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Activities of Daily Living in Mexican American Caregivers: The Key to Continuing Informal Care

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Abstract

La familia drives elder care in Mexican–American (MA) families, but nursing home placement can result from day-to-day caregiving demands that increase caregiver difficulty with activities of daily living (ADLs). Using *life course perspective*, this article describes the initial data wave of 31 MA caregivers from a descriptive, longitudinal, mixed-methods study of 110 MA caregivers and care recipients over 15 months in their caregiving trajectories. Fifteen of 31 caregivers consistently indicated “no help needed” on the Katz ADL, whereas all but one reported “help needed” during semistructured interviews with cultural brokers. In addition to the discrepancy between results on the Katz ADL and interviews, findings include consideration of nursing home placement by moderately acculturated caregivers and minimization of their illnesses by caregivers. Additional methods of MA caregiver assessment may be needed due to the questionable accuracy of the Katz ADL; additional research should explore minimization and acculturation in MA caregivers.

Keywords

family caregivers; Mexican-American; activities of daily living; minimization

Introduction

Children and daughters-in-law need to keep their eyes on the elders, to understand the care that gave us our lives so that elders are not forgotten, not abandoned, nor cast out.

“Nana,” Tucson, Arizona

Continuing informal care for parents is central to the Hispanic culture (Dilworth-Anderson & Gibson, 2002). Traditionally, such families strenuously avoid nursing home placement, keeping elders at home longer than Anglo families (Espino, Neufeld, Mulvihill, & Libow, 1988; Meyer, 2001), but the day-to-day physical and emotional demands of informal care may result in increasing caregiver difficulty with activities of daily living (ADLs). Such declines are of grave concern to them because caregivers know that their functional abilities are the key to keeping older family members at home, honoring their long-term commitment to care, and providing end-of-life care without institutionalization (Funk et al., 2010).

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La familia, where the family is the main source of social interaction, transcends socioeconomic status or gender (Becerra & Shaw, 1984) and drives elder care in Mexican-American (MA) families, making their caregiving trajectory quite different than that of Anglos. Caregivers want to reciprocate for care they previously received and they feel a strong obligation to care for their parents and grandparents (Clark & Huttlinger, 1998). The importance of *la familia* persists even with increasing acculturation and socioeconomic status, so most MAs remain committed to informal caregiving (Hurtado, 1995; Schaffer, 1996). In fact, Hispanic Caregivers are almost twice as likely to reduce work hours or quit work to provide care as Anglos (Covinsky et al., 2001); four in 10 have cut back on working hours, changed jobs or stopped work entirely as a result of their caregiving role (Evercare & National Alliance for Caregiving, 2008).

The purpose of this article is to describe the influence of *la familia* in terms of caregiver acculturation, cultural expectations, and ADLs over a 15-month period in the informal caregiving trajectory of 31 MA caregivers. These caregivers represent the initial wave of data from a federally-funded, descriptive, longitudinal, mixed-methods study of 110 MA caregivers and their care recipients.

Background

Although MAs are the largest ethnic minority in the United States (Marotta & Garcia, 2003; U.S. Census Bureau, 2010), literature about caregiving in such families is sparse and dated. Hispanic representation in caregiving studies is low (Aranda & Knight, 1997; Bourgeois, Schulz, & Burgio, 1996; Morano & Bravo, 2002) and studies fail to differentiate data collected from MAs from other Hispanic subgroups (e.g., Cox & Monk, 1993, 1996; Giunta, Chow, Scharlach, & Dal Santo, 2004; Harwood et al., 2000; Sink, Covinsky, Newcomer, & Yaffe, 2004; Weiss, Gonzalez, Kabeto, & Langa, 2005). In addition, if differentiated, samples are too small for accurate conclusions or participants may be dissimilar to MAs living in border regions such as Arizona, making generalization of findings difficult (e.g., Depp et al., 2005; Gallagher-Thompson, Areán, Rivera, & Thompson, 2001; Gallagher-Thompson et al., 2003).

