



Beyond Familism: A Case Study of the Ethics of Care of a Latina Caregiver of an Elderly Parent With Dementia

Yvette G. Flores , Ladson Hinton , Judith C. Barker , Carol E. Franz & Alexandra Velasquez

To cite this article: Yvette G. Flores , Ladson Hinton , Judith C. Barker , Carol E. Franz & Alexandra Velasquez (2009) Beyond Familism: A Case Study of the Ethics of Care of a Latina Caregiver of an Elderly Parent With Dementia, Health Care for Women International, 30:12, 1055-1072, DOI: [10.1080/07399330903141252](https://doi.org/10.1080/07399330903141252)

To link to this article: <https://doi.org/10.1080/07399330903141252>



Published online: 04 Nov 2009.



Submit your article to this journal [↗](#)



Article views: 308



View related articles [↗](#)



Citing articles: 28 View citing articles [↗](#)

Beyond Familism: A Case Study of the Ethics of Care of a Latina Caregiver of an Elderly Parent With Dementia

YVETTE G. FLORES

Chicana/o Studies Program, University of California, Davis, Davis, California, USA

LADSON HINTON

Department of Psychiatry, University of California, Davis, Davis, California, USA

JUDITH C. BARKER

Department of Anthropology, History, and Social Medicine, University of California, San Francisco, San Francisco, California, USA

CAROL E. FRANZ

Department of Psychiatry, University of California, San Diego, San Diego, California, USA

ALEXANDRA VELASQUEZ

Medical Center, University of California, San Francisco, San Francisco, California, USA

Caregiving for elderly relatives with dementia is described as a stressful and challenging obligation that disproportionately befalls women in families. Studies of Latina caregivers tend to focus on how the cultural value of familism shapes caregiving expectations and experiences. However, these studies tend not to distinguish between familism as ideology and familism as practice to evaluate how caregiving may or may not conform to prescribed cultural

Received 13 August 2008; accepted 23 June 2009.

The project reported here was funded by the National Institute on Aging, grants AG20343 and AG19809 and by a UC Davis Health System Award to Ladson Hinton, MD.

We acknowledge the careful review and comments on earlier drafts of the article by Dr. Julia Cottle, Dr. Adela de la Torre, and Ms. Vitalee Giammalvo, and the assistance of Emily Prieto in preparation of earlier versions of this article. We extend our deepest appreciation to the families who allowed us into their homes and shared their stories of challenges and courage.

Address correspondence to Yvette G. Flores, PhD, Chicana/o Studies Program, University of California, Davis, One Shields Avenue, Davis, CA 95616, USA. E-mail: ygfloresortiz@ucdavis.edu

scripts nor to examine the ethics of care utilized by family caregivers. Through a case study of a second-generation daughter, we explore the nuances of an ethics of care that constitute her caregiving experiences and the tensions generated by efforts to respect divergent cultural mandates.

In the ethnogerontological literature, familism plays a central role in the academic discourse on the Latino experience of (dementia) caregiving and the propensity of Latinos to underutilize formal services. Yet there is a dearth of ethnographic or qualitative data on Latina/o caregivers examining how historical, structural, and cultural factors may influence caregiver experience and practices. Furthermore, much of the caregiving literature tacitly assumes a somewhat homogenized view of the Latina caregiver, with little attention to how caregiving expectations, experiences, or practices may vary by social characteristics such as gender, generation, or acculturation. The goal of our article is to address some of these gaps in the literature through the presentation and analysis of a case study of a U.S.-born Latina caring for her immigrant mother who suffers from dementia. Our analysis moves beyond notions of familism and examines the nuances of an ethics of care that constitute caregiving by Latina daughters. Our discussion of Latina ethics of care, the values and practices of caring *for* others, is framed by the distinction between familism as “ideology” and as “practice” that was highlighted by Wallace and Facio (1987). More specifically, we use the concept of “an ethics of care” drawn from feminist and Chicana literature on the gendered nature of caregiving (Ibarra, 2003; Tronto, 1993) to move beyond familism as a general ideology to a more “experience-near” account of dementia-caregiving experiences and practices within Latino families.

Familism refers to the value of the family as an institution, the ideal of interdependence in family relationships, and the priority placed on reliance on family members rather than on more impersonal institutions for instrumental, emotional, and material support (Marin & Van Oss Marin, 1991). Familism as ideology refers to cultural values that guide family relationships (Sabogal, Marin, Otero Sabogal, & Marin, 1989). While familism is possibly a universal value and not unique to Latinos, the high priority accorded to family often is regarded as the most significant common cultural denominator among Latinos of various national origins, and the value most likely to remain unchanged despite migration and increased acculturation (Hurtado, 1995; Marin & Van Oss Marin, 1991; Velasquez, Arellano, & McNeil, 2004). The influence of familism on caregiving behaviors among Latinos has been studied only recently. With the exception of Ibarra (2003) and Henderson (1996, 1997), few researchers have examined how familism as a cultural value or ideology may influence family relationships through performance of the ethics of care for Latina caregivers. Moreover, no studies to date have examined how cultural values are translated into caregiving behaviors among Latina daughters. Likewise, the extant literature does not articulate

how Latina caregivers negotiate their performance of the caregiving role when dementia in their parents challenges their enactment of and respect for traditional cultural scripts (Henderson, 1996; Ibarra 2003). In this article we are not proposing that Latinos are unique in their value of familism or in their performance of familistic values; rather, we aim to provide a clear and in-depth analysis of how a U.S.-born Latina daughter of immigrant parents struggles to enact and honor the value of familism as her “Hispanic” and U.S. values clash. Furthermore, we examine how such clashes work in ways obvious and subtle for one Latino case and we suggest that this might be the experience for many Latina caregivers.

