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Concepts of burden in giving care to older relatives: A study of female caregivers in a Mexico City neighborhood

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Abstract

Objectives—This study examined how women in a Mexico City suburb conceptualized the construct of burden within the context of giving care to older relatives.

Methods—Data were collected on forty-one women through semi-structured interviews regarding their caregiving experiences to elderly relatives. Phenomenological principles were used to analyze meanings and understandings of caregiving experiences.

Results—Burden was a multi-dimensional construct that referred to specific situations that made caregivers feel emotionally or physical "heavy." Burden also referred to "being a burden" by being in the way, making things difficult, or being a 'weight' on caregivers' shoulders. However, women in this study also viewed burden as a positive sacrifice that involved love, initiative, and good will.

Discussion—This study is an important first step in defining the ways in which caregiving is positively and negatively meaningful for Mexican caregivers and their families. Our findings offer an additional dimension of caregiver burden to broaden our understanding and measurement of the construct. The development of culturally appropriate instruments to measure caregiving burden in Mexico is necessary to provide an empirical foundation for policy recommendations that address the growing need for institutional support of caregivers. Moreover, our findings suggest that researchers studying caregiving in Mexico should think about how burden is measured on existing instruments before adapting them for widespread use.

Keywords

aged; caregiver burden; informal caregiving; Mexico

Introduction

Mexico's population will rapidly age in the 21st Century. The nation's age 60 and older population is expected to increase from 7% (6.8 million) of the total population in 1990 to over 24 % (35.7 million) by 2050 (United Nations, 2002). The country's mortality shift from communicable to chronic causes of death and trends of increased longevity (Alcantara-

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Vazquez *et al.*, 1993; Ham-Chande, 1996; Lara-Rodriguez *et al.*, 1996; Martínez & Leal, 2003) suggest that the demand for long term care will become overwhelming as Mexico continues to gray. However, few research studies have focused on the long-term care needs of older adults and their families. Low utilization rates of nursing homes by the elderly in Mexico City (Gutierrez-Robledo, 2002; Gutierrez-Robledo *et al.*, 1996) suggest that the daily needs of older adults are being met elsewhere, particularly by informal care networks. These data underlie the pervasive belief in Mexico that the family is the main resource and caregiver to elderly members (Varley & Blasco, 2000).

Informal elder care falls within the scope of unpaid care work—activities that serve others, require time and energy, and are not financially rewarded (UNIFEM, 2000). Throughout the world, unpaid care work has predominantly been seen as a woman's responsibility, including in Mexico. A recent Mexican study found that elder caregiving falls predominantly to women because it is considered a woman's job (Robles-Silva, 2000). The Mexican literature on women's occupations in the private domain suggest that individuals are trained or socialized into roles that define caregiving as a woman's responsibility (K. Finkler, 1994a; Oropesa, 1997; Willis, 1993). However, little is known about elder caregiving in Mexico and the role of women in this process.

Trends in women's delayed fertility and increased entry into the work force raise important, unanswered questions about the future of Mexico's strong extended family orientation (Gutierrez Robledo, 1990). A review of the research on the changes in gender role responsibilities and family functioning in Latin America over the past 100 years suggest that conflict within the home as result of these changes will impact elder care (Chant, 2002). The results from one study suggest that working women in Mexico are becoming more reluctant to take on the role of caring for older relatives (Montes de Oca, 1998; Varley & Blasco, 1999). The changing social roles for Mexican women thus raise questions about the effects of caregiving on their health and well-being. Research in other countries has clearly demonstrated a link between caregiving and poor caregiver health outcomes, including stress, burden and multiple role strain (Pinquart & Sorensen, 2003, 2005, 2006, 2007). However, the dearth of literature points to our lack of understanding of the caregiver experience in Mexico, especially in terms of caregiver stress and burden. The current study was undertaken as an important step in filling this knowledge gap. The purpose of this article to is describe how women in a Mexico City neighborhood viewed the concept of burden as it related to caring for older family members. Our examination of burden was part of a larger study on how women conceptualized the construct of elder caregiving and their role as caregiver.

Subjects and methods

This research study used a grounded theory approach to explore the conceptualizations and definitions of caregiving, including caregiver burden, among a small sample of female caregivers living in a Mexico City neighborhood. We used qualitative methodology to obtain women's points of view through ethnographic techniques. Qualitative methodology was appropriate because we sought to generate theory from data and contribute to the knowledge development of caregiving as a phenomenon (Glaser & Strauss, 1967; Hendricks, 1996). Abel (1991) has suggested that qualitative methodologies are particularly valuable approaches to understanding the experience of caregivers. Additionally, Blieszner & Hamon (1992) have argued that in-depth interviewing techniques can reveal both the emotional and the symbolic meanings of filial obligation that are not detected in typical survey approaches.

Theoretical framework

The overall objective of our study was to explore how Mexican women conceptualized caregiving for their elderly family members and their role as caregivers in this process. We applied a social constructionist framework to examine how they organized their behaviors and interpreted their experiences. Social constructionism uses interpretive approaches in the sociological traditions of symbolic interactionism, phenomenology, and ethnomethodology (Bengtson *et al.*, 1997) to understand social events on an individual level. We used this framework to guide all aspects of the study, including developing the research questions, the kinds of questions to ask on the interview guide, and the approach we took in analyzing the data.