Thirteen percent of Hispanic households presently provide care to an adult aged 50 or older (National Alliance for Caregiving & AARP, 2004) but this number is expected to burgeon (Coon et al., 2004). Little is known about the health of these families, including the transition from health to disability (Schneider & Shardell, 2008), but health disparities are more prevalent and severe in MAs at earlier ages than Anglos (Crist, Garcia-Smith, & Phillips, 2006; Espino et al., 2002; Hazuda & Espino, 1997; Torres, 2001; Villa & Aranda, 2000). Such disparities result in greater deterioration in MAs' physical and emotional health, resulting in more functional limitations, higher levels of disability, and an increased need for care (Espino et al., 1988; Espino & Burge, 1989; Ostchega et al., 2000; Zsembik, Peek, & Peek, 2000).

Conclusions about ADL disability are mixed. Such disabilities declined in older Americans during the 1990s but, although the brief time period of 2000–2005 is too short to identify a trend, one recent study suggests a significant increase (Fuller-Thomson, Yu, Nuru-Jeter, Guralnik, & Minkler, 2009) in community-dwelling populations. In addition, the average age in the initial wave of caregivers presented here (not dissimilar from the remainder of the demographic data representing the full sample; Table 1) is almost 53 years. Given that ADL disability rates in U.S. working-age populations are rising, although not among older people (Bhattacharya et al., 2008; Bhattacharya, Choudhry, & Lakdawalla, 2008; Lakdawalla, Bhattacharya, & Goldman, 2004), we could be faced with caregivers who have disabilities that are as significant, or more so, than the older people for whom they are providing care.

One component of rising disability rates particularly important for Hispanic populations is obesity; MA men and women both have higher rates of obesity compared with Anglos, resulting in increased risk of functional impairment, although they tend to live longer (Lakdawalla et al., 2004; Samper-Ternent et al., 2012).

Although there is limited research documenting changes in MA elders' ADLs over time (Caskie, Sutton, & Margrett, 2010), loss of ability to perform ADLs has more serious consequences than loss of instrumental activities of daily living (IADL) capacity does, including institutionalization and higher mortality rates (Angel, Angel, Aranda, & Miles, 2004; Caskie et al., 2010). In fact, age, male gender, and ADL disability are predictors of mortality in both MAs and Anglos (Samper-Ternent et al., 2012). The effects of cardiovascular problems on ADLs may be especially great for MAs, who are known to have high rates of hypertension (approximately 60%; Satish, Stroup-Benham, Espino, Markides, & Goodwin, 1998) but who may not adhere to medication, diet or exercise regimens (Wang & Wang, 2004). ADL limitations increase over time in these adults, with greater age related to more baseline limitations and greater rates of change during a 7-year period (Caskie et al., 2010), especially in those with hypertension. The high prevalence of pain in older Mexican Americans also interferes with functional performance and is independently associated with ADL disability (Weaver et al., 2009). The effect of pain is greatest in participants with high cognitive ability, such as the caregivers in this study, and increasing age is associated with increased pain.

Most MA caregivers are female (Espino et al., 2001), some are single women who also work outside the home (Fields & Casper, 2001; Torti, Gwyther, Reed, Friedman, & Schulman, 2004), and more than 70% of them fulfill most of the caregiving duties alone (Herrera, Lee, Palos, & Torres-Vigil, 2008). Southwest Hispanic women report higher disability than do men (de Leon, Eschbach, & Markides, 2011) and, although they are less disabled in ADLs than Anglo women (56.5% vs. 69%; (Samper-Ternent et al., 2012), the stress of living with their disabilities cannot be overstated (Harrison, 2009). Among these women, English language use is associated with lowered odds of ADL limitation, perhaps because, although they may acquire poorer health habits with acculturation, they also may have better access to health care (Salinas & Sheffield, 2009).

Disability also may be an issue for the 13.8% of MA male caregivers who comprised our sample in the overall study. If foreign born, MA men have some health advantage, but if U.S.-born, they tend to have increased cognitive, mobility, and independent-living disability levels (de Leon et al., 2011). This may reflect the acquisition of the same socioeconomic disadvantage and health risks as other disadvantaged minority groups in the United States.

Mixed-methods studies are needed to build the scant knowledge base on functional impairment and health disparities in MA caregiving families. Such studies allow the juxtaposition of case-oriented (qualitative) data with variable-oriented (quantitative) data to provide a clearer picture of the phenomenon and insight into causal mechanisms. The theoretical framework for this mixed-methods study, *life course perspective*, is one way to examine the psychological, biological, cultural, and political factors complicating disability in MA family caregivers (Harrison, 2009).