In general the literature on Latino caregivers assumes that Latinos in the United States still are socialized within a paradigm that views obligation and respect toward elders as part and parcel of family life (Ibarra 2003). Based on her study of Latina caregivers, Ibarra posits that women learn about caregiving from their experience in family groups. Ibarra argues that family caregiving lessons delineate a gendered division of labor. Moreover, the ideology of familism holds that caregiving for elderly is a family obligation for all family members, with specific tasks distributed on the basis of availability and willingness. The enactment of familistic cultural scripts that mandate respect for elder autonomy, preservation of elder dignity, and maintenance of the elder’s role within the family typically falls upon women, however, particularly unmarried daughters, granddaughters, or daughters-in-law, rather than on men. It is predominantly women who enact care and develop and perform the ethics of care.

Ibarra drew on the work of Tronto (1993) and other feminist scholars (e.g., Harrington Meyer, 1999) who have argued that caregiving responsibilities typically are assigned to women due to cultural assumptions of women as natural nurturers and caregivers, and cultural expectations that women *should* prioritize family needs over individual desires. Feminist scholars raise a distinction between caring *about* others (which is viewed as a masculine form of caring) and caring *for* others, which is construed as a moral position related to the psychological importance of *being in* relationships and caring for others within the context of those relationships. Thus, for women, the issue is not whether one should care for another, but *how* one should care *for* and how one should deal with conflicting caring concerns (Tronto 1993). Furthermore, Harrington Meyer (1999), among others, highlighted the importance of class and the power differentials between men and women, which can impact caregiving. Although feminist scholars have raised a number of important questions concerning the values and performance of the ethics of care among women, they have cautioned against universalistic assumptions, as few studies have examined how women of various ethnic origins and class backgrounds experience or negotiate the challenges of caregiving.

Ibarra (2003) defined ethics of care as “behavioral scripts” that mandate that elders should maintain their former roles within the family and that, to the extent possible, their autonomy should be honored. Furthermore, Ibarra

(2003) and Valle (1998) are just two of the many scholars who have noted that, among U.S. Latinos, caregiving is guided by an ethics of care that responds to cultural scripts, to the ideals of family harmony and cohesion. Thus, caregiving of elders ought to embody the noblest aspects of familism: sacrifice of individual or personal desires or goals in the service of others, altruism, collectivism, and interdependence. Furthermore, older adults should be treated with respect. Emerging from these ethics of care is a model of care grounded in the belief that *la tercera edad* (the third and final cycle of life) entails a need for increased assistance from family, an increasing transition of responsibility across the generations as the elderly individual's mind and body begin to follow a normal process of aging. Consequently, caregivers should be attentive to and supportive of the elders' routines because these provide comfort and a sense of identity. Likewise, because elders will recognize that the end of their life is near, they may become afraid and need consideration, affection, and family members who can simply be there, to hear their stories, and to bear witness to their lives and final bereavement related to the losses experienced in old age (Kleinman, 1988).

A number of studies of Latino elders with dementia have found that their caregivers are less likely to seek outside sources of support, are more likely to rely on family, and that these elderly individuals typically receive less medical care than do European American elderly adults in similar circumstances. Latino caregivers are unaware that behavioral symptoms of dementia can be treated medically, which could result in a reduction of the elder's distress and potentially assuaging caregiver stress (Harwood et al., 2000; Hinton, Haan, Geller, & Mungas, 2003). Few researchers however have examined how dementia may intersect with cultural ideology and the ethics of care to produce practical models of care rooted in the Latino value of family care (Ibarra, 2003). Furthermore, little information is available on how Latina caregivers attempt to honor and respect an older person's autonomy in the face of the elder's diminishing abilities and, at times, frightening behavioral symptoms.

In this article we examine how cultural scripts and a behavioral ethics of care within a context of family both establishes and influences caregiving for a U.S.-born Latina daughter. We discuss continuities and disjunctures, transitions and tensions in the caring relationship between this woman and her mother.

METHODOLOGY

Our particular case study is drawn from a sample of Latina participants in a larger qualitative study of European American and Latina/o caregivers and their patterns of help seeking (Hinton et al., 2003). Trained bilingual, bicultural research assistants interviewed the participants utilizing a semi-structured qualitative interview lasting hour. The interviews were conducted

in the caregivers' homes or at the project office. Ten of these 18 women, including our case study, chose to be interviewed in English, and the rest chose Spanish. The interviews were audiotaped, transcribed, and analyzed thematically, using standard qualitative techniques. Topics examined follow: pathways to care, the caregiving experience, presence of neuropsychiatric symptoms, and utilization of formal and informal resources. Caregiving experiences were further analyzed for central themes related to the ethics of care and cultural influences on patterns of caregiving.

