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Using an emic lens to understand how Latino families cope with dementia behavioral problems

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Abstract

Focus group data collected for a larger project to develop a fotonovela for Latino caregivers was used to conduct a meaning-centered thematic analysis in order to elicit Latino family caregiver perspectives on how behavior problems occurring in the context of dementia are perceived and managed. A sample of 42 Spanish-speaking Latino caregivers were recruited from organizations affiliated with the Alzheimer's Association near San Diego, California. Caregivers were queried on challenging behaviors, coping strategies, as well as other daily challenges. Focus group sessions were conducted in Spanish, translated and transcribed into English, and analyzed using qualitative, grounded anthropological methods. In addition to a range of behavior problems, five indigenous approaches to managing challenging behaviors were identified: acceptance, love, patience, adaptability, and establishing routines of care. Additionally, participants identified persistent challenges which deter effective coping. These include: issues with providers, problems with family members, limited knowledge of resources, emotional distress, and financial strain. To our knowledge, this is one of the few qualitative studies to report indigenous coping strategies for dementia behavioral problems. These findings have the potential to inform culturally-tailored intervention.

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Introduction

The Alzheimer's Association reports that 5.2 million people have Alzheimer's disease or a related dementia; among the many ethno-cultural groups affected, Latino elderly patients are particularly vulnerable to this disease as they are 1.5 times more likely than non-Hispanic whites to be diagnosed with dementia.¹ Recent population projections provide clues to how severely this pandemic² is likely to affect Latinos. Specifically, due to the tripling of the U.S. Latino population in the next four decades,³ Latinos will comprise 20 percent of America's elderly by the year 2050.⁴ Additionally, a recent nationwide study indicates that Latinos have the highest percentage of family caregivers over all other ethnic groups including Caucasians.⁵ Given the impact of projected population increases on aging Latinos, studies which examine the experiences and unmet needs of Latino dementia caregivers are imperative.

Growing evidence indicates that Latino caregivers suffer health disparities associated with dementia behavioral problems and caregiving distress or depression. Further compounding this disparity is that Latinos with dementia often demonstrate higher levels of behavioral problems when compared to other groups.^{6,7} Consequently, Latino caregivers also report higher levels of depressive symptoms when compared to caregivers who are non-Hispanic white⁸, as well as those from other ethnic groups.⁹

A number of studies have found that Latino dementia care-givers who deal with significant behavior problems suffer the consequence of diminished mental health; other investigations have identified familial and systemic factors that contribute to inadequate receipt of care among Latino recipients of health services. Accumulating evidence shows that behavior problems are a salient contributor to depression in Latino caregivers,^{6,8} and are associated with higher levels of disability in the person with dementia.⁶ We also know that Latino dementia caregivers report seeking help for dementia-related problems in primary care but do not receive adequate professional support.¹⁰ According to Hinton et al.¹⁰, the most commonly reported service barriers were information and counseling which would assist caregivers in managing challenging recipient behaviors. Further exacerbating unproductive dementia care, is the tendency of Latino families to attribute behavior problems to causes other than dementia itself, which may impede the diagnosis process as well as opportunities for professional help-seeking.¹¹

Although Latino caregivers can be non-kin relatives of the recipient, studies focused on the Latino family provide a framework for understanding how caregivers experience and negotiate caregiving obligation in their day-to-day lives. *Familism*, identified in the literature as a defining characteristic of Latino culture¹², describes the way in which Latino family units display attachment that is rooted in feelings of solidarity, loyalty, and reciprocity.¹³ It is a major cultural value that influences who will take on the caregiving role and how that role will be enacted.¹² Henderson and Guitierrez-Mayka¹⁴ note that caregiving duties, most often carried out by a female in nearly every ethno-cultural group, including non-Hispanic whites, actually have a ranked preference in Latino cultures. Usually a female spouse, provided the recipient is male and married, is the primary caregiver. If she is not present, caregiving duties fall to the sister or another female 'blood relative'. The next

preferred person to assign caregiving duties is a female who is non-kin. Only when all attempts for procuring a female caregiver have been expended, are male relatives considered for caregiving duties.¹⁴

For both family and non-kin caregivers, behavioral management is a primary challenge Latino caregivers contend with.^{6,10} Ethnographic studies have the potential to illuminate nuances in family dynamics related to behavioral management not frequently reported in large-scale studies. In ethnography conducted by Apesoa-Varano et al.,¹⁵ Latino families impacted by a dementia diagnosis and associated aggressive behavior described their strategies for alleviating neuropsychiatric symptoms exhibited by the recipient with dementia. Findings revealed that when a family (a) elicited other family member help in boosting the primary caregivers' coping skills, (b) obtained education about the caregiving role, and (c) adopted a biomedical view of Alzheimer's disease, the unit increased their capacity to deal with aggressive behavior.