Theoretical Framework

Our study uses life course perspective to examine informal caregiving events in MA families (Elder Jr., 1995, 1999; Elder, Kirkpatrick Johnson, & Crosnoe, 2003). Life course perspective permits consideration of cultural and contextual influences across the caregiving trajectory, such as acculturation and socioeconomic status, in concert with timing of life events such as immigration. The framework also allows exploration of adaptive caregiving

strategies and important transitions in care over time, guides examination of continuing caregiver ability and potential or progressive disability, assists in exploration of cultural expectations in relation to caregiving, and facilitates derivation of testable hypotheses in regard to the caregiving trajectory (George, 2003; Moen, 2003; Pearce & Davey Smith, 2003; Settersten, 1999; Singer & Ryff, 1999; Wethington, 2005).

Method

Design

This study is primarily case-oriented and qualitatively-driven, relying on life course perspective to present the facts of information-rich cases in everyday language (Sandelowski, 2000b). The addition of a simultaneous, complementary, quantitatively-driven, variable-oriented component enables integrated naturalistic and statistical examination of patterns within- and across-cases, and facilitates the drawing of inferences during the analytic and interpretive phases of the study (Creswell & Clark, 2007; Morgan, 1998; Morse, Niehaus, Wolfe, & Wilkins, 2006; Ragin, 2000). To facilitate the deep, intensive examination needed for case-oriented methods and maximize understanding of the “one” in all its diversity (Sandelowski, 1996), we first analyze successive “waves” of data, examining a set of interviews and corresponding variable-oriented data from each case (within-case) and then comparing sets of interviews and variable-oriented data across-cases.

The longitudinal nature of this study requires that a baseline and 5 follow-up visits are made to caregiving families at 10-week intervals over the 15-month course of their participation. Consequently, we are able to plot their progress over time in ADL ability or disability with both case- and variable-oriented data, as described under “Findings and Discussion” in this article.

Sample and Setting

The overall study explores the caregiving experiences of 110 MA families in the American southwest, and defines a “case” as at least one informal caregiver and one care recipient. Because of the collective ethos of the MA family, it is not uncommon to encounter multiple caregivers or care recipients. In this initial wave of 30 cases, 1 family unit was comprised of 2 caregivers and 1 care recipient, hence 31 caregivers are examined. Caregivers are family members, at least 18 years of age, with no self-reported psychiatric history other than depression (determined by screening), who provide continuous assistance with a community-dwelling care recipient’s daily needs.

Caregivers are screened for executive function using the 5-minute clock drawing task (CLOX), which is valid in community-based Hispanics, regardless of education or acculturation (Royall et al., 2003). The CLOX is a drawing of a circle on which the data collector instructs the participant to, “Draw numbers representing a clock face” and “Set the time to 10 minutes past 11.” Results are scored 0 to 5, according to exemplars of clock faces on scoring sheets. Caregivers need a CLOX score of 3 or above to participate with their family member (60 years of age or older) in the study, ensuring each caregiver’s ability to respond appropriately to our questions. Mean sensitivity and specificity are at 85%, interrater reliability is 0.94–0.97, and correlation with the minimum mean square error (MMSE) is –0.77, (reflecting the negative scoring system used for the CLOX; Shulman, 2000).

A stratified purposeful sampling plan ensures case variation on preselected parameters relevant to understanding caregiving in MA families (Sandelowski, 2000a). Parameters include acculturation, the nature of the caregiving relationship, functional and cognitive status of the caregiver, and the elapsed time of the caregiving trajectory.

Initial wave—For this initial wave, we addressed the first 30 completed cases in the study. It is noteworthy that the longitudinal data include 180 semistructured interviews, along with results from 8 standardized instruments for each of 6 caregiver visits at 10-week intervals, over a period of 15 months. Although data analysis is still proceeding for the remaining 480 interviews in the study, these first 30 cases provide an initial look at MA caregiving families, about whom we know little. In addition, findings in these cases are congruent with those noted in the next wave of interviews, echoing Sandelowski's (1995) assertion that we often have all the information we need in the first pieces of data we collect, although we cannot know that until we collect more. This sample size of 30 is commonly regarded as adequate (e.g., 20–30 participants are recommended by Creswell, 2007; see Butcher, Holkup, Park & Maas, 2001), yet manageable for the detailed analyses required by case-oriented methods; in fact, we have achieved informational redundancy (Sandelowski).