"Ana," the caregiver we selected for our case study, is one of nine Latinas born and raised in the United States. She comes from a working-class background (determined by her family of origin's economic status and occupation). Although she works full time, Ana is her mother's primary caregiver. We selected her story because she articulated most clearly the ethics of care utilized by U.S.-born Latina daughters and their struggle to fulfill cultural mandates in the face of their mothers' diminishing capacities and their rootedness in U.S. society.

CASE STUDY: ANA'S STORY

Ana is a 52-year-old primary caregiver to her mother, Mrs. C. Ana is a second-generation Mexican American born in Northern California. The oldest of four children, she has one sister and two brothers. Ana completed a high school education and earns between \$30,000 and \$45,000 a year working 40–60 hours a week taking care of people with disabilities. Ana is unmarried and lives with her mother and her sister Rose's two teenage children. Because she is not responsible for a husband and children of her own, Ana became the primary caregiver, attending to her mother's daily needs, while Rose assists Ana by taking charge of their mother's medical appointments. Since Rose remarried, her children from the first marriage live with Mrs. C. and Ana.

Mrs. C. was born in Northern Mexico and is 73 years old. Mrs. C. has lived in the United States for almost 50 years but remains primarily Spanish speaking. Ana has lived most of her adult life with her mother. She briefly left home after finishing high school; however, when her mother and father separated, Ana returned to live with her mother. Ana is 8 years older than her sister and 13 years older than her brothers. She reported that she "played the mother role" with her siblings at times, preparing her siblings for school and attending school meetings and parent conferences, as Mr. and Mrs. C. did not speak English well.

Understanding Her Mother's Illness

Ana began to notice changes in her mother 2 years prior to our interview:

She would start to forget, like, she'd, you know, leave the stove on and wander off. Sometimes she would sit down and watch TV and then forget what she was doing, or go into another room and she would forget what she actually had started doing.

Mrs. C. also began to miss taking her medications as indicated. When confronted with her forgetfulness, Mrs. C. would minimize the incidents, confabulate, or deny that such situations had happened altogether. As Ana had worked with Alzheimer's patients, she was familiar with its presentation and began to look for signs. She began to ask her mother if she was forgetting things. Mrs. C. invariably denied she had memory problems. At Ana's sister's insistence, Mrs. C. went to see her primary care physician. Ana has not spoken to Mrs. C.'s physician directly; furthermore, Ana appears uninformed about the course of her mother's illness or what resources may be available to her and her mother. She has not utilized any informal support groups to help her deal with her mother's symptoms. She reported looking for information from other sources and participating in our research project in hopes of receiving some guidance:

That is why I came to this, you know. I feel like I am getting burned out here. And I need to get more motivated, you know, because the other part is I work also with disabled people, so that's kind of like carrying two loads.

At the time of the interview, Ana described her mother as forgetful, combative, at times physically and often verbally aggressive, and frequently nervous and obsessive about the well-being of her teenage grandchildren, who live with her and Ana. Ana described her mother as a woman who always had become "stressed" easily. Ana had become concerned, however, because the intensity of her "stressfulness" had increased substantially. Ana appeared unaware that her mother's behaviors were symptoms of dementia and were not solely an exacerbation of her tendency to "stress easily."

Mrs. C. suffers also from hypertension and arthritis, a sleep disorder, and a hearing loss; she also has a pacemaker. Mrs. C. has Medicaid/Medicare as her health insurance. She sees her primary care physician regularly for her medical problems. While her daughters generally accompany her to the appointments, they do not routinely go in with their mother to see the doctor, as Mrs. C. refuses to let them accompany her in the examining room. Out of respect, Ana and her sister comply.

Ana's sister did speak to Mrs. C.'s doctor on one occasion regarding their concerns about Mrs. C.'s symptoms. At that time, the physician had diagnosed Mrs. C. with mild dementia. Ana does not know, however, to what extent the doctor is aware of Mrs. C.'s behavioral symptoms. Ana's behaviors

are indicative of the passiveness that is viewed as culturally appropriate for children and women in the face of a parent's illness.

Ana reported that over time her mother's combativeness has grown, and, in some instances, Mrs. C. has become physically aggressive toward Ana and other family members. On one occasion, Mrs. C. became so angry at her daughters that she locked them out of the house. Although Ana reported her concern over a number of cognitive and behavioral changes in her mother, she stated that for her the most challenging change in her mother is "*her forwardness*":

She's very vocal; she'll tell it like it is. She's not, she doesn't sugar coat-things, not that she ever did, but what I'm saying is if she had a real nasty opinion about somebody, she would reserve it. Now she doesn't; she just blurts it out, you know.