Despite growing evidence that behavior problems exhibited by the recipient have consequences for the mental health of the Latino caregiver,^{6,8,9,16} and that qualitative methods have the potential to enhance our understanding and development of culture-specific intervention,^{17,18} few studies have used an emic, meaning-centered lens to capture the everyday experience of the Latino caregiver for the purpose of informing ecologically valid intervention design. Utilizing an *emic* perspective is consistent with qualitative approaches described by Cresswell,¹⁹ which indicates that the participant viewpoint, or emic perspective, in combination with the researchers position, or *etic* viewpoint, facilitates the goal of a holistic cultural picture in cross-cultural qualitative studies. Meaning centered analysis,²⁰ the method used to obtain the emic component of this investigation, is an interpretative branch of medical anthropology first coined by Kleinman²¹ in a seminal paper asserting that health care delivery is enhanced when medical systems are conceived as cultural systems. Outlined therein is the premise that understanding the patients' explanatory model, which incorporates the varied 'clinical realities' among all stakeholders in health system (including the patient), is a fundamental component of effective communication, and thus, productive relationships among patients and their providers.²¹ Our study embraces this meaning-centered tradition in a cross-cultural research setting to reveal the participant-described lived experience, as well as participant-derived solutions to challenges faced by dementia family caregivers. Specifically, focus group data collected to create a caregiver *fotonovela* about managing caregiver stress, was used examine how Latino caregivers in the southernmost counties of California perceive, represent, and cope with dementia behavior problems in their daily lives. Our findings have the potential to inform both intervention and research undertakings, and they facilitate the objective of tailoring services to meet the distinct needs of this fast-growing underserved ethnocultural group.

Method

Focus groups were conducted with Latino caregivers of persons with Alzheimer's disease and/or a related dementia. Using an a priori interview guide developed by the research team, we asked caregivers to share personal experiences about difficult behaviors, how they coped with or managed those behaviors, and any other difficulties they experienced related to

dementia behavioral symptoms. The goal of the focus groups, as described to participants, was to elicit their perspectives and opinions in order to help investigators develop content for an intervention. Due to the thematic density of the data associated with problem behaviors and coping, as well as the potential for the information gleaned to augment intervention work beyond the scope of the fotonovela, we embarked on an additional qualitative investigation to fully capture the wealth of information the caregivers provided us.

The meaning-centered analysis described in this study utilized anthropological methods to examine focus group data. Thematically-guided focus groups are ideal for cross-cultural and gerontological settings,²² and have a history of being used to assess health education messages, attitudes toward health behaviors, and stakeholder experiences of illness and service use.²³ The use of meaning-centered qualitative inquiry^{20,24} allowed us to give substance to nuances not explicated in previous research about how Latino caregivers cope with behavioral problems, and it illuminated organizational, social, and family dynamics which characterize the dementia care relationship among Latino caregivers living in the southernmost areas of California.

Four focus groups were held with predominantly monolingual Spanish Latino caregivers living in San Diego and Imperial counties in the months of November and December, 2008. The two groups assembled in San Diego County were held at the San Ysidro Health Center and at Casa Familiar, a community redevelopment agency also in San Ysidro. The two groups conducted in Imperial County took place at community centers in the towns of Calexico and El Centro. All locations were coincident with the service catchment area of the Alzheimer's Association chapter providing services to these California counties, and they facilitated recruitment site linkages. Participants were recruited via convenience sample through community health clinics, day care centers, and other senior-serving organizations. Within these establishments, we obtained contact with potential participants through referrals from staff who worked with elders having dementia, their caregivers, and other family. Recruitment, which involved posting bilingual fliers containing the meeting place information, was used to publicize the date, time, and location of each focus group.

Just prior to the focus group session, each participant filled out a survey to gather the demographic information depicted in Table 1. A Spanish version of the survey was provided for those who were monolingual Spanish. Focus groups lasted approximately one-and-a-half to two hours and were conducted by Dr. Ramón Valle who facilitated these discussions using an interview guide developed by the research team. The interview guide elicited information associated with the following domains:

1. Specific behaviors that caregivers find difficult in the day-to-day management of persons with dementia
2. Coping and management strategies that caregivers presently use in their daily lives to deal with behavior problems
3. Opportunities to discuss other emergent themes and topics

This a priori discussion guide encouraged open conversation during a data collection process that involved two phases. First “raw” data were obtained by digitally recording each focus group session. During that time, at least one bilingual/bicultural assistant was present and taking notes on the dialogue. During facilitation, the investigator was required to mindfully convey discussion points in a form understood by the participants while simultaneously interpreting participant commentary and then adapting subsequent questions to accommodate unanticipated answers. Occasionally conversations would stray from the discussion outline and the facilitator would then redirect the exchange in order to cover each of the prompts. During Phase 2, digital recordings for all four sessions were transcribed, translated, and thematically organized into matrices using the table feature in MS Word. The matrix outline corresponded to points in the discussion guide. Data was translated by converting colloquial Spanish content to colloquially equivalent English, taking into consideration the flow, local syntax, and popular idioms. Attention to this detail helped ensure that meanings extracted from the verbal data were valid for both languages. The matrices, composed of Spanish and their linguistically equivalent English, became the data sets used for analysis.

