perform that behavior with the expectation of similar consequences (Bandura, 1977). Bandura (1986) also noted the effectiveness of observational role modeling to learn behaviors. Role modeling enables persons to learn from role models that are presented to them, leading them to pattern-observed behavior, resultant rewards, and consequences into their own set of behaviors. Piercy and Chapman (2004) reported that role modeling was often more powerful than the actual relationship with the care-receiver in assuming caregiving activities.

Placing more importance on the well-being of the family than on a single individual and sharing the responsibility of caring for a family member can be explained by a sense of collectivism related to family interactions. Familismo and collectivism play a central role in how Latinos interact and perceive themselves (Chong & Baez, 2005). The harmony embodied in a sense of collectivism is essential to Latino caregivers' sense of belonging and self-worth. In a Latino's life, it is extremely important to achieve a balance between work and family with equal emphasis placed on meeting the expectations of both employer and family (Chong & Baez). This may explain in part the tendency of family members to hire the caregiver, and the reluctance that the caregivers may have had to take or ask for time off.

The third overarching theme was caregiving is satisfying. Three major components emerged as caregivers talked about the satisfaction, they derived from being able to provide care to their relatives: caregiving is my opportunity to give back, caregiving is knowing that I am doing my best, and caregiving is a sacrifice. Caregivers talked about a profound sense of satisfaction from having the chance to repay the care-receiver for affection, care, support, and teachings from the care-receiver. Sacrificing for their care-receiver was something positive. For several caregivers sacrificing had become an inspiring life-changing experience. Sacrificing for their relative was a moral obligation and a source of pride. Jolicoeur and Madden (2002) have reported this sense of pride among females in their description of the "good daughters" role in Mexican-American daughter caregivers living in the U.S. Even though role expectations were more traditional among Spanish-speaking daughter caregivers than English-speaking daughters, "caregiving was considered by both groups to be an integral part of being a good daughter" (p. 116). Caregivers in South Texas provided descriptions consistent with Jolicoeur and Madden's report.

Linguistic Exploration Results

The second aim of this study was to explore the language used by bilingual LatinoAD family caregivers to describe their experience. It was confirmed that the words burden and carga lack cultural congruency with Latino values and role fulfillment expectations.

Caregivers did not spontaneously use the word burden to describe their experience. Only one caregiver used the word *burden* by code switching during the interview conducted in Spanish. This caregiver understood the meaning of the word carga as "a thing" that you carry and stated her mother was "not an object or a carga." The other caregivers denied experiencing burden. Only two understood the meaning of carga as a physical attribute and did not see their care-receivers as such. Caregivers of Mexican descent stated that cargameant *estar al pendiente* (to be attentive to) or *estar encargado de* (to be in charge of). The youngest of the Mexican-American caregivers stated she had never heard the word carga. These findings confirm that for English-speaking Latino caregivers the word burden is not culturally appropriate (Calderon-Rosado & Tennstedt, 1998; Gallagher-Thompson, Solano et al., 2003; John & McMillian, 1998; Roth et al., 2003). In addition, findings support the assertion that just as burden is not acceptable to English-speaking Latino caregivers, the word carga is just as culturally incongruent for bilingual Latino caregivers. These findings apply to all Latino subgroups included in this study.

The caregiving literature from Spain reflects the use of the word *malestar* to describe the difficulties faced by dementia caregivers (Losada, Márquez-González, Peñacoba, Gallagher-Thompson, & Knight, 2007). *Malestar* can be translated to English as *discomfort* and in some cases as *malaise*. This

Spanish word appears to be much more culturally sensitive for labeling the emotional as well as the physical consequences of caregiving without conflicting with the sense of duty and role fulfillment expectations described by Latino caregivers. All caregivers in this study agreed that there was no Spanish word to translate what they understood as burden.

Limitations

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

Another limitation of the study was the inability to obtain an understanding of how collectivistic views and the premorbid relationship between the caregiver and the care-receiver may have affected the perception of the caregiving experience. Inclusion of Latino caregivers born in Mexico, Puerto Rico, Peru, and the U.S. limit the findings to these subgroups. In terms of perception and terminology used to describe the caregiving experience, these findings should be applied with caution to other Latino subgroups until they are studied.

Contribution to Knowledge and Future Research

Delivery of culturally competent healthcare services to Latinos is a priority if we are to continue attempting to close the existing gap and disparities in the delivery of care as documented by the Institute of Medicine (2003). Speaking Spanish improves the ability of healthcare providers to communicate during clinical encounters, however, knowledge of Latino culture and the values that motivate patients' decisions and behaviors can allow healthcare providers to be more effective and provide personal and respectful care. Implying that a caregiver is experiencing burden or that a care-receiver is a burden or a carga without explicit validation from the caregiver may not be the best way to promote communication with caregivers and their families.

Latinos value the sincere interest that a person shows in them. Healthcare providers can use this knowledge to initiate and maintain productive and therapeutic relationships with Latino caregivers. Contrary to the individualistic view that a healthcare provider must remain professional, not share personal information, or intrude in the personal situations of patients, Latinos trust and engage those who ask, "How are you?" and who are willing to make the time to listen to the answer. Healthcare providers must be prepared to engage in active listening and not assume that an encounter with a Latino caregiver will be limited to a specific health concern about the caregiver or the care-receiver. Disregarding this type of interaction with a Latino caregiver would be going directly against the values of personalismo and respeto.