Social constructionism was an appropriate theoretical framework for us to understand how Mexican women viewed the role of caregiver and defined what constituted caregiving because the meaning of caregiving in a particular cultural setting depends on contextualizing giving care within the rich tapestry of multiple social roles. We specifically applied two characteristics of the framework advanced by Bengtson et al. (1997) in the area of aging. First, we examined how caregiving was socially defined by linking caregivers to social-structural contexts. The literature on familial and gender roles suggests that caregiving is socially labeled as women's work (K. Finkler, 1994a; Oropesa, 1997; Willis, 1993). The “naturalness” of women's domestic responsibilities is part of the social construction of gender identity that begins in early childhood (Pitkin & Bedoya, 1997). Using these arguments, caregiving is assigned to women because it falls within the private domain of the household and is a natural extension of their gender identity as nurturers. A social constructionist framework enabled us to examine how caregiving was socially defined in Mexican culture by exploring women's definitions of caregiving and concepts related to caregiving. Examining Mexican women's definitions of caregiving helped us to understand their perceptions of caregiving as a “natural” extension of the nurturing mother or as an externally reinforced social expectation.

Second, we explored the situational, emergent and constitutive features of caregiving to older relatives. A social constructionist framework recognized how individuals actively participated in their everyday lives, creating and maintaining social meanings for themselves and those around them. This process can be seen as individual behavior producing a “reality” that in turn structured individual lives. Modeling our study on other exploratory studies of caregiving in a North American setting, we posited that study participants negotiated the meanings of care through interactions with care recipients and the nature of these interactions (Diamond, 1992).

Data sources and collection procedures

Study site—Mexico City, as known as the Federal District, is composed of 16 geographic units called *delegaciones*, and each *delegación* is divided further into *colonias* or neighborhoods. The site for this study was the neighborhood of Tetelpan (el pueblo de Tetelpan) located in the *delegación* of Alvaro Obregón (Figure 1).

We chose Tetelpan as a study site because it had specific elements we wanted for a field site. We wanted a location that increased our chances of finding women undertaking the primary caregiver role themselves. Purchasing in-home services through the informal work sector is a common labor practice in Mexico among middle and high income families (Lomnitz, 1982; Lomnitz & Perez-Lizaur, 1979). Such services can include laundry, housecleaning, child care, and elder care. We therefore wanted a location where the majority of the population was low-income and had limited economic resources to purchase in-home elder care services. Although neighborhood-level data were not available through Mexico's National Center on Statistics, the *Instituto Nacional de Estadística Geografía e Informática* (INEGI), data at the *delegación* level showed that Alvaro Obregón had fewer middle-income and more low-income population compared to the Federal District. Although 11% of Alvaro Obregón's population earned more than five times the minimum wage compared to 10% for all of Mexico City, almost two-thirds of Alvaro Obregón's population earned two times or less the minimum wage compared to 61% for the entire Federal District. The minimum daily wage in Alvaro Obregón was 26.45 pesos (Instituto Nacional de Estadística Geografía e Informática, 1998), the equivalent of $2.82 US dollars.

We also chose Tetelpan because we wanted a location with long-time residents and intergenerational living arrangements since we were interested in examining traditional views of women's roles about elder care. As a vast metropolis, Mexico City is in constant flux from interstate migration from other parts of the country. Some areas of the Federal District are more sensitive to influences from these migratory changes and transient populations than others. We found that Tetelpan was home to many multi-generational households and to generations of families dating back to the turn of the 20th Century. A handful of surnames persisted among many residents from ancestors who lived in the neighborhood at a time when cattle grazed and vegetable crops grew on open land. Although recently-built homes in private, gated communities sat perched atop the canyon overlooking Tetelpan's south-facing gorge, most long-time families lived in modest cinderblock homes with wood and aluminum roofs.

Sample recruitment—Women who met the following criteria at the time of interview were eligible to participate in the study: 1) minimum of 18 years old; 2) self-identified as the primary caregiver for an older family member who needed help with one or more Activities of Daily Living (ADLs) or Instrumental Activities of Daily living (IADLs) (National Center for Health Statistics, 2006); and 3) caregiver and family member lived in the same household. An older family member was defined as a person at least 60 years old related through blood or marriage.

Study participants were selected using a combination of snowball and purposive sampling methods. Study participants were solicited using life-long neighborhood residents and members of a local parish ministry group. Snowball sampling is a technique for finding study participants using referrals from other study participants. This technique was especially useful for finding participants with similar characteristics (Bernard, 1995), such as being a caregiver. As interviewed data were collected, we conducted purposive sampling to find study participants that represented a range of caregiving situations to explore relevant themes that emerged from previous interviews. Although purposive sampling is criticized for its low external validity, it is particularly useful in ethnographic studies, especially involving hard-to-find populations (Bernard, 1995). This was critical in our study where low-income caregiving women would not have been likely to receive formal work sector or governmental benefits and therefore not readily identifiable through census or Mexican Social Security Institute (IMSS) data.

Data collection—After obtaining informed consent, data were collected through semi-structured interviews using a previously pilot-tested interview guide that covered the following topic areas: 1) the story of becoming a caregiver; 2) the activities and contexts of caregiving; 3) the social and cultural beliefs about aging; and, 4) the beliefs about the caregiver role. Interviews were tape-recorded, conducted in Spanish by a trained native speaker and lasted an average of 50 minutes. The principal investigator was present during the interviews to make observational notes. The interview tapes were transcribed verbatim in Spanish by a professional native-speaking transcriber.