Caregiver Measures and Interview Protocol

Demographic questionnaire—A demographic questionnaire solicits caregiver data on a variety of parameters, including those displayed in Table 1. Socioeconomic groups are identified using indicators from the National Occupational Classification.

Katz activities of daily living (ADL)—The 7-item ADL scale measures capacity in bathing, dressing above and below the waist, toileting, transferring to bed or chair, grooming, and eating (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). The measure demonstrates predictive validity in discharge status and function; is correlated highly with MMSE ($r = .76$); Guttman—coefficient of reproducibility 0.95–0.98 (Foreman & Vermeersch, 1997). It has reported psychometrics in a variety of populations, it is commonly used with adults/ elders in research and clinical applications, and it is applicable to community-dwelling adults/elders (Kane & Kane, 2000). The widely used tool is considered highly reliable and sensitive to change across cultures in homecare (Sherwood, Morris, Mor, & Gutkin, 1977).

General acculturation index (GAI)—The 5-item GAI is a brief abbreviated version of the Acculturation Rating Scale for MAs that explores preferred language, childhood setting, preferred circle of friends, and pride in a Hispanic heritage (Balcazar, Castro, & Krull, 1995; Castro, Cota, & Vega, 1999). It is a widely used instrument and exhibits good internal consistency, with a Cronbach's coefficient of .78 (Balcazar et al., 1995). GAI values of 1.00–2.39 (average of item score) correspond to lower levels of acculturation; values of 2.40–3.69 indicate a bilingual/bicultural orientation; 3.70–5.00 indicates a high-level of acculturation.

Center for epidemiological studies-depression (CES-D)—The 12-item scale assesses depressive symptoms during the past week through statements such as, "I had trouble keeping my mind on what I was doing," and "I could not get going." Higher scores indicate greater depression, with a score of 16 indicating clinically significant symptoms (Radloff, 1977). Roberts (1980) reported internal consistency with a Cronbach alpha of 0.83–0.88 in Chicanos.

Interview protocol—A semistructured interview protocol explores the caregiving experience and associated life events in terms of transitions, turning points, and adaptive strategies, reflecting life course perspective. Interview questions, derived from multidisciplinary caregiving literature, include openended items such as, "What are the roles and responsibilities of the people in your family concerning caregiving?" We also elicit particular "rules for caregiving" in the family and ask, "How does being MA influence your caregiving?" Questions take about 60 min. to administer, with 10-week updates requiring slightly less time.

Data Collection Procedures

Prior to Senate Bill (SB) 1070 that struck fear into the immigrant population, Spanish-speaking cultural brokers recruited cases (caregiver-care recipients) in community venues for this Arizona State University Human Subjects Institutional Review Board approved study. After the passing of SB1070, however, recruitment became restricted almost entirely to word-of-mouth. Our cultural brokers, trusted members of the Hispanic community, received referrals from multigenerational families who participated in the study, families whom they told about their participation (“talking to 1, talking to 20”; (Evans, Coon, & Crogan, 2007), and families who listened to the cultural brokers on Spanish language radio and television. Brokers visited caregivers in their own homes for enrollment, informed consent, and data collection (demographic data, standardized instruments, timeline drawings of the caregiving trajectory, and interviews). Interviews were read to participants to avoid any vision or literacy issues.

Data Analysis

Case-oriented research methods (Gerring, 2004; Miles & Huberman, 1994) guide data analysis. After intensive training in coding by the principal investigator, during which interrater-reliability is established at the 90% level (Miles & Huberman, 1994), interviews are examined separately by two cultural brokers. The trained brokers use a coding manual (developed from life course perspective and constructs identified in interviews; validated against 60 interviews) that assists in organizing codes into conceptual domains. Codes are reconciled by cultural brokers and entered into Atlas.ti, a computerized program for qualitative data analysis which can be queried for relevant exemplars associated with themes, that is, ideas or concepts that occur repeatedly in the text (Miles & Huberman). Similar themes are clustered into categories that emphasize description of ADL status and cultural expectations about MA family caregiving.