Human subjects clearance

Human subjects’ oversight was provided by the Stanford University Institutional Review Board and a signed informed consent was obtained for each participant. We note here that a 16 year-old providing a major portion of the hands-on caregiving for her grandmother had an aunt present at the discussion and she provided consent for the young woman's participation.

Participant characteristics

A total of 42 caregivers participated in the four focus groups, and each group accommodated between 8 and 12 participants. The two San Diego groups hosted 8 and 10 participants respectively, and the Imperial Valley groups hosted 12 participants each. Caregiver ages ranged from 16 to 86 years, and 93% were women. Slightly more participants cared for a family member (55%) compared to those caring for a friend or family friend (45%). Table 1 provides a profile of the participants in this study.

Analysis

Data analysis proceeded in iterative stages between November 2011 and February 2012 by three qualitative researchers having prior experience conducting studies in cultural gerontology. A co-investigator (Dr. Ladson Hinton) held team meetings between each coding session to discuss coding results, assist research assistants with developing and refining themes, and insure that coders developed inter-rater agreement. During the first step of the process, researchers read each data set and noted (a) any problem behavior described by the participants, and (b) each type of coping response including those that resulted in both positive and negative outcomes. In this first exercise, researchers identified links between particular management and coping styles and the outcome of the respective styles on the caregiver or recipient. During a subsequent discussion and coding exercise, research assistants determined the three major categories of inquiry (i.e. behaviors, coping strategies, and major challenges) based on their prevalence in the data. Subcategories of the major

themes emerged through a process of saturation²⁵, and five subcategories within the core categories of coping strategies and major challenges emerged from the data during the third coding meeting. The next task was for research assistants to recode all of the data using these newly refined themes. Problematic behaviors were documented when they were described by caregivers in the data. Following the second round of coding, a final meeting was called to discuss and identify focus group dialogue that both optimally characterized subthemes and reflected agreement between raters. These passages comprise the results of the study.

Results

Prominent behaviors

Caregivers described a wide range of behavioral problems including aggression, delusions, sundowning, agitation, diminished hygiene and body function, paranoia, wandering, and disinhibition. Diminished hygiene, disorientation, wandering, overt sexuality, and agitation were described often, and emerged as common behaviors caregivers contend with. Diminished body function refers, in this context, to the reduction of the recipients' ability to eat, use the bathroom, and talk without assistance, and it was another prominent behavior category discussed by caregivers interviewed here. Behaviors that were less often mentioned, but exceptionally challenging, included paranoia as well as eating and smearing feces.

Coping and management

In the discussions, caregivers described how they coped with difficult behavioral problems on a day-to-day basis. In the following section, we describe five categories of caregiver approaches to managing difficult behavior problems that emerged during the focus group sessions. These include: acceptance, communicating love, maintaining patience and tolerance, adaptability, and establishing routines.

Acceptance—Multiple caregivers identified acceptance of the recipients' dementing illness and associated behavior problems as a key strategy for coming to terms with difficult circumstances. The following quote from one participant summarizes a consensus expressed within several group discussions—that acceptance preconditions a smoothly functioning dyad: “We've talked here that the first thing we need to do is accept the illness.” And as another participant stated: “There has to be acceptance of the disease—that it is progressive and worsening and that there is not cure.” For some caregivers, acceptance involved taking a non-judgmental attitude toward the recipient's behavior. “*But as we are talking here, the patients* who are doing these things, it's not for us to criticize or scold them, but rather to understand them and learn how to treat them.” A final aspect of developing acceptance of the disease, involved the presence of mind to not take difficult behaviors personally: “I recommend to everyone not to be offended because your family member rejects you—not for a minute.”

Demonstrating love—Cultivating a loving rapport and finding ways to respond with affection although the nature of the relationship has changed, was another recommended

care management strategy. In the following example, a caregiver acknowledges the remaining bond he has with his wife who is diagnosed with dementia: “Even though she's no longer aware that I am her husband, unconsciously she knows I am someone who is always there for her...[even] in those moments when she doesn't know me or who I am.” Another participant reflected on the importance of applying a loving response in combination with other key attributes while engaged in the caregiving role: “The most important thing is to be able to touch the person's heart and to do so we need many different qualities. I can't remember all of them, but for example, one of the most marvelous in the world is love for others, there's also tons of patience, understanding, and being able to handle situations as they present themselves.”

Patience and tolerance—Patience and tolerance were commonly cited in tandem as a coping response to highly disturbing behaviors, and especially those observed late in the disease process: “To care for persons with Alzheimer's disease, and who are very advanced, there needs to be much, much patience...” Another participant dealing with a family member demonstrating difficult repetitive behavior added: “We have to be patient, because one loses patience when one has to repeat the same thing every five minutes—at times this is a little frustrating.” A third caregiver who experienced challenges related to overt sexuality added: “There are persons whose talk is purely sexual. This can't be easily changed...because of the Alzheimer's or dementia he had, [he] would begin to touch all the girls because he couldn't distinguish if they were girls or grown women. Again, with patience, we were able to distract him.”