Data analyses—The interview transcripts were analyzed in Spanish. The transcripts were interpreted through a grounded theory approach (Strauss & Corbin, 1994) that involved an iterative process of taxonomic organization, content analyses, and code mapping. Each transcript was hand-coded from repeated examinations of the text. The text was first broken down into fragments and “clustered” around single words or phrases. Clusters of text were coded and organized into a hierarchy of categories at consecutively higher levels of abstraction to build thematic content. The interview guide was modified for subsequent interviews as new concepts emerged from the iterative analytic process that ran concurrently with data collection activities.

Quotes were subsequently translated into English for use in this article. The original quotes in Spanish are available from the authors upon request. A language consultant translated five interviews into English as a verification check of the researchers' translations.

Results

Sample characteristics

A total of 41 caregivers participated in this study. The study sample tended to be long-time residents of Tetelpan, and to have low levels of income and education (Table 1).

Three-quarters of study participants lived in Tetelpan for more than two decades, and over half of study participants (56%) lived in the *colonia* for their entire lives. The median and mean age of the participants was about 50 years old, with a range from 19 years old to 83 years old. The study participants' educational levels ranged broadly from one year (kindergarten) to 18 years (graduate school), with an average of just under eight years, the equivalent of primary plus one year of secondary education. However, just over half of the study participants had education equivalency levels of primary school only, with 19 of them not completing their primary education. Although the majority of study participants did not work outside the home, 25% had part-time jobs and 10% had full-time employment. The median monthly household income was 2,000 pesos, with a broad range from 800 to 10,000 pesos. The monthly household income was a gross estimate for the entire household, including working and nonworking persons. Therefore, when the number of working persons in the household was taken into account, the average monthly income was under 500 pesos per person or the equivalent of $53 US dollars.

The median number of years study participants spent caregiving was 5 years, with a broad range from two months to 65 years (Table 1). Two participants identified the length of caregiving as their “entire lives” since their family members had always lived with them. The average spousal caregiver in this study was a 70 year-old woman who gave care to a 73 year-old man to whom she had been married for 52 years. The average spousal caregiver and her husband lived with two adult children and their families (spouses and children) in separate homes on the same property. The average non-spousal caregiver was caring for a 75 year-old female relative for the past 13 years in a home they shared with the caregiver's husband and two minor children.

The majority of participants gave care to parents (41%), followed by husbands (27%), grandparents (15%) and in-laws (10%) (Table 2). The mean age of care receivers was 75 years old, with a range from 56 years to 92 years. The functional impairment levels of care receivers varied from no impairment to severely impaired or bed-bound. Almost equal numbers of care receivers were functionally independent (40%) and dependent (37%) with self-care tasks related to the basic activities of daily living (ADLs), such as bathing, eating, dressing, transferring, mobility, feeding, and personal hygiene (Katz, 1983). Study participants cared for care receivers with a variety of illnesses, ranging from diabetes or high blood pressure (19%), stroke (10%), and multiple ailments that included these three chronic conditions (17%), to physically healthy care receivers (27%).

Concepts of burden

We asked study participants a series of open-ended questions that included what they liked most and least about being a caregiver and believed was the most important aspect about taking care of their older relative. We also asked them to describe a typical day and the things they usually did to help their relatives. We had them recall their day from the moment they woke up to when they went to bed and describe what they did in the mornings, afternoons, and evenings. We asked which activity during the day they enjoyed the most and the least. We did not initially ask study participants specific questions about burden because we did not make *a priori* assumptions about whether or not they were experiencing burden. However, as the data collection progressed, we found that participant themselves brought up the idea of burden, and we subsequently pursued this topic as it arose in interviews. Based upon participants' descriptions about their day, activities related to caregiving, and follow-up questions about burden, we found that three major themes on the concept of burden emerged from our analyses of the data: 1) Caregiver burden was *pesado*, which included tangible situations that were a) physically or b) emotionally taxing for the caregiver; 2) *Ser carga* (being a burden to others) was considered a negative state of being; and 3) Burden was a positive sacrifice made on behalf of others.

Pesado—The word ‘burden’ (Gold, 1997) in Spanish is either *peso* or *carga*. Both words refer to a physical weight. For example, *peso* is used to describe weight (measured in kilos in Mexico), and *sobrepeso* refers to being overweight (Menchaca Martin & Zonana Nacach, 2006; Moraes *et al.*, 2006; Osuna-Ramirez *et al.*, 2006; Unikel-Santoncini *et al.*, 2006). *Pesado* translates to ‘heavy’ in English and back-translates to burdensome in Spanish. While we did not initially ask questions about *pesado*, we found that five out of the first 19 study participants used the word in relation to caregiving. For the subsequent 22 interviews, we added the following question to our interview guide, “Other caregivers have said that sometimes caregiving is *pesado*. Could you describe a situation when caregiving is *pesado*?” We found that 18 of the 22 participants agreed that caregiving was *pesado* and gave us examples of *pesado* situations. They described *pesado* caregiving situations that were literally or figuratively heavy. In other words, a caregiving situation that was *pesado* referred to a situation that was either physically taxing or emotionally heavy on the study participant.