Caregiver ADL capability expressed in interviews and caregiver scores on the ADL instrument ($n = 31$) were both dichotomized, “no help needed” versus “help needed”; (Al Snih et al., 2009; Salinas & Sheffield, 2009) and compared. Data matrices (Miles & Huberman, 1994) were constructed to juxtapose interview data with variable-oriented acculturation data (ADL, GAI, and CES-D). Demographic data such as age range, mean age, acculturation level, years of education, socioeconomic group, income level, and stage of caregiving also were considered. Working back and forth across the matrices, we looked for patterns and relationships among physical, social, and cultural phenomena that influenced the trajectories of these MA caregivers (Patton, 2002).

Findings and Discussion

Table 1 compares demographic data for the 30 cases (31 caregivers) with the remainder of the 116 total caregivers. The two groups were similar in age range, mean age, acculturation level, years of education, socioeconomic group (although there was some difference in percentages of mid-level managers, skilled/semiskilled, and unskilled workers), income level (slight differences in the higher income ranges), and stage of caregiving (early-middle stage defined as 0–24 months, late stage defined as more than 24 months). They varied in gender, with the 30 cases discussed here being predominantly female, although the 110-case remainder included a surprising number of sons as caregivers (Evans, Belyea, & Ume, 2011).

Table 2 compares demographic data for the 30 cases (32 care recipients) with the remainder of the 119 total care recipients. The two groups are similar in mean age but the initial wave displays lower levels of acculturation and formal education, with accompanying lower

socioeconomic status. There was also a higher representation of male care recipients in the initial wave.

Dichotomized ADLs

When dichotomized according to “help needed and “no help needed,” 15 caregivers out of 31 indicated “no help needed” on the standardized ADL instrument. Thirty caregivers, however, reported “help needed” during the interviews, whereas one caregiver reported “no help needed” on both standardized instruments and interviews. Of the 16 caregivers who reported on the instrument that they needed help with ADLs, 14 had mean scores of 1–3 ADL impairments out of 7 possible, across the 10-week visits.

Caregivers whose responses to the instrument and the interview questions were incongruent foreshadowed the recognition of *minimization*, described later in relation to somatization and acculturation, as a means of coping with ADL problems. An example of this incongruency was a caregiver who reported no ADL limitation on the standardized instrument but confided to the cultural broker,

Like I told you, my knees [hurt] sometimes, but I’m good, like I try to stay on top of myself. I don’t like to say, my knee hurts, I need a rest, because then the knee will give up for sure....I told my mom, if I need an operation, I’ll have to take some time off [from caregiving].

Another caregiver who reported no ADL limitations until the interview needed physical therapy (PT) on her legs.

But I haven’t, I can’t find the time and it costs me US\$60 to go to PT. So I can’t do it and justify the expenses for the house and utilities. Pay US\$60 to go have somebody play with my legs, you know! It gets sometimes where I can’t walk, my right knee and besides, the doctor told me it’s arthritis growing in my knees anyway, so it’s not actually going to cure anything. Mind over matter. As long as I don’t pass out or start feeling sick, that means I don’t need anything.

The interview followed the administration of the standardized instrument battery at each visit, so the enhanced reporting of ADL difficulties in the interview may have been the result of previous sensitizing to the topic. Over time, however, participants knew they would be asked about ADLs at each visit, so other factors may have come into play. For example, the relationship between participants and cultural brokers is a close and supportive one, developed over time and supported by respect and personal warmth (*personalismo*), both foundational to the MA culture. The *personalismo* expressed in their interactions may encourage communication of ADL problems, which lie close to the bone for caregivers (Evans et al., 2007). In addition, MA caregivers find it culturally inappropriate to acknowledge “burden” of any kind, although discussions about “obligation” and “duty” are acceptable. Our MA cultural brokers hypothesize that indicating “help needed” on the formal standardized instrument may be seen as conceding the presence of burden, whereas informally discussing ADLs in the context of duty and a personal relationship is not.

Reluctance to acknowledge burden also could reflect the values of *marianismo*, rules for saintliness and goodness modeled on the suffering of the Virgin Mary. Such rules strongly shape the socialization process of Latina girls, but their requirement of self-sacrifice must be balanced by a sense of dignity and nobility (Arredondo, 2002). If MA women see acknowledgment of burden on the ADL as undignified, they may fail to report ADL concerns. Under some circumstances, this reluctance could be buttressed by *machismo* in MA males, thereby hindering accurate response to the instrument because outside help is seen as inappropriate.