Along with her memory lapses, Mrs. C.'s deviation from culturally expected behaviors for her age and gender, that is, being reserved and polite, led Ana to suspect her mother suffered from Alzheimer's disease. Nevertheless, she explained her mother's symptoms as tiredness:

She's getting up there in age, and I think she's tired. She's tired of all the things that are going on in her life, and she just wants to rest. She just wants to be by herself, you know, and I think there's too much, maybe at times there's too many things going on.

Ana also believes that her mother's combativeness is the result of pent up-anger, perhaps relating to how Mr. C. treated her during the marriage:

My mom used to be a very reserved woman. Even though she knew that the other person was in the wrong, she would reserve her opinion. Now she just voices everything that comes out, no matter who she hurts or what, who she says it to, and. . . . She was brought up to be a reserved woman, to keep everything in; now she's just letting it out. I don't know, you know, I know that some of it is not a normal behavior.

Although Ana expressed concern about the behavioral changes evident in her mother, she normalized them:

[She] has always been a stressful person; she's always been a worrywart. She has always been a nervous person, a tense person.

Ana's explanatory model of her mother's illness is consistent with other accounts of how Latino caregivers and family members "explain" the cognitive and behavioral symptoms of dementia as being related to "nerves" or long-standing personality traits (Hinton & Levkoff, 1999; Valle, 1998). Despite

Ana's nativity in the United States, her awareness of dementing illnesses, and her belief that her mother suffers from dementia, she relies on a "cultural" explanation for her mother's behaviors.

On Becoming a Caregiver

Ana described her mother as a traditional woman who never handled financial matters. Thus, with her mother and father separated, Ana returned to the family home and assumed some of the tasks her father had performed:

It goes back to the Hispanic culture, that the woman always is by the man, and my dad always took care of my mom, financially, and for everything basically, so she had no need to go to the grocery on her own, to budget a checkbook, you know, all those things, which I now do because she's used to that, you know, and she's kind of lost in that point. It's common among the Hispanics, especially if they're from the old, we'll say old school, you know. It's a tradition. It's like I've carried through it, you know, and I found myself that I've been caught into that.

Thus, Ana unquestioningly assumed her role as caregiver even before her mother became ill, following the "old school" tradition of children helping the parents when needed. Unmarried and already living with her mother, Ana was regarded by the family as the logical hands-on caregiver when Mrs. C. became ill. Her younger sister helps with medical appointments but because she is married and has children, she is not expected to be as involved in her mother's day-to-day care. The two brothers participate minimally, visiting occasionally but not providing any other form of support. Ana explained their lack of involvement in the following way:

My brothers are kind of in their own little world, you know. I think it has to do with the culture a lot of it, you know, how they're brought up. Like my Mom has always had this thing that men are to be catered to and women are pretty basically on their own.

Ana accepts the brothers' lack of support as a culturally appropriate fact. As the eldest child and as a daughter, particularly being unmarried and having no children, she somewhat unquestioningly conforms to the cultural (and familial) expectation to become her mother's main companion and hands-on caregiver. While female caregiving of elders is not a uniquely Latino phenomenon, Ana assumes the primary caregiver role because she sees it as a cultural mandate rooted in familistic values; thus, she carries forward the tradition by assuming the caregiver role for her mother.

Model of Care

Ana and her sister encouraged their mother to talk to the physician about her forgetfulness, but they did not insist on visiting the doctor with her when their mother refused. They assumed and hoped that Mrs. C. would talk to her physician about their concerns. Ana reported that her mother told them that her doctor stated that there was nothing wrong with her. In fact, Mrs. C. alleged that the doctor stated that the daughters were crazy. Although distressed by this situation, Ana has not insisted on communicating with the doctor directly. She appears torn between honoring her mother's autonomy and independence and taking a more active approach to her mother's medical care, "Cause she's [Mom] always been, she's still playing the mother role, so she's not quite letting go of that part, you see what I mean?" Ana's narrative demonstrates her attempts to embody a model of care that respects her mother's agency, authority as a mother, and elder status. This is a source of stress to Ana, however: "I kind of, I kind of hate acting like I'm her, you know, the grownup, and she's, you know..."

Although Ana accepted becoming her mother's assistant in handling the details of her mother's life, which was previously done by Mr. C., she struggles to make sense of Mrs. C.'s behavioral symptoms and to respond in a caring and respectful way without overstepping what she perceives to be the boundaries of her role as a daughter. As Ana struggles to maintain her mother's autonomy, Ana oscillates between empathic responses she considers appropriate and angry responses that lead to guilty feelings, as she is violating the ethical rule of treating parents with respect:

Well, first, she gets angry and she bursts out in anger, and then she'll, you know, start crying. I listen to her. She'll, you know, stop crying, and I'll say, "Well, tell me what happened," and I ask her and then she starts talking about it and I just listen to her, and I say, "Well, don't listen to her [Rose], or maybe she didn't mean it, you know." And she goes, "Oh, okay"; then she goes about her business. When she gets verbally (abusive), sometimes I will listen, but then there are other times that I just, I find myself losing it to be honest, you know. I just answer back, you know, and then she becomes more . . . and I try, you know, to be more on top of it. I just walk away. I just walk away and she will continue.