Physically *pesado* situations: In study participants' discussions of *pesado* situations, they identified some physical activities as *pesado*. These activities primarily involved carrying heavy loads, such as bags of groceries (*el mandado*) and laundry (*lavar la ropa*). In these kinds of activities, study participants literally put physical stresses on their bodies which made them feel *pesado*. For example, some study participants told us what they liked least about caregiving was doing the wash. One participant said she did not like to do the wash because it “tires me a lot. My back gets tired, it makes me *pesado*.” She found washing her husband's clothes especially difficult but did not know why. She then revealed that she suffered from “arthritis so it [laundry] makes me *pesado*. Yes, I do it [the laundry] but I do it *a fuerzas*.” For this study participant, the laundry was physically hard on her arthritis, illustrating her difficulty in performing this physically strenuous activity. She also continued to do the laundry “*a fuerzas*,” meaning that she forced herself to do it although it made her *pesado*. It bears mentioning that washing clothes in Mexico was commonly a manual process using washboards (*tablas*) and large containers or washtubs (*tinas*). Washing machines were expensive and not routine household purchases, especially for poor families. Families without washing machines were faced with either paying for a laundry service or washing their clothes by hand. Given the modest household incomes of this sample, paying a third party was not an affordable option when caregivers themselves were available to do the work.

Physically *pesado* situations were not limited to inanimate objects like groceries or clothes. Fourteen study participants cared for an older family member who needed help with at least three ADLs, including walking or transferring. Five of these study participants stated that they felt *pesado* when they helped their older family members get in and out of bed or chairs and use the toilet or bathtub. One study participant, 63 year-old Eva, was caring for her 66 year-old husband who had suffered a diabetes-related stroke six years prior to interviewing her. At the time of the interview, her husband was "*vale por si sólo*" or self-sufficient and could walk on his own with the aid of crutches. However, right after the stroke, there was a period of time when he was not able to get himself out of bed or chairs, and Eva had to help him out. She stated that for her, lifting him and helping him to sit down was "very *pesado*" during that time and that, "the truth is I was very tired," suggesting that bearing the weight of her husband made her physically *pesado*. Another study participant shared that lifting the care recipient "has made me very *pesado* and I say, "Ay! I can't [do it anymore]. I think my entire body gets tired and sometimes and I [can't] give but at the same time, I try to revive myself and keep going." Yet another study participant had to sometimes "physically carry" her mother to the bathroom and said, "with my little knees hurting, well, it takes extra strength."

Emotionally *pesado* situations: Forty three year-old Laura, long-time divorced, had been a full-time caregiver of her mother, a blind insulin-dependent diabetic, for 18 months at the time of interview. Laura was the first caregiver we interviewed and the first to describe caregiving as *pesado*. She related her experience of a *pesado* situation when her mother got sick. She stated that, "it's very *pesado* because that's when we are most enslaved to her." She also stated that, "I have to be here so I can watch my mother and when it's a typical day of her being sick, you have to spend the whole day watching only her." Laura identified her mother's sick days as *pesado*. This excerpt was an example of an emotionally and physically *pesado* situation and conveyed the magnitude of her heaviness by using the word 'enslaved.' She was emotionally enslaved by having to constantly watch over her mother and was physically confined to her home during these sick episodes.

Fifty year-old Estela had previously been a caregiver to her husband and her daughter (prior to their deaths), and was currently taking care of her 73 year-old mother at the time of the study. Similarly to Laura, Estela described a *pesado* situation in terms of the time and attention required by her mother:

> "I felt it when she started (getting sick). That was when I felt *pesado* because I couldn't separate myself for one moment from her, day and night. I used to lie down on the floor next to her….there was one time when it was very *pesado* because it was day and night that I was taking care of her. That lasted around a month. I was feeling very *pesado* because I was also attending to Ramón (her husband)."

Like Laura, Estela was constantly at her mother's side for an extended period of time that proved to be physically and emotionally heavy for her. Another study participant, Regina used to take care of her mother-in-law until she died and was currently caring for her elderly father at the time of the interview. She provided another perspective on *pesado* as it related to caring for her ill mother-in-law and father:

> "Okay, yes, I used to see that it was making me *pesado* but I didn't know it. Now, I see it that way, right? It used to be very *pesado* to take care of her [mother-in-law]. After a while I was getting frustrated because she didn't want to eat and I almost had to force her to take food, I had to get her get up to go to the bathroom and all that. And you know, I have seen it with my dad [too]. Yes, I feel that, yes, it's *pesado* to take care of a sick person."

These three excerpts suggested that *pesado* was related to periods of intense care, measured by time or level of attention. Further analyses showed that these specific *pesado* situations were more likely due to episodic bouts of illness rather care recipients' impairment levels. We found that each of these study participants gave care to elders with different impairment levels. Estela did not help her mother with any ADLs, Laura helped her mother with bathing, and Regina helped her father with bathing and dressing. We also found that 12 of the 22 study participants who discussed *pesado* situations gave care to functionally independent care receivers.

Pesado also referred to being physically and emotionally tired from having to manage caregiving with other familial responsibilities. Being pesado for one study participant meant "*muerta en vida*" or dead in life. She clarified that she felt physically, emotionally, and morally *pesado* at times when she thought, "How am I doing this and the other?" regarding her multiple responsibilities at home and at work. In further analysis of the data by age, we found that of the 22 study participants asked specifically about pesado situations, those who agreed that caregiving was *pesado* were on average nine years younger than those who did not agree.