Further qualitative research is needed to explore the influence of collectivism in Latino AD caregiving. Caregiving theory informed by an understanding of the Latino culture is needed. This theory should specify the basic nature of the concepts of burden and carga in this culture and the manner in which these concepts relate to constructs and other concepts.

Although reliable caregiver burden instruments are available, these instruments have been normed with non-Latino populations. Further scale-level analyses need to be conducted to confirm that the scores obtained with the instrument relate well to other scores obtained using instruments that measure other constructs and concepts in the manner dictated by the culturally informed theory. Qualitative research could also be used to explore the degree of measurement equivalency of the existing burden instruments. Both qualitative and quantitative research are needed in the Latino caregiving area to provide reasons why burden instruments may not be equivalent across cultures, to dictate the direction in which modifications need to be made to achieve equivalence, or to develop new instruments for Latino caregivers.

The addition of the concepts of caregiver satisfaction and caregiver duty fulfillment are proposed as concepts central to the Latino caregiving experience. Figure 1 depicts a culturally informed conceptual orientation of caregiving, in which culture and language play a moderating role in the relationship between caregiver expenditure and caregiver coping, and between caregiver coping and the caregiver perceptions of the experience.

Notes 1. For ease of reading, the abbreviated term *Latino* is used throughout most of the article, though it is intended to represent and be understood as *Latino/Hispanic*.

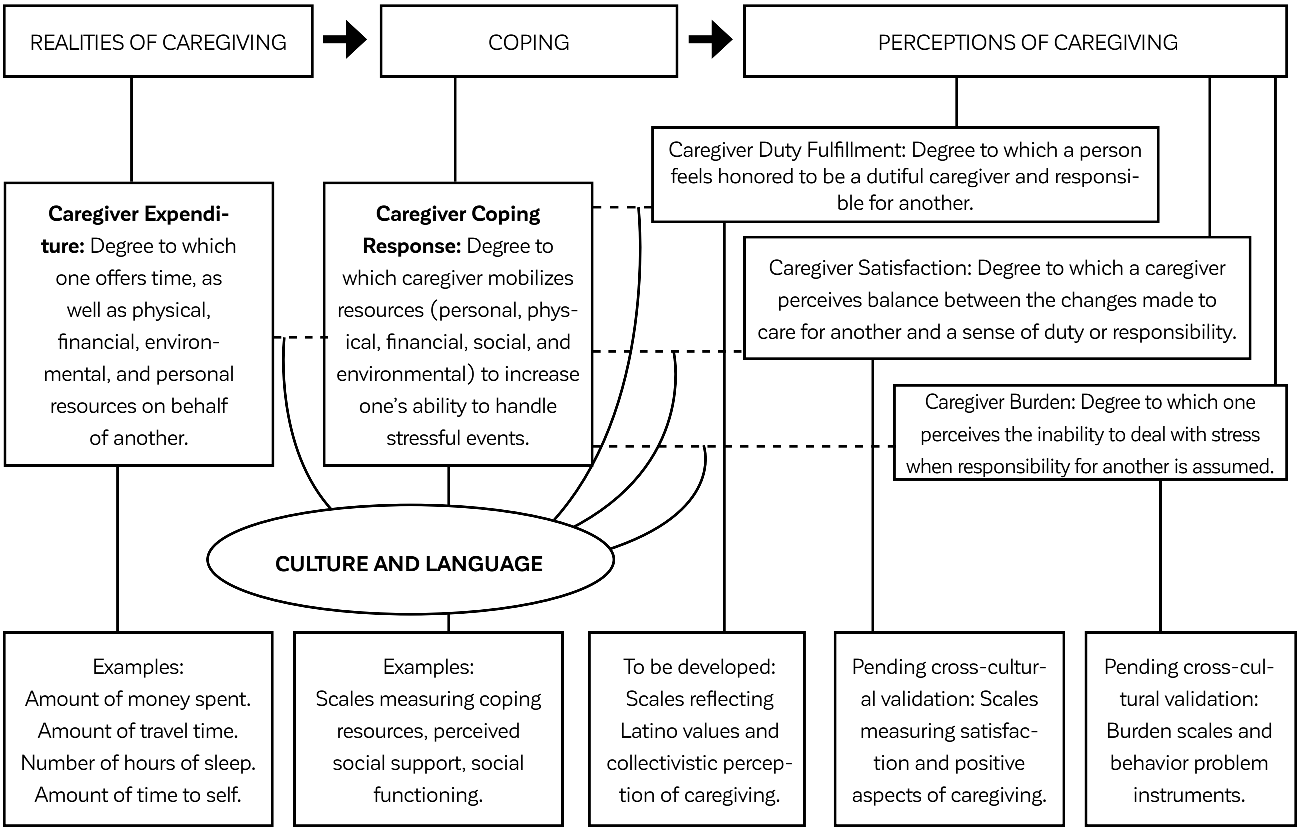

Figure 1. Culturally informed conceptual orientation of caregiving

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