Ana reported relying on her love for her mother to remain patient and compassionate. She alternates between accepting her caregiver role as an obligation, given her cultural upbringing, and wanting to run away and escape her mother's outbursts, which she sometimes does by locking herself in her room.

Ethics of Care

Tronto (1993) outlined three areas of caregiving that are central to an ethics of care grounded on relational values. First is attentiveness to the needs of the other; second are questions related to autonomy and authority; and third are problems that arise out of the particularity of caring for another. Ana's narrative offers multiple examples of her attentiveness and her struggles to find a middle ground where she can respect her mother's wishes and authority and yet find the information she needs to be a better caregiver. When asked how difficult it had been for her not to be able to speak to Mrs. C.'s doctor directly, Ana stated the following:

It's been hard, you know, because I respect her wishes. If she doesn't want me to talk to him, then, you know, that's okay, but still, you know, I kind of go around her, you know, and try to find other information, other resources, you know, that will help me, understand it better. But I think there is . . . I am going to be talking to him, maybe also talking to my sister. Maybe we can both go and talk to him.

While Ana respects her mother's authority, she attempts to break the generational boundary, respectfully, by indirectly obtaining information. It is not clear, however, how actively Ana seeks other resources, as she also reported not having read books on the subject or having contacted any agencies to obtain information. Ana described the biggest challenge to caregiving.

Patience, patience, being able to cope with it. I have a lot of patience, but like with my Mom, it's kind of running thin, but outside I still have patience. It's like with a loved one. It hurts. It hurts a lot, and it's like, how can I help her, how can you make things better for her? You know. That is where I am at right now. I just don't want to let it be and just let, I don't know. Maybe I have a different view of things, you know, I have a different view as far as, how could I put it, being Hispanic totally means different, it's two different worlds, that's how I feel sometimes, like I live in two different worlds, and that's hard.

For Ana, caregiving is connected to how she enacts her role as a Latina and familistic values that she sees as carrying more responsibility toward parents: "You become their parents, but they choose not to see it that way, they still want to continue their role, which I can understand, but it's hard." Ana attempts to fulfill the values and ideology—the cultural script—behind the Hispanic/Latino ethics of care and the ideological mandates of familism by assuming responsibility, yet attempting to maintain her mother's dignity and not forcing her mother to give up the independence she still has. Ana does not appear aware that, in so doing, her mother may not be getting

appropriate care, particularly to manage the behavioral symptoms that are a source of stress for both her and her mother.

Negotiating the challenge of fulfilling the practices of care is very stressful for Ana. As a bicultural woman, she judges herself according to two cultural standards, which at times she experiences as incompatible, and she feels that she fails to fulfill both standards properly. She tries to reduce her own stress by taking time out on the weekends, when her mother is calm enough to stay with her grandchildren, but she struggles with feeling selfish and cold, which she experiences as a manifestation of her more “Americanized” self:

In the Hispanic community, as a woman, you have more responsibilities and you are brought up, like I am older, so I was brought up from the old school, so that means a lot more catering to people in general, being more of a homebody, being more sensitive, being more aware to [*sic*] the family. And then the other world is more cold; I shouldn't say that, but it's reality. You have to learn to take time for oneself and, you know, do the things that are going to make you happy, not someone else. So I am kind of battling, you know, both situations. It's kind of like a seesaw thing, and I don't know, maybe I haven't adjusted to either world.

Ana embodies a familistic ethics of care as she attempts to maintain her mother's autonomy, treat her with respect, and help her maintain a routine, that preserves her dignity and her hierarchical place in the family. Moreover, this pattern of caregiving is stressful for Ana:

Being Hispanic totally means different, it's two different worlds, that is how I feel sometimes, like I live in two different worlds and that is hard. Being a Hispanic woman is, you're more responsible. As you get older, you have more responsibility towards your parents. You become their parents.

Ana frames her struggle to be a compassionate caregiver as rooted in her biculturalism. She attempts to follow a cultural script she considers Hispanic, while recognizing that her actions have been influenced by her socialization in the United States. She is challenged to bridge her “old school” training and her more “Americanized” desires, which she perceives as cold. She views caregiving as straddling both worlds, but in her own judgment, she may be falling short in failing to adequately bridge these worlds. Ana is sufficiently Latina to feel bound to respect a familistic ideology of care and sufficiently Americanized to realize there may be a different, if not necessarily a better, way of handling this dilemma.

DISCUSSION

Ana's narrative shows the struggle of a second-generation, working-class Latina daughter to conform to a Latino ethics of care, to negotiate the cultural mandates of familism, and to provide compassionate care for her mother. She regards her cultural upbringing as "old school," exemplifying Latino values. Although she does not appear to subscribe to these values entirely, they have been passed on to her, and she's "carried them through," doing the best she can. She can explain her brothers' lack of involvement in caregiving as being culturally influenced, and although she perceives the situation as not just unequal but unfair, she does not challenge it. At all this stage of her mother's illness, Ana has accepted her mother's refusal to allow more direct involvement of her daughters in her medical treatment. Ana's reticence to challenge her mother is consistent with an ethics of care that calls for respecting elder authority and preserving the mother's status as an elder for as long as possible. Thus, Ana attempts to find indirect ways of gaining information about and greater understanding of her mother's illness in order to become a better caregiver.