Ser Carga—The second theme that emerged from our open-ended questioning of study participants was the notion of being a burden (*ser carga*). Twenty-two of 41 study participants viewed being a burden as a negative and undesirable state; being a burden implied being in the way, or a 'weight' on another person's shoulders. Being a burden was not related to one specific caregiving situation or directed at the care recipient. Rather, the meaning of being a burden was implicit in study participants' views about their own future caregiving needs. We asked participants a series of questions on their future long term care needs and what would happen to them when they could no longer care for themselves. In answering these questions, despite emphasizing that they did not view taking care of their loved ones as a burden, they viewed the prospect of being taken care of by someone else as placing a negative burden on these future caregivers.

Cristina was characteristic of the contradictory way that study participants viewed the notion of being a burden. The 27 year-old identified herself as her 63 year-old mother's caregiver even though her mother did not suffer from any immediate or identifiable health problems. In fact, Cristina insisted she had spent her entire life being her mother's caregiver. Single with no children at the time of study, we asked her who was going to take care of her when she grew old. She pondered the question, and responded that she didn't know and that she preferred that, "they put me in a nursing home." When asked why, she answered, "…so as not to waste their time. I'm not saying that I am wasting my time on my mother but I don't want to be a burden to my [future] children." Another participant revealed a similar perspective when asked the same set of questions. She stated that, "I would like to go to a nursing home. I wouldn't like to give problems to the people around me, the people that love me." Excerpts from two other study participants with young daughters further illustrated this point:

> "Let's imagine that I'm 70 years old and she [daughter] is twenty-something and married with children. I'd tell her, 'listen, daughter, attend to your children, your husband, your life. Don't worry about me. If I can serve you in some way, I'm here but I'm not going to be a burden on you.'"
>
> "I am 40 years old and I barely have a little one-and-a-half-year-old, so oh gosh! It doesn't seem fair to me to complicate their lives with a little old lady, too."

All of these interview excerpts indicated that being a burden was not a desirable position to be in. Study participants did not describe their older relatives as being a burden, but viewed caregiving as a burden on some level even when they did not associate it with their current situations.

The distinctions they made between their current situations and their eventual long-term care needs suggested that some caregivers had contradictory feelings about being caregivers. Caregiving was sometimes emotionally and physically *pesado* yet study participants did not perceive care receivers as burdens. Further analysis showed that study participants with these views were at least 10 years younger than study participants who did not express this views. Therefore, younger generation caregivers found that the burden of care was difficult enough that they did not want their children, particularly their daughters, to be in the same positions they currently found themselves in. This dissonance between study participants' current lives as caregivers and the non-caregiving lives they wanted for their children suggested that burden had dimensions beyond the negative.

Burden as Sacrifice—A third theme emerged from study participants' discussions of caregiving that may partially explain why study participants continued on their caregiving lives despite the tremendous challenges to their bodies, minds, and time—burden was a sacrifice. We asked study participants open-ended questions on how their lives were different as a result of taking care of their older relatives. We found two-thirds of study participants viewed caregiving as a life-changing event (Table 3).

Some of the sacrifices study participants reported as a result of becoming a caregiver included exiting the paid work force or reducing employment (12); terminating or postponing formal education (5); relocating their primary households (10); assuming financial hardships (10); and reducing social activities (23).The majority of spousal caregivers (9 of 11) and non-spousal caregivers taking care of male relatives (6 of 7) reported that caregiving resulted in some or all of these life changes. However, only half of non-spousal caregivers taking care of female relatives (12 of 23) reported caregiving as a life-changing event. We also found that the average age of study participants was almost the same for those who viewed (51 years) and did not view (49 years) caregiving as life-changing.

However, Table 3 shows that sacrifice was not an entirely negative construct. We found that 27 of 41 study participants described caregiving as a sacrifice of love, initiative, willingness, and good will. We found that study participants who expressed caregiving in positive terms were at least 10 years younger than those who did not view caregiving as showing love or good will. One study participant stated that it was up to each child to “take the initiative to give care or not.” Another study participant acknowledged that “it is good will to do it [give care] even though right now you're sharing their [care receiver's] emotional burden (*duele*) as well.” *Duele* usually refers to a physical or emotional pain, and can also mean stress, difficulty or suffering. Within the context of this conversation, however, the study participant was referring to the burden that she was suffering along with the care recipient. Her reference to the care receiver suggested that the care receiver was aware of being a burden and the suffering that being a burden caused the caregiver. This revelation may help further explain why study participants did not want to be a burden to their own children.

Another example of burden's positive features comes from Rosi, a 46 year-old divorcée who lived with her young daughter, teenage nephew and a 72 year-old mother with multiple diabetes-related ailments. Rosi was “constantly watching over” her frail mother because she was “no longer self-sufficient.” Rosi was a caregiver not because she felt “obligated” but because she felt “this love to do it, this good will that [makes me] want to do it.” Rosi's situation represented an extreme manifestation of the positive feelings towards caregiving expressed by many respondents. She sacrificed her marriage to take care of her mother. Her husband did not want his mother-in-law to move in with them and did not want Rosi to spend so much time caring for her mother. Rosi ultimately chose to leave the husband in favor of her mother and moved into her mother's home to start caregiving full-time. Therefore, sacrifice for Rosi meant adapting her lifestyle to accommodate being a caregiver. For example, she shared with us the details of her financial situation and how she made ends meet:

> “I believe that money used to go a little further for certain luxuries, for certain extra things, conveniences. But times are more difficult [now], so I believe that one has to adapt and, in fact, I am very adaptable. If there's not enough for a luxury, we deprive ourselves of the luxury. The basic necessities are more important than a luxury.”