Adaptability—This theme refers to instances where caregivers revealed strategies that demonstrate flexibility and creative problem solving and ultimately facilitate successful adaptation to challenges in the caregiving environment. Dialogue from two participants in a focus group revealed information about the process of adapting while working with care recipients: “All cases are different, not all [with dementia] are the same...there are many different things that can happen. You have to adjust to the patient, if they want to play...or [sometimes you have] to distract them, or [you may have to] act in many different ways.”

In the following instances, redirection is described as an effective problem-solving strategy for working with sexual disinhibition, delusions, and repetitive questions: “The gentleman I take care of sometimes takes his clothes off and says to me, ‘let's go to bed’, but I say, ‘no, I have to cook’, or I do something else, and I leave the room, and he says, ‘OK’, and he dresses, forgetting what he did.” A specific example of creative problem solving is portrayed in this caregiver's response to her mother's delusional wish to “go home”: “Sometimes Mama gets very anxious even though she's in her own home. She says to Papa, ‘come on Honey, let's go home’. And she keeps this up until I say, ‘come on Mama, come on Papa, I'll take you’. And I put them into the car and we drive for a while, and when I return to their home, Mama says, ‘look Honey, we're here!’ She forgets everything.” Another caregiver who encountered monotonous questioning from her recipient employed the following strategy: “I know a woman who asks every 15 seconds, ‘what time is it?’, and we talk to her and say, ‘were going to do this, and this, and that’ [engages recipient in an activity], and then we go ahead and do something different. In this way she's not always watching the clock.”

Establishing routines—The need to create routines and the concurrent difficulty implementing them was especially prominent for caregivers who coped with *sundowning* whereby the recipient has a tendency to sleep during the day and remain awake throughout the night. To better cope with this nocturnal activity, multiple caregivers expressed a desire for help with establishing care routines which they saw as a way to manage these difficult behaviors. “We want information about how to establish routines for toileting, bathing, eating, dressing, exercise, and [how] patients can keep busy and enjoy themselves.”

Major unresolved challenges

During discussions of behavioral problems and coping strategies, caregivers also described additional unresolved challenges in the respective focus group sessions. Five major categories included: ongoing issues with providers, problems with other family members, the caregivers’ general limited knowledge of available resources, unremitting emotional distress, and financial strains.

Issues with providers—As focus group discussions progressed and often became intense, caregivers candidly described ongoing provider non-responsiveness, “I ask the doctor and I get no reply...they don't give us answers. They see us as ignorant persons...If we don't ask, they don't tell us anything.” Another caregiver expressed her frustration with social workers: “I've told you about the experiences I've had with social workers...I've felt that they know nothing about the illness. They don't get training [about Alzheimer's disease]...they fill out a paper and they do this and that, and then they make notes and comments...one [even] said to me, ‘look I know nothing about [Alzheimer's disease].’” The same caregiver added: “I feel [that]...they don't even take the trouble to train the social workers.”

A common challenge impacting many dementia-affected communities is the lack of accurate and timely diagnoses—even when symptoms of dementia are evident²⁶. In this passage, the caregiver confronts provider non-responsiveness so that he can obtain a dementia diagnosis for his wife who is exhibiting symptoms of dementia.

“And I said, ‘you know doctor I see my wife in this way and you in another’. And he said [in reference to the symptoms], ‘it might be because of the medications she's taking for her diabetes’. Well, we left it at that, and some days passed, and I lost her in Tijuana, and there I [was] looking everywhere. And then somehow she remembered where we were parked, and we found each other. Then, I went back to the doctor and told him, ‘you know, this and this happened in [in Tijuana]. Why don't you have her examined to see if this is Alzheimer's, because for me, this is really serious.’ Then he said, ‘OK, I'll do a test’, and he referred me to a neurologist. But for me, I had to go through so much!.”

Problems with other family members—Major sources of strain for primary caregivers in this study were unavailable and unresponsive family, and they reported conflicts at various levels. Many acknowledged the inherent struggle of being the sole caretaker when other family members are incapable of taking part in the caregiving role: “I take [my mom] to my sister and brother's so that I can get a little rest, and they...bring her right back. And

they say that they don't know what to do with her.” Another caregiver added, “...none of my other family members want to provide care.” Still another primary caregiver said: “My other family members don't understand. I want to take them to the doctor to help them understand, but they won't go.”