In this narrative we can see how a daughter's understanding of family values rooted in her culture of origin informs her caregiving and her interactions with the health system, both providing her with an ethics of care that gives meaning to her experience while also constraining her desires to be more assertive and more individualistic. She describes feeling trapped in the interstices of her Hispanic family background and her more Americanized individual experience and expectations. As Kleinman (1988) has stated, "For the care giver what is important is to witness a life story, to validate its interpretation, and to affirm its value" (p. 50). Indeed, for Ana, caregiving is her way to honor and be present with her mother in Mrs. C.'s *tercera edad*, to offer cultural interpretations of her mother's illness (being tired, nervous, tense, full of pent-up anger), which are less pathological or potentially stigmatizing than a diagnosis of dementia might be. Ana attempts to affirm the value of her mother's life by attempting to preserve Mrs. C.'s authority and respect her wishes. Negotiating the interstices between love and obligation, Ana embodies a family-based ethics of care.

Throughout the larger study (Hinton et al., 2003), the narratives of the daughters also revealed a discourse about caregiving practices embedded within a culturally rooted ideology of family. In general, caregiving was talked about in terms of reciprocity and obligation and the enactment of filial duty. Immigrant women, however, appeared to accept more easily than did U.S.-born women their assigned cultural and gender roles. Those born outside the United States spoke of stress and difficulties balancing their nuclear family needs with the demands of their aging parent, but they tended not to describe the latter experience as a burden. This sense of proper obligation rather than undue burden was present even within conflictual relationships

with parents and irrespective of the gender of the parent. Furthermore, the ethics of care that emerged reflected an adherence to traditional gender values; daughters attempted to protect their mothers and support them in performing traditional gender roles (cooking, cleaning, being around to provide companionship). When the fathers were ill, the daughters' efforts were geared toward supporting their dignity and minimizing their deficits, engaging in jointly making puzzles, and driving their fathers to appointments or to visit friends or former places of work.

Whereas most of the daughters accepted their caregiving role, greater internal conflict regarding gender expectations was evident on the part of U.S.-born women. The internal conflict centered on negotiating and attempting to resolve the sometimes conflicting cultural views and expectations of what it meant to be a good daughter. U.S.-born daughters of immigrant families spoke directly about cultural conflict and guilt over their occasional resentment, as did Ana.

The Role of Familism in Latina Ethics of Care

The social science literature on familism helps contextualize how Latino family values influence caregiving and how Ana's "old school" views may have developed in the U.S. context. While familism is a widespread concept, it has been given great importance in Latino studies. Familism has been conceptualized in the literature in three ways: (a) as a structural phenomenon related to the social status of Latinos in the United States; (b) as a structural outcome due to the social inequities faced by many Latinos; and (c) as a cultural condition. From a structural perspective, reliance on the family for social and economic support may be due more to the economic disparities faced by most Latinos than to cultural values (Wallace & Facio, 1987). Thus, structural changes as a result of economic advancement and greater acculturation would be expected over time to change how Latinos embody and perform the expectations of familism. In fact, researchers have suggested that modernization and changes in family structure both in Latin America and among Latinos in the United States already have impacted the performance of caregiving and cultural scripts, particularly among the middle class (Wong, 2003).

As a cultural *ideal*, familism creates behavioral scripts that prioritize and privilege the family over the individual, accord more freedom and rights to men than to women, and promote respect and obligation toward elders. Sabogal and colleagues (1989) differentiated between behavioral familism, or the enactment of scripts, and ideational familism, or the cultural scripts that reflect underlying values. Wallace and Facio (1987) also proposed that familism often operates as an ideology that informs how Latinos negotiate family relationships and responsibilities rather than simply as a set of

behaviors or practices. Some individuals demonstrate greater cognitive acceptance of and conformity to the ideology or values than does their actual behavioral performance of familistic ideals. Thus, familism theoretically can be manifested in social actors as just behavior, just ideology, or both. Ana's caregiving practices reflect the cultural ideal of respect for elder autonomy and dignity—underlying values that inform her performance of care. Her narrative also illustrates how difficulties enacting the cultural ideal create stress for Ana due to both her bicultural experience and her mother's diminishing abilities.