Rosi adapted to her financial situation by depriving herself and her family of luxuries and gave us a specific example of what she meant:

> "In some way all of their necessities are met. So for example, milk. Well, obviously, milk is for the girl [daughter] and for her [mother], so then my nephew and I we maybe drink milk no more than two times a week. We don't drink it every day because if we did, there wouldn't be enough. We prefer that they drink it and that we abstain a little, not that it's traumatic for us or that we feel bad for each other. On the contrary, it's a matter of adaptability and that's the way we see it."

While Rosi was an extraordinary caregiver, her story exemplified the sacrifices that study participants made to shoulder the burden of caring for their older family members. Rosi and her nephew (who helped her with caregiving activities) limited their milk intake so that her young daughter and her mother would have enough to drink. Financial sacrifices were common among other study participants as well as changing their diets to accommodate the care recipient's dietary needs and the other sacrifices previously mentioned.

Another study participant provided further insight into caregiver burden being both a positive and negative construct, and stated "that having to deal with sick persons, for me, is a form of purification, of unification; I don't see it as a punishment and I don't complain. No, for me it has been something positive. We asked her if she thought being a caregiver was one of her reasons for living. She replied, "Uh-huh, it's one of my missions [in life]." The notion of caregiving as a form of "unification and purification" and something to be dealt with illustrated burden's negative attributes. However, caregiving as an endeavor for a higher purpose suggested that burden was also a positive sacrifice.

Discussion

This exploratory study of low-income female caregivers in a small Mexico City neighborhood found that the concept of burden has multiple dimensions. For the women in this study, burden referred to tangible situations that were emotionally or physically *pesado* for them. The women also viewed burden as an undesirable state of dependency (*ser carga*) that inflicted stress or pain on others. However, burden meant sacrificing for others in ways that were rewarding for caregivers. We found that the perceptions of burden differed between younger and older generation caregivers; younger caregivers tended to view burden positively and negatively whereas older caregivers were neither positive nor negative in their assessments of caregiving. We also found that the relationship to care receivers was a factor in views about caregiving as a life-changing event whereas age was not.

Our findings on the multi-dimensionality of burden are consistent with the large body of literature that conceptualizes burden as the physical, emotional, social and financial hardships experienced by family caregivers (Deeken *et al.*, 2003; Montgomery *et al.*, 1985; Pinquart & Sorensen, 2003; Schulze & Rössler, 2005; Zarit, 2004). However, our findings offer another dimension of burden to comprehensively measure the construct. We found that burden reflected being emotionally *pesado,* (tired, sad or frustrated), consistent with findings from many studies that have examined the emotional costs of caregiving in terms of depression, stress, happiness, satisfaction, and well-being (Chappell & Reid, 2002; Chumbler *et al.*, 2003; Spurlock, 2005; Stull *et al.*, 1994; Zarit *et al.*, 1980; Zarit *et al.*, 1986). However, the women in this study also conceptualized burden in terms of being physically tiring, and that *pesado* referred literally to the physical demands of care. They identified actual situations that were physically difficult to perform, such as carrying the laundry or sacks of groceries, and lifting the care recipient. They reported that these kinds of tasks took a physical toll on their bodies above and beyond the emotionally draining experience of caring for their family members. Many studies have examined the association between burden and poor physical health outcomes. Research in this area has focused on the relationship between stress and physical functioning, such as immune deficiency (Kiecolt-Glaser *et al.*, 1991; Pinquart & Sorensen, 2006; P Vitaliano *et al.*, 2004; P Vitaliano *et al.*, 2003), health behaviors (R. Schulz *et al.*, 1997) and mortality (Richard Schulz

& Beach, 1999). However, our understanding of the effects of burden on health is limited by how burden is being defined and measured in studies (Deeken et al., 2003; P. Vitaliano *et al.*, 1991). The physical costs of caregiving are often measured in terms of caregiver health outcomes such as changes in self-reported health status. Most burden scales do not ask questions on physically strenuous activities such as lifting heavy objects, thereby omitting one potentially important contribution to caregivers' experiences of burden that would be particularly salient to low-income caregivers in Mexico.

We also found that the construct of burden had positive features. This finding is consistent with earlier research that showed caregiving can be a rewarding and uplifting experience (Given *et al.*, 1992; M. Lawton *et al.*, 1989; M. P. Lawton *et al.*, 1991; Picot SJF *et al.*, 1997). This early body of work incorporated the positive feelings related to caregiving and the potential negative association with caregiver depression. This early research suggested that burden should not only be measured in terms of negative costs but in terms of positive benefits as well (Grant *et al.*, 1998; Kramer, 1997).