Acculturation

As shown in Table 1, none of the caregivers acculturated at a low level (1–2.39 on the GAI) would admit their care recipient to a nursing home, per interview data. All cited *la familia*, saying that they care for older relatives in their family and their culture, and/or that they believe in reciprocal care for the care that was given to them as children. One daughter-in-law reported, “I told my husband to bring her to the house....this is the mother of my husband and the grandmother of my children. I took care of my [own] mother until she closed her eyes.” Another explained, “For generations we have done the same thing—everyone helps care for him at home.” Yet another emphasized, “I take care of him as if it were me. I love him, I will not leave him.”

The single exception was a caregiver who placed her husband’s mother permanently in a nursing home, with his agreement, citing severe security issues and only after herself having a stroke. Her story is reflective of the length to which MA families will go before giving up on caregiving and the level of distress that drove this decision.

I’m going to be sincere. I’ve had some really bad days. One day, she took off at midnight. We all went to look for her and thank God, she had not gone too far. My blood pressure went way up and my sugar went up to 174. She treats me badly and shouts at me, she damages my health, [but] I need my health to take care of everyone else. She had to have help with everything, absolutely everything. It reached the point where I had to go to the hospital for three or four days with a ministroke. The stress, the lack of sleep and the constant state of worries became a 24-hour horrific situation. Nothing was enough—she would reject everything. We gave her everything in a silver spoon, we treated her like a queen and that hurt us a lot because she took off her crown and threw it in the garbage.

Caregivers who were moderately acculturated, that is, bicultural and bilingual (GAI scores 2.4–3.69) were willing to consider nursing home placement if they were unable to provide a critical level of care needed at home, and 3 of them had already admitted their family members on a temporary basis. Highly acculturated caregivers (GAI 3.7–5) all cited the reciprocal care of *la familia*, along with the need to protect and respect the care recipient.

These findings confirm the notion that *la familia* persists across acculturation levels (Hurtado, 1995; Schaffer, 1996), although some flexibility in nursing home placement as a “last resort” is seen in our bilingual/bicultural group of caregivers. Hispanic ethnicity is inversely associated with nursing home placement—in fact, there is a “striking association between ethnicity and the risk of nursing home admission” (Yaffe, 2002, p. 2094), with Mexican-American families doggedly avoiding it, even in the face of a growing inability to continue informal caregiving (Escandón, 2006). Although literature suggests that more acculturated, younger caregivers may tend to acknowledge possible benefits of formal services such as nursing homes, we cannot make that claim based on our initial wave of data (Ayalon, 2002; Evans et al., 2007).

Somatization and Minimization

Traditionally, researchers have reported that Hispanics are more likely than Anglos to externalize cognitive processes in somatization (e.g., Angel & Guarnaccia, 1989; Escobar, Nervi, & Gara, 2000). Somatization is defined in a number of ways, all of which have one element in common: the presence of somatic symptoms such as headache, muscle or joint pain, or irritable bowel that cannot be explained by organic findings (De Gucht & Maes, 2006). Somatization may vary as a function of acculturation status and MAs, specifically, may cope through somatization more than Anglos, with social class moderating the effect of acculturation, (Cervantes & Castro, 1985). Socioeconomic status is commonly used as a

proxy for social class, as it was in this study. About 58% of our initial data wave and 56% of the overall sample (Table 1) were unskilled, semiskilled, or skilled workers, so the influence of social class on our sample was small.

Although it has been thought that persons of lower acculturation are more vulnerable to somatization because of stressors associated with minority status (Cervantes & Castro, 1985), other studies question the somatization hypothesis. For example, Anglo-oriented, culturally blended west Texas MA students, like the moderately acculturated, bilingual, bicultural caregivers in our initial data wave, may be more likely to report severe headaches than less-acculturated students (Montgomery, 1992). In fact, Hispanics may be no more likely than Anglos to give excessive weight to psychological problems in their self-assessments of overall health (Bzostek, Goldman, & Pebley, 2007).

Rather than evidence of somatization in our initial wave of interviews, we encountered a seemingly different and perhaps opposing phenomenon, that of minimization. We defined minimizing as, “ignoring or diminishing the importance of illness or other life disruption due to caregiving.” Caregivers brushed aside the deleterious effects of illness or other disruptions as pesky, low-priority problems that interfered with the commitment to provide long-term continuation of care. One reported, “My asthma bothers me and my blood pressure also (laughing) but it is under control. I am healthy, thank God.” Two others described worrisome health issues but in an offhand manner: “Just a tumor that grew in my stomach....I worry ‘cause my little girl is just a baby still. So I have to be in good health to take care of her and my papa” and “No, I was just a little sick. I went to the doctor and they just cleaned my three arteries of my heart and that’s it.” Caregivers took different approaches, some monitoring their health whereas others pushed it aside, but the specter of ADL incapacity lurked beneath each rationale.