There is considerable evidence that familism as an ideology remains strong among U.S. Latinos of various generational levels (Marin & Van Oss Marin, 1991; Ramirez, 1998). Recent studies in Mexico (Robles Silva, 2003; Wong, 2003) document the relationship of lower socioeconomic status to stronger endorsement of familistic attitudes. These authors have argued that traditional family values are held most strongly by the poor and working-class segments of Mexican society, who have not been influenced as much as the middle-class by structural changes and modernization and who lack the resources to delegate the performance of familistic tasks, such as caregiving of older adults, to other individuals. No such information, however, is available for Latinos in the United States. Given that most U.S. Latinos are poor or working class, it is possible that more strongly familistic views are held by immigrants and second-generation Latinos who have less contact with other ethnic groups or who have limited access to dominant-culture ideas about family obligations. Perhaps, as in Ana's case, familistic values are strongly held, but the performance of familistic tasks is challenged by more Americanized attitudes, thereby creating tension and stress. Moreover, most studies consistently have reported that familism is an important factor in the lives of Latinos, whether familism is conceptualized as a structural, cultural, or combined occurrence (Wallace & Facio, 1987).

In Ana's narrative, we see an example of the influence of familism both as an ideology and as a set of cultural practices in the context of caregiving to a family member with dementia. She strongly adheres to an ideology of familism and enacts this through a specific ethics of care tailored to the needs of older Latinos and Latinas in *la tercera edad*. Yet there is a tension in her narrative resulting from her own self-reflexive awareness that she is between the "old school" and a more individualistic "American" orientation to the family and caregiving. This tension forms an essential aspect of her own personal experience of caregiving, one that is likely shared by many other Latinas, and that reflects her social position as a working-class Latina daughter of immigrants. Through her eloquent articulation of this tension, Ana's narrative also gives us the sense that her story, like her life, is unfinished, pregnant with both the constraints and the creative possibilities that exist for her as she negotiates an ethics of care. Her embodiment of familism is a double-edged sword, giving meaning to her caregiving experience

through a specific ethics of care that informs her practice of caregiving and help seeking, yet also contributes to her isolation from potential sources of formal and informal support. In this way, her story adds to our understanding of underutilization of formal resources and its relationship to familism as a social process.

A number of studies point to the dual nature of traditional family values in that familism may serve both as a protective factor and a source of support (Vasquez, 1998) when families experience health problems, or as a deterrent to seeking help outside the family in situations of crisis (Perilla, 1999). Likewise, most studies point to the intersection of familism and gender with the burden of enacting traditional family scripts tending to fall disproportionately on women, rather than on men (Flores-Ortiz, 2004). We see this pattern in Ana's story as she and her sister deal directly with their ailing mother's medical and day-to-day needs, whereas the brothers are only marginally involved, visiting once in a while.

Although Ana is not representative of all second-generation Latina daughters, her story sheds light on how familism both underpins and nuances the caregiving experience. Ana is aware of divergent cultural views on a daughter's duty to her ailing parent; however, she embodies more traditional Latino caregiving values and practices than European American ones. These views, along with her socioeconomic status as a working-class woman, may hinder her from seeking formal sources of support.

Moreover, Ana's story also suggests that we need to move beyond a simple analysis of familism as a variable influencing caregiving. Instead, we must understand how familism influences caregiving and nuances ethics of care *and* how these ethics of care also are nuanced by generation and social class. As the numbers of elderly Latinos grow in the next decade, the numbers of first- and second-generation Latinas who are and will be providing care for older adults in their family will increase dramatically. Future studies with larger samples should consider the role of nativity, generation, class status, education, and adherence to familistic values on Latina caregivers' ethics of care.

Ana's story also points to potential areas of intervention. During the interview, Ana expressed interest in learning more about dementia and the management of behavioral symptoms. It is not known whether she would have obtained that information from Mrs. C.'s primary care physician if she had contacted him directly; however, other studies have indicated that often Latino patients and their family members do not receive such information or are referred to specialists who can treat the behavioral symptoms (Hinton et al., 2003). Therefore, educational campaigns in the media (in both Spanish and English) easily could offer explanations about dementia and available courses of treatment utilizing cultural metaphors and idioms of distress (e.g., nerves, being tired, etc.) that working-class Latinos understand. Likewise, Ana was concerned about her episodes of "losing it" with

her mother. Understanding the nature of caregiver stress and its physical and emotional sequelae can go a long way to assuage guilt. Offering culturally appropriate and sensitively framed alternatives to constructing a life focused solely around her mother's needs might lessen the emotional burden of her caregiving role.

Cancian (1986), Cancian and Oliker (2000), and Robles Silva (2003) described caregiving as unpaid, devalued, and unrecognized labor that is not considered work (especially when it is done by women) because family caregiving is rooted in social policies that situate caregiving as a *natural* and normative responsibility (or obligation) of the family and not of the state. Access to the limited formal resources that are available depends on knowledge of their existence and willingness to assert one's rights to access them. In the context of migration and the marginalized economic and political status that many U.S.-born Latinos occupy, caregiving is located within the family due to both familistic notions *and* limited access to social services. Thus, psychosocial interventions must account for the structural as well as cultural contexts of Latina/o caregivers and respond to the bicultural realities of women such as Ana. Such interventions might facilitate an integration of the "two worlds" and promote bicultural solutions that might increase caregiver agency and lessen distress.