Our findings on burden as a positive sacrifice may have reflected the way study participants made meaning of an otherwise obligatory role as daughters or wives. The dissonance between being caregivers and not wanting to be a future burden on their families may be explained by placing our findings within the context of the abundant literature on family formation and functioning in Mexico (K. Finkler, 1994a; García & de Oliveira, 1997; LeVine *et al.*, 1986; LeVine, 1986; Oropesa, 1997; Vázquez-Nuttall *et al.*, 1987). Gender role differentiation and social role functioning, particularly the female *marianisma* role, are important to the social organization of Mexican culture (Staton, 1972). The *marianisma* role is inculcated from early childhood and is particularly influential in women's expected behaviors of femininity, submission, weakness, reservation, and virginity (Bridges, 1980; K. Finkler, 1994a; K. Finkler, 1994b; García & de Oliveira, 1997; LeVine *et al.*, 1986; Nader, 1986; Olson, 1977; Peñalosa, 1968). As the *mariana*, a mother is expected to be completely submissive to her husband, acknowledge his authority, and perform self-sacrificing behaviors (García & de Oliveira, 1997; Hubbell, 1993; Peñalosa, 1968). This female gender role is based on the emulation of the Virgin Mary in the Catholic religion and has also been referred to as *la madre abnegada* (Hubbell, 1993) meaning “self-sacrificing mother.” Thus, the ideal mother sacrifices her own needs and happiness for the sake of her children and family regardless of the personal hardship (K. Finkler, 1994a; K. Finkler, 1994b; Hubbell, 1993).

Although we did not specifically ask study participants for their views about *la marianisma*, our findings that women viewed burden as a positive sacrifice but one that they did not want to place on their children suggest that women continue to fulfill this obligatory role. We further find that the *marianisma* role extends beyond the marital relationship and child-rearing to the care of elderly relatives. Thus, we can argue that caring for elders represents one facet of the overall social obligation that women have been assigned in Mexican society.

The embeddness of women in domestic spheres, such as unpaid care work in the home, may be particularly reflected in older women's views on caregiving. Older caregivers compared to younger caregivers tended not to describe burden in either positive or negative terms. It could be that the older participants in this study had spent more of their lifetimes in this social role, and as a result, considered it as part of their normal life. Paradoxically, however, we did not find that age was a factor in study participants' views of caregiving as a life-changing event. Therefore while younger study participants had more polarizing views on caregiver burden compared to older study participants, participants of all ages indicated that caregiving changed their lives. The fact that the majority of these caregivers was taking care of an older male relative suggests that for older women, caregiving fell within the scope of their marital obligations; for younger women, their relationship to the care receiver may have influenced their views on burden but not on their decisions to fulfill their obligatory social role as caretaker. In either case, the older and younger participants in this study took on the caregiver role, consistent with the principles of being a *mariana*.

There are some limitations to our study that are worth mentioning. First, males were purposely excluded from this study. We focused on women because they have historically predominated as primary caregivers, and thus represent the norm of caregiving. We acknowledge that focusing solely on female caregivers does not advance our understanding of gender differences in the caregiving experience (Horowitz, 1992). However, we focused on the experience of female caregivers as a first step in the knowledge development of the Mexican literature in this area. Lastly, we acknowledge that in response to Mexico's lack of long-term care provisions for the elderly, unskilled homemaking services, such as housekeeping and elder care, are widely available in informal labor markets. However, the majority of our study sample had low household incomes and limited resources for purchasing unskilled labor. Therefore, this study does not take into account women's limited life options in taking care of older relatives, but rather the meaning they gave to such activities within the contexts of their life situations and social role obligations.

Caregiving research is in its infancy stages in Mexico and the findings from this exploratory study suggest that Mexican women are experiencing caregiver burden in negative and positive ways. Our findings offer an additional dimension of burden to broaden our understanding and measurement of the construct. Current instruments on burden are becoming routinely used in countries outside the United States (Kao & Acton, 2006; Miyashita *et al.*, 2006; Serrano-Aguilar *et al.*, 2006; Taub *et al.*, 2004). Our findings suggest that researchers studying caregiving in Mexico should think about how burden is measured on existing instruments before adapting them for widespread use; the current conceptualizations and measurements of caregiver burden on these instruments may be problematic in non-U.S. populations. Failure to do so may inadvertently result in not properly characterizing caregiver burden in Mexico. The development of culturally appropriate instruments to measure caregiving burden in Mexico is necessary to provide an empirical foundation for policy recommendations that address the growing need for institutional support of caregivers. Successful social policy efforts would adequately address the negative aspects of caregiver burden while acknowledging the culturally defined positive aspects of the social role of caregivers.

Elder care is becoming an increasingly pressing and complex public health concern as the Mexican population continues to gray. Further research is needed to understand women's abilities to care for their older family members within a changing social landscape, especially the effects of multiple role strain, stress, and burden on caregiver health.