Limited knowledge of resources—As one caregiver stated: “There are many persons who need services but they just don't go to get them because they don't know how to.” Another focus group participant inquired, “...are there medications for those who have Alzheimer's? My mother is always very agitated, she is a bundle of nerves and we can't calm her, is there a medicine for this?” Still another participant said: “I didn't know there were [day care] centers for Alzheimer's patients...I didn't know there was a center in Tijuana.” An additional participant speaking in reference to the dissemination of Alzheimer's disease literature added, “It's not a well-publicized illness in the community.”

Emotional distress—One family caregiver who noted the physical and emotional toll placed on his wife, the primary hands-on caregiver, stated: “[She] becomes visibly anxious...and her diabetes worsens, [and her] insulin uptake increases.” Another caregiver spoke about the danger of prolonged depression: “Some caregivers...remain in a depression that can take them to their death.” This was followed by other evocative comments:

“When one starts to give care, well one cries a lot and feels bad and depressed, because [the recipient] is always saying [bad] things, and they are always bothering you...that you are a thief, that you are always robbing them...when she loses her glasses, she accuses me...and she also says that thieves come at night and eat her food. But I never treated her badly...behind this, there are lots of tears.”

Financial strains—A major unresolved obstacle reported by participants was maintaining an income while caring for the person with dementia. One focus group participant openly described her conflict between needing to be employed and having to be present for a demented spouse, which ultimately resulted in placing the recipient in an unsafe situation: “I have to work, and I have to leave my husband home alone.” Financial conflicts also presented themselves to caregivers receiving In-Home Supportive Services (IHSS). These caregivers were caught between the need for respite, and also needing the income IHSS provided them: “How can I pay whomever [when] I want the hours...” Caregivers paid through the caregiver support program who also provided constant hands-on care described another form of financial strain: “We get paid, but not for all of the care...what they pay is not equal to the care needed.”

Discussion

Latino caregivers in this study underscored the importance of problem behaviors while emphasizing a set of coping strategies and contextual factors that complicate the care of a loved one with dementia. While the importance of problem behaviors among Latino families affected by dementia has been described in other work,^{6,15,27} our study advances the literature by identifying specific culturally-based coping strategies and approaches that caregivers report using in their day-to-day lives. These strategies include maintaining

flexibility, accepting behaviors, demonstrating love and patience in the interactions with the person with dementia, and establishing routines of care. Caregivers attempt to deal with behavioral problems of their loved one despite strains and stresses, including problematic relationships with providers and family members, socioeconomic constraints, their own emotional distress, and limited knowledge of resources. Thus, our study provides a description of several aspects of the sociocultural context in which problem behaviors and caregiving happen.²⁸

A framework for understanding how cultural values differentially influence the caregiving experience and the caregivers' subsequent ability to cope is proposed by Knight and Sayegh.²⁹ This model postulates that choice and use of coping strategy as well as the coping strategies available are influenced by cultural values. As such, research focused on how to help Latino caregivers reduce behavior problems and burden appraisal would serve to enhance coping capacity. In this vein, Apesoa-Varano et al.¹⁵ give clues to the components of optimal behavioral management. Authors elucidate three disparate coping responses observed from Latino families struggling with the aggressive behaviors of a person diagnosed with dementia. This ethnographic representation of Latino family caregiving dynamics adds to our understanding of the effective coping strategies demonstrated in this study because it shows that when appropriate educational supports have been implemented, successful management is possible. In particular, when families adopt a biomedical view of dementia, that is, attribute cognitive impairment and resulting aggressiveness to a medical condition or 'brain disease' there is a reduced tendency to interpret the diagnosed person's behavior as volitional. Specifically taking the caregivers' conception of adaptive coping one step further, the Apesoa-Varano et al.¹⁵ findings have additional relevance. One aspect of learning to adjust to the recipients' needs would be acquiring the ability to not reciprocate aggressive behavior with further aggression. In realizing the futility of trying to reason with a person who has dementia, the caregiver then has an increased skill-set with which to effectively cope with the difficult behaviors demonstrated by the family member who has dementia.

Caregivers in this study did not overtly reference religious affiliation as a coping strategy, but religiosity among caregivers has been examined as a moderator to caregiver stress³⁰ and caregiver well-being.³¹ It is worth noting that several of the coping strategies that emerged in this study reflect Christian values such as patience, tolerance, and love. Referring specifically to love, caregivers in the current study used this attribute in a number of different ways. First, caregivers referenced love as a mechanism to look past current barriers and still provide effective care despite knowledge that the disease process altered the way in which the recipient contributed to the relationship in the past. Love was also used to convey the importance of human-centered care, particularly when caregivers described the need to 'touch the heart', or that 'reaching the heart' of the recipient was still possible even though the disease had significantly impaired the recipients' memory. Finally, love was described by caregivers as a universal value, whereby an all-encompassing 'love for others' facilitated the caregivers ability to persist in a difficult role. Neary and Mahoney³² provide an additional perspective on the attribute of love in a similar qualitative analysis of Latino dementia caregiving. Here, love was determined to be both an impetus to take on the caregiving role as well as a facilitator of ongoing care. Additionally, authors describe how