In this article we shed light on how family caregiving values, nativity, and gender may nuance the ethics of care of second-generation Latina daughters and point the way for community-based interventions to assuage caregiver stress. Future research with larger samples also should explore the overt and subtle roles that acculturation and generational level play in the stress experienced by Latina caregivers. Family caregivers rarely are acknowledged by other family members for the role they perform; moreover, the assumption that a daughter, such as Ana, is obligated to assume a caregiving role without support from other family members is *not* intrinsically supported by a familistic orientation. Relying on notions of familism, family interventions with Latino families who adhere to "old school" values can be used to explain that a primary caregiver ought to be supported, appreciated, and relieved, and that the practical burden of obligation can be shared by all family members. Caregiving can be both a shared obligation and an act of love.

REFERENCES

- Cancian, F. M. (1986). The feminization of love. *Signs: Journal of Women in Culture and Society*, 11, 692–709.
- Cancian, F. M., & Oliker, S. J. (2000). *Caring and gender*. Thousand Oaks, CA: Pine Forge.
- Flores-Ortiz, Y. (2004). Domestic violence in Chicano families. In R. J. Velasquez, L. M. Arellano, B. W. McNeill (Eds.), *The Handbook of Chicana/o Psychology and Mental Health* (pp. 267–284). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

- Harrington Meyer, M. (1999). *Care and equality*. New York: Knopf.
- Harwood, D. G., Barker, W. W., Ownby, R. L., Bravo, M., Agüero, H., & Duara, R. (2000). Predictors of positive and negative appraisal among Cuban American caregivers of Alzheimer's disease patients. *International Journal of Geriatric Psychiatry, 15*, 481–487.
- Henderson, N. J. (1996). Cultural dynamics of dementia in a Cuban and Puerto Rican population in the United States. In G. Yeo & D. Gallagher Thompson (Eds.), *Ethnicity and dementia* (pp. 153–166). New York: Taylor and Francis.
- Henderson, J. N. (1997). Dementia in cultural context: Development and decline of a caregiver support group in a Latin population. *Cultural context of aging* (pp. 425–442). Westport, CT: Garvey Bergin.
- Hinton, W. L., Haan, M., Geller S., Mungas D. (2003). Neuropsychiatric symptoms in Latino elders with dementia and mild cognitive impairment and factors that mediate their impact on caregivers. *The Gerontologist, 43*, 669–677.
- Hinton, W. L., & Levkoff, S. (1999). Constructing Alzheimer's narratives of lost identities, confusion and loneliness in old age. *Culture, Medicine and Psychiatry, 23*, 453–475.
- Hurtado, A. (1995). Variations, combinations, and evolutions: Latino families in the United States. In R. E. Zambrana (Ed.), *Understanding Latino families: Scholarship, policy, and practice*. (pp. 40–61), Thousand Oaks, CA: Sage.
- Ibarra, M. L. (2003). The tender trap: Mexican immigrant women and the ethics of elder care work. *Aztlan: A Journal of Chicano Studies, 28*(2), 87–113.
- Kleinman, A. (1988). *The illness narratives: suffering, healing, and the human condition*. New York: Basic Books.
- Marin, G., & Van Oss Marin, B. (1991). *Research with Hispanic populations*. Newbury Park, CA: Sage Publications.
- Perilla, J. L. (1999). Domestic violence as a human rights Issue: The case of immigrant Latinos. *Hispanic Journal of Behavioral Sciences, 21*(2), 107–133.
- Ramirez, M., III. (1998). *Multicultural multiracial psychology: Mestizo perspectives in personality and mental health*. Trenton, NJ: Jason Aronson.
- Robles Silva, L. (2003). Género, Pobreza y Cuidado: La Experiencia de Mujeres Cuidadoras Pobres Urbanas. In N. Salgado de Snyder & R. Wong (Eds.), *Envejeciendo en la Pobreza: género, salud y calidad de vida* (pp. 123–152). Cuernavaca, Morelos, México: Instituto Nacional de Salud Pública.
- Sabogal, F., Marin, G., Otero Sabogal, R., & Marin, B. (1989). Hispanic familism and acculturation: What changes and what does not? *Hispanic Journal of Behavioral Sciences, 8*, 232–243.
- Tronto, J.,(1993). *Moral boundaries: A political argument for an ethic of care*. New York: Routledge.
- Valle, R. (1998). *Caregiving across cultures: Working with dementing illness and ethnically diverse populations*. Washington, DC: Taylor and Francis.
- Vasquez, M. J. T. (1998). Latinos and violence: Mental health implications and strategies for clinicians. *Cultural Diversity and Ethnic Minority Psychology, 84*, 319–334.
- Velasquez, R. J., Arellano, L. M., & McNeil, B. W. (2004). *The handbook of Chicana/psychology and mental health*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

- Wallace, S. P., & Facio, E. L. (1987). Moving beyond familism: Potential contributions of gerontological theory to studies of Chicano/Latino aging. *Journal of Aging Studies, 10*(1), 337–354.
- Wong, R. (2003). Prólogo. In N. Salgado de Snyder & R. S. Wong (Eds.), *Envejeciendo en la Pobreza: Género, salud y calidad de vida* (pp. 15–22). Cuernavaca, Morelos, México: Instituto Nacional de Salud Pública.