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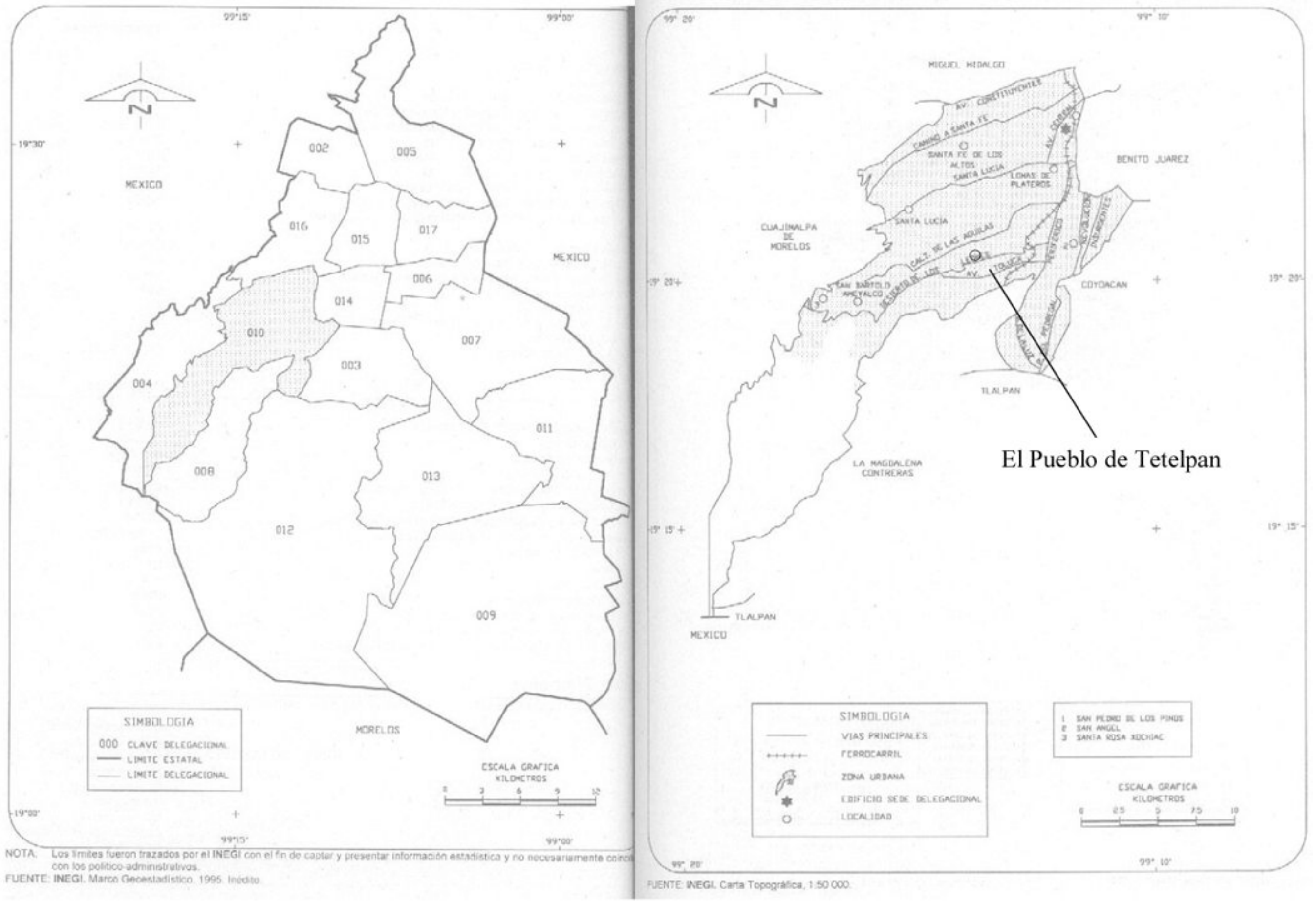

Delegación Alvaro Obregón 010 within Mexico City Limits

Tetelpan within Alvaro Obregón Delegación limits

Figure 1.

Maps of Alvaro Obregón (Left) and El Pueblo de Tetelpan, Mexico City (Federal District)

Table 1

Sample characteristics of respondents (n = 41)

Characteristics		**SD**
Mean age (in years)	49.8	18.2
Median age (in years)	50.0	
Mean years of caregivers' education	7.7	4.3
Median length of caregiving (in years)	5	18.5
Median monthly household income (in pesos)	2000 ($213 USD)	1865.5 ($199 USD)
Mean years of marriage for spousal caregivers	52	8.1
	n	*%*
Caregiver employment status		
Not employed	25	61
Part-time employed	12	29
Full-timed employed	4	10
Marital status of non-spousal caregivers		
Married	15	50
Never married	9	30
Divorced or separated	4	13
Widowed	2	17

Table 2

Care receiver characteristics (n = 41)

	#	%
Mean age (in years)	**75.2 (SD=10.9)**	
Relationship to caregiver		
Husband	11	27
Parent	17	41
In-law	4	10
Grandparent	6	15
Sibling	2	5
Other relative	1	2
Needed help with ADLs		
0 ADLs	17	41
1-2 ADLs	9	22
3-5 ADLs	15	37
Main illness complaint		
Diabetes	5	12
High blood pressure	3	7
Mental illness	2	5
Stroke	4	10
Other (chronic lung disease, glaucoma, old age, overweight, thyroid, rheumatism)	6	15
Multiple ailments that included one or more of the following: diabetes, heart disease, mental health, high blood pressure, and stroke	8	19
Unspecified condition	2	5
None	11	27

Table 3

Study participants responding affirmatively about caregiving, by relationship to care receiver

		% (#) Yes		
Relationship to study participant	**N**	**Good will**	**Love**	**Life-changing**
Spouse	11	36% (2)	27% (3)	82% (9)
Male other than spouse	7	28% (4)	28% (2)	85% (6)
Female	23	48% (11)	78% (18)	52% (12)
Total	41	17	23	27
% Yes life-changing	27	41% (11)	52% (14)	-