Latino caregivers used a loving stimulus, including caress, to help control agitation among recipients of care.³²

While the findings in our study indicate that caregivers are indeed using the knowledge and resources they have to manage a difficult situation, it is also evident that unresolved challenges exist and contribute to caregiver strain. Caregiver dialogue that delineated the five unresolved challenges gives valued feedback about what systems' are presently missing in their quest to provide culturally competent care; participant dialogue also provides a glimpse into difficult family dynamics that question stereotypical notions of familism. Specifically, these challenges included (a) ongoing issues with providers who lacked knowledge of dementia; (b) problems with other family members who were incapable of assisting with the burden of care; (c) the participants' own admitted or general lack of knowledge about available resources; (d) the unremitting emotional distress the participants feel; and (e) the financial strains which are brought on by the dementing illness of one family member and the non-involvement of other family members.

One important finding consistent with a common trend seen in the Latino caregiving literature is the lack of adequate general knowledge about dementia.³³⁻³⁵ In our study, caregivers were not aware of the medications available to supplement the management of problem behaviors, nor were caregivers always cognizant of the social-organizational supports which could potentially alleviate caregiver burden. In other studies, lack of basic knowledge, particularly regarding onset, course and symptoms of dementia is repeatedly noted. For example Neary and Mahoney³² found that among the least educated Latino caregivers, when queried about initial responses to dementia onset, they would frequently attribute behavioral symptoms to 'old age', 'craziness', or 'spells'. Hinton et al.¹¹ found similar results among a multiethnic (including Latino) sample of family caregivers. They determined that minority caregivers having less education were significantly more likely to use a 'folk' attribution, such as 'craziness' to explain dementia-related changes in the recipient of care.

Limitations

This study has a number of limitations, beginning with the most significant, which affect the interpretation of these findings. Focus groups were assembled based on a convenience sample in which unpaid family caregivers, unpaid close family-friend caregivers, as well as paid IHSS caregivers (both family and non-family) were invited to participate. Due to the informal nature of these meetings, in-depth demographic data are not available to explicate similarities and differences among these groups. It may be that family caregivers face somewhat different challenges (and cope in different ways) compared to non-family caregivers and those who receive payment. This is an area for future research to explore. Second, our study sample was compiled of 42 caregivers all living in the southernmost areas of California. The size of the sample would make it difficult to generalize our results to a larger population of Latino caregivers. Third, we recognize that the participants who attended these focus groups could have been higher functioning and could have been more socially connected than many other caregivers due to the fact that they had the time, energy, and resources to attend these meetings. This is especially relevant to our assertion that many

caregivers are coping well, a conclusion that may be influenced by these factors. Finally, due to the fact that qualitative methods were used to collect and analyze data, the findings described here are subject to observer bias.

Conclusions

The purpose of this study was to qualitatively analyze focus group data collected from 42 Latino dementia caregivers in order to glean information about how they explain and cope with dementia-related behavioral problems and other challenging aspects of the caregiving experience. We sought information in this manner for the purpose of informing future interventions for Latino caregivers which have a high degree of ecological and cultural validity. In this vein, our emic¹⁹, meaning-centered inquiry^{20,24} captures the lived experience of the people affected by a given phenomenon in order to include the perspectives of each stakeholder in the illness process and contribute a holistic solution to current barriers of care. Consistent with an emic investigative approach, through closely attending to how individuals describe the complex details of their lives, and then bringing these observations to the forefront, we have enabled the unadulterated voice of the participant to be the focus of inquiry. This strategy provides a distinctive opportunity for the research and lay community to hear the perspectives of people often relegated to the sidelines. Furthermore, when such dialogues are utilized by larger organizational and systemic structures, there is an increased potential to implement ecologically valid interventions.^{17,36,37}

Considering our larger objective of using the information gleaned from this study to directly inform future interventions intended to support Latino caregivers, findings from Napoles et al.³⁸ give clues to how the information we obtained will supplement culturally-attuned intervention design intended to boost coping skills and augment family and organizational environments utilized by Latinos. In particular, Latino participants in other studies have experienced greater self-efficacy, better anger control, decreased burden, and diminished depression when they engaged in skill training interventions.³⁸ The findings from our study provide support for multi-systemic³⁹ therapeutic interventions which would potentially increase skills at intrapersonal, interpersonal, and group-level functioning. For example, at the individual and interpersonal levels, coping would be enhanced by utilizing a therapeutic strategy which assists caregivers with coming to terms with the inevitability of the recipient's progressive changes, while also providing techniques for implementing flexible, creative responses to challenging behavior problems. At the group and systems level, caregiver coping would be enhanced by intervening within the organizational structures that serve Latino elderly patients. The findings from our study imply that care providers working with cross-cultural elderly often lack the expertise needed to effectively work with family members affected by dementia. A recommended systems-level intervention would be for educational intuitions and health care systems to more routinely train and employ providers who are both bicultural and adequately prepared to work with families affected by a dementia diagnosis.