I feel stable, I feel fine. Sometimes I get sick due to the situation, the stress of the house. But I always take care of myself and I never miss my physicals. When I have my appointments, I follow them to make sure that I can serve her because if I am useless, I would not be able to help her either.

I think I’m pretty normal, maybe not, I’ll find out later on. But actually, it’s harder for me to do now. If I’m sick I can’t take care of people. I’d rather not know, but I’ve been doing good. I’m doing good.

Our initial wave demonstrated no significant differences between minimizers’ and nonminimizers’ mean scores on the somatic subscale of the Center for Epidemiological Studies Depression (CES-D), although means for minimizers were lower (minimizers $M = 3.07$ [$SD 2.58$] in comparison to nonminimizers $M = 4.18$ [$SD 3.76$]). For this t -test, a post hoc power analysis indicated that with 30 caregivers, a power of .8 and alpha of .05, there is enough power to detect a difference of slightly more than one standard deviation.

Minimizing occurred across acculturation levels but 57% of minimizers were bilingual and bicultural. It could be that minimizing acts as a coping strategy for decreasing *caregiver strain*, defined as the objective assessment of lasting, potentially harmful emotional, psychological, physical, and financial problems from caregiving. Channeling one’s worries into minimization may positively affect the tendency to somaticize. For example, one cannot acknowledge symptoms of ill health because they might interfere with continuation of care, or one might minimize as a way to preclude culturally unacceptable acknowledgment of caregiver burden or strain.

Conclusions

Disability is a robust quality-of-life indicator and, in fact, may be more accurate than traditional morbidity and mortality data (Fuller-Thomson et al., 2009). In this study, however, reports of ADL disability among MA caregivers frequently differed between standardized instruments and interviews conducted by cultural brokers. The cause of this discrepancy is unknown but disinclination to formally acknowledge burden on the study instruments may be related to *marianismo* or *machismo* and an unwillingness to threaten the bonds of *la familia*, which persists across acculturation. The cultural importance of *personalismo*, however, exemplified in the warm relationships with cultural brokers that were established during regular visits over 15 months, may have fostered a candid, informal interview discussion in which ADL disabilities were not viewed as conceding burden.

Evidence continues to mount concerning a negative effect of acculturation on mental health in MAs in the United States. For example, the lingering protective effects of *la familia* in less-acculturated MAs produce more two-parent families, a healthier diet, and less recreational drug use (Escobar et al., 2000). Immigrant families may also have lower expectations concerning education and income than more acculturated groups, reducing the potential for demoralization and depression if achievement is not high. As families become more acculturated, however, other persistent, unidentified causal mechanisms may remain to protect the collective caregiving vision. One such causal mechanism could be minimization, which may reinforce the closeness and commitment engendered by *la familia*. Although not discussed in terms of somatization or explored as a possible causal mechanism, the concept of minimization is mentioned in two other studies, one with MA cancer family caregivers and one with community-based MA elders, where caregivers minimized their physical and emotional symptoms, along with self-care needs (Crist et al., 2006; Wells, Cage, Marshall, & Hollen, 2009). In this study, caregivers minimized their disabilities, perhaps as a coping strategy to address caregiver strain.

ADL problems may develop in MA caregivers due to the need for dual incomes to keep the family going, the obligations of single-parent families, and geographic separation (Herrera et al., 2008; Min & Barrio, 2009). Friends, family, and spiritual leaders who see declining caregiver health may encourage caregivers to seek formal assistance, including nursing home placement, although as last resort (55.6% caregivers; Herrera et al., 2008; Min & Barrio, 2009). Even with pastoral permission, socioeconomic status and stringent cultural expectations may prohibit seeking formal care and thereby create additional burden (Evans et al., 2007; Torti et al., 2004), but moderately acculturated caregivers in this study considered institutionalization if informal care became too onerous.