With the above noted, we believe this study contributes original knowledge to our current understanding of Latino dementia caregiving dynamics. In doing so, we have a nascent, but

replicable, meaning-centered approach through which to examine Latino perspectives on dementia care within the current social environment. We recognize that there is still considerable work left to do. In this context, we present our findings in the hopes of assisting others with how to draw a composite picture for their own working environments. The Latino community, and by extension the broader community residing alongside Latinos, are facing a massive, growing, and yet still largely hidden dementing illness crises. We have presented an outline for how others might proceed in future studies in order to strengthen and extend this knowledge base.

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References

1. Association As. 2013 Alzheimer's disease facts and figures. *Alzheimer's and Dementia*. 2013; 9(2): 1–71.
2. Holtzman JL. Are we prepared to deal with the Alzheimer's disease pandemic? *Clinical Pharmacology and Therapeutics*. 2010; 88(4):563–565. [PubMed: 20703225]
3. Passel, JS.; Cohn, D. U.S. populations projections: 2005-2050. Pew Hispanic Center; Washington, DC: 2008.
4. Jacobson, LA.; Kent, M.; Lee, M.; Mather, M. America's Aging Population. *Population Bulletin*. Population Reference Bureau; Washington, DC: 2011. <http://www.igwg.org/pdf11/aging-in-america.pdf>
5. Caregiving EaNAf. Evercare Study of Hispanic Family Caregiving in the U.S. National Alliance for Caregiving; Bethesda, MD: 2008.
6. Hinton L, Haan M, Geller S, Mungas D. Neuropsychiatric symptoms in Latino elderly with dementia and mild cognitive impairment without dementia and factors that modify their impact on caregivers. *The Gerontologist*. 2003; 43(5):669–677. [PubMed: 14570963]
7. Ortiz F, Fitten J, Cummings JL, Hwang S, Fonseca M. Neuropsychiatric and behavioral symptoms in a community sample of Hispanics with Alzheimer's Disease. *American Journal of Alzheimer's Disease and Other Dementias*. 2006; 21(4):263–273.
8. Harwood DG, Barker WW, Cantillon M, Loewenstein DA, Ownby R, Duara R. Depressive symptomology in first-degree family caregivers of Alzheimer disease patients: A cross-ethnic comparison. *Alzheimer's Disease and Associated Disorders*. 1998; 12(4):340–346.
9. Covinsky KE, Newcomer R, Fox P, et al. Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of General Internal Medicine*. 2003; 18(12):1006–1014. [PubMed: 14687259]
10. Hinton L, Chambers D, Velasquez A, Gonzalez H, Haan M. Dementia neuropsychiatric symptom severity, help-seeking patterns, and family caregiver unmet needs in the Sacramento Area Latino Study on Aging (SALSA). *Clinical Gerontologist*. 2006; 29(4):1–15.
11. Hinton L, Franz CE, Yeo G, Levkoff SE. Conceptions of dementia in a multiethnic sample of family caregivers. *Journal of the American Geriatrics Society*. 2005; 53(8):1405–1410. [PubMed: 16078970]
12. Losada A, Robinson Shurgot G, Knight BG, et al. Cross-cultural study comparing the association of familism with burden and depressive symptoms in two samples of Hispanic dementia caregivers. *Aging and Mental Health*. 2006; 10(1):69–76. [PubMed: 16338817]

13. Sabogal F, Marin G, Otero-Sabgal R, Marin BV, Perez-Stable E. Hispanic familism and acculturation: What changes and what doesn't? *Hispanic Journal of Behavioral Sciences*. 1987; 9(4):397–411.
14. Henderson JN, Gutierrez-Mayka M. Ethnocultural themes in caregiving to Alzheimer's disease patients in Hispanic families. *Clinical Gerontologist*. 1992; 11(3-4):59–74.
15. Apesoa-Varano, EC.; Barker, JC.; Hinton, L. Mexican-American families and dementia: An exploration of "work" in response to dementia-related aggressive behavior.. In: Angel, J.; Torres-Gil, F.; Markides, K., editors. *Aging, Health, and Longevity in the Mexican-Origin Population*. Springer; New York: 2012. p. 277-292.
16. Harwood DG, Barker WW, Ownby R, Bravo M, Aguero H, Duara R. Predictors of positive and negative appraisal among Cuban American caregivers of Alzheimer's disease patients. *International Journal of Geriatric Psychiatry*. 2000; 15(6):481–487. [PubMed: 10861912]
17. Bernal G. Intervention development and cultural adaptation research with diverse families. *Family Process*. 2006; 45(2):143–151. [PubMed: 16768015]
18. Hughes D, Seidman E, Williams N. Cultural phenomena and the research enterprise: Toward a culturally anchored methodology. *American journal of community psychology*. 1993; 21(6):687–703. [PubMed: 8085565]
19. Cresswell, JW. *Qualitative inquiry and research design: Choosing among five approaches* 3rd Edition ed. Sage; Thousand Oaks, CA: 2013.
20. Farmer, P.; Good, BJ. Illness representations in medical anthropology: A critical review and case study of the representation of AIDS in Haiti.. In: Skelton, JA.; Croyle, RT., editors. *Mental representation in health and illness*. Springer-Verlag; New York: 1991. p. 132-161.
21. Kleinman A. Concepts and a model for the comparison of medical systems as cultural systems. *Social Science & Medicine*. 1978; 12:85–95. [PubMed: 358402]
22. Knodel J. Focus groups as a qualitative method for cross-cultural research in social gerontology. *Journal of cross-cultural gerontology*. 1995; 10(1-2):7–20. [PubMed: 24389769]
23. Kitzinger J. Qualitative research: Introducing focus groups. *British Medical Journal*. 1995; 311(7000):299–302. [PubMed: 7633241]
24. Kleinman, A. *The illness narratives: Suffering, healing, and the human condition*. Basic Books; New York: 1988.
25. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*. 2002; 1(2):13–22.
26. Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer's Disease and Associated Disorders*. 2009; 23(4):306–314.
27. Gallagher-Thompson D, Coon DW, Solano N, Ambler C, Rabinowitz Y, Thompson LW. Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: Site-specific results from the REACH national collaborative study. *The Gerontologist*. 2003; 43(4):580–591. [PubMed: 12937336]
28. Dillworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist*. 2002; 42(2):237–272. [PubMed: 11914467]
29. Knight BG, Sayegh P. Cultural values and caregiving: The updated sociocultural stress and coping model. *Journal of Gerontology: Psychological Sciences*. 2010; 65B(1):5–13.
30. Leblanc AJ, Driscoll AK, Pearlin LI. Religiosity and the expansion of caregiver stress. *Aging and Mental Health*. 2004; 5(5):410–421. [PubMed: 15511739]
31. Hebert RS, Weinstein E, Martire LM, Schulz R. Religion, spirituality and the well-being of informal caregivers: A review, critique, and research prospectus. *Aging and Mental Health*. 2006; 10(5):497–520. [PubMed: 16938685]
32. Neary SR, Mahoney DF. Dementia caregiving: The experiences of Hispanic/Latino caregivers. *Journal of Transcultural Nursing*. 2005; 16(2):163–170. [PubMed: 15764640]

33. Mahoney DF, Cloutterbuck J, Neary SR, Zhan L. African American, Chinese, and Latino family caregivers' impression of the onset and diagnosis of dementia: Cross cultural similarities and differences. *The Gerontologist*. 2005; 45(6):783–792. [PubMed: 16326660]
34. Mukadam N, Cooper C, Livingston G. A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*. 2011; 26(1):12–20. [PubMed: 21157846]
35. Gray HL, Jimenez DE, Cucciare MA, Tong HQ, Gallagher-Thompson D. Ethnic differences in beliefs regarding Alzheimer disease among dementia family caregivers. *American Journal of Geriatric Psychiatry*. 2009; 17(11):925–933. [PubMed: 20104051]
36. Bernal G, Bonilla J, Bellido C. Ecological validity and cultural sensitivity for outcome research: Issues for the cultural adaptation and development of psychosocial treatments with Hispanics. *Journal of Abnormal Child Psychology*. 1995; 23(1):67–82. [PubMed: 7759675]
37. Bronfenbrenner U. Toward an experimental ecology of human development. *American Psychologist*. 1977; 32(7):513–531.
38. Napoles AM, Chadiha L, Eversley R, Moreno-John G. Reviews: Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer's Disease and Other Dementias*. 2010; 25(5):389–406.
39. Robbins, SP.; Chatterjee, P.; Canda, ER. *Contemporary Human Behavior Theory: A Critical Perspective for Social Work*. 2nd ed.. Pearson; Boston, MA: 2006.

Table 1

Characteristics of focus group participants n = 42

Characteristics	Categories	N (%)
Mean age	53.6 (Range: 16-86)	
Gender	Female	39(93)
	Male	3(7)
Relationship to Recipient	Family	23(55)
	<i>Spouse</i>	<i>6(14)</i>
	<i>Daughter or son</i>	<i>8(19)</i>
	<i>Other family member</i>	<i>9(22)</i>
Educational attainment	Friend or family friend	19(45)
	0-6 grade	13(30)
	7-9 grade	5(12)
	10-12 grade	12(29)
Duration of caregiving	13 or more years	12(29)
	Less than one year	7(17)
	One to three years	10(24)
Caregiving hours per week	More than three years	25(59)
	20 hours or less	19(45)
	30 hours or more	23(55)
	<i>3-4 days per week (30-40 hours)</i>	<i>4(10)</i>
	<i>Nearly the whole week (50-60 hours)</i>	<i>8(19)</i>
	<i>Throughout the week (60+ hours)</i>	<i>11(26)</i>