The resultant lower nursing home admission rates for Hispanics are thought to be a result of more informal care. Lower rates may also be associated with economic hardship for families who bear the costs of informal caregiving, a matter of increasing public concern (Yaffe, 2002). Ultimately, the continuing physical and emotional strain of caregiving provides a rhythm for the relentless march of MA caregivers toward disability.

The Need for Future Research

Despite the growing numbers of disabled MA elders who increase demands on families for informal care (Funk et al., 2010), few studies consider contextual features of caregiving such as cultural, political, and economic factors or use longitudinal designs to examine phenomena over time. The constraints of our present knowledge base present a formidable challenge to design, development, and provision of affordable, accessible, and culturally relevant community-based services for MA family caregivers (Herrera et al., 2008). This descriptive, longitudinal study adds to that knowledge base by attempting to

provide an accurate account of events, accurately interpreted while staying close to the data, along with the meaning of those events to participants (Sandelowski, 2000b).

Limitations of this study include the possibility that findings from this initial wave of data analysis may not hold true across all 110 cases, that underlying causal mechanisms such as minimization may be seen as more congruent and representative than they really are, and that inaccurate interpretation of cultural nuances may occur, despite the involvement of MA cultural brokers. These limitations, however, will be addressed by testing conclusions across the remainder of the cases, thereby validating findings through replication (Creswell, 2007; Miles & Huberman, 1994). We also can generate propositions for further mixed-methods testing, such as, “MA caregivers who minimize their health issues will demonstrate less evidence of somatization.”

Although a well-established, pragmatic, and widely used index, the Katz ADL has been criticized for a lack of theoretical foundation in development and a lack of formal evidence for reliability or validity (Hartigan, 2007). Because it was developed for use with severely ill patients, low levels of disability may not be detected due to its inability to measure small increments of change in community-based samples (Fieo, Austin, Starr, & Deary, 2011). Therefore, it could be that the MA caregivers are simply too “well” and their ADL changes are too small to be accurately assessed by the Katz.

Given the questionable accuracy of the widely used ADL instrument, other means of assessing disability in MA caregivers may be necessary. Along with interview data, the addition of performance measures such as the Berg Balance scale could increase validity and sensitivity to change in ADLs, and reduce ceiling effects where most participants report “no help needed” (Fieo et al., 2011; Wennie Huang, Perera, VanSwearingen, & Studenski, 2010). Combining the self-report ADL with a performance measure also could refine prognostic information, particularly among persons with high self-reported functioning in community-based samples (Reuben et al., 2004).

Finally, monitoring changes in disability can lead to development of intervention strategies (Institute of Medicine, 2007) designed to support MA caregiving families. As a means of accurate monitoring, additional research needs to further address the reasons for discrepancies between interview and ADL instrument data in our MA population, exploring the relationships between various data collection methods for other instruments, as well. Any additions to the scholarly knowledge base concerning causal mechanisms which support ADL maintenance and keep the key to continuing informal care in the hands of *la familia* would be embraced by these caregivers.

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Table 1

Comparison of 31 Caregivers (Initial Wave) With Remainder of 116 Caregivers

	1st wave caregivers <i>N</i> = 31	Remainder of caregivers <i>N</i> = 85
Age		
Range	19–79	20–78
Mean	<i>M</i> = 52.9	<i>M</i> = 54
Acculturation		
Low level	9 (29%)	30 (35%)
Bicultural/bilingual	19 (61.3%)	50 (59%)
High level	3 (9.7%)	6 (6%)
Gender		
Male	2 (6.45%)	14 (16.47%)
Female	29 (93.55%)	71 (83.53%)
Years of education		
Range	6–18 yrs	0–19 yrs
Mean	<i>M</i> = 12.71	<i>M</i> = 11.78
Socioeconomic group		
Executive and high-level	1 (3.23%)	0 (0%)
Manager and technical	2 (6.45%)	5 (5.88%)
Mid-level management	2 (6.45%)	12 (14.12%)
Skilled/semi-skilled worker	12 (38.72%) 6 (19.35%)	43 (50.59%) 11 (12.94%)
Unskilled worker	8 (25.8%)	14 (16.47%)
Other		
Annual family income	16 (51.63%)	43 (50.59%)
Less than \$20,000	7 (22.55%)	27 (31.76%)
\$20,000–\$39,999	8 (25.82%)	15 (17.65%)
Over \$40,000		
Stage of caregiving	8 (25.8%)	21 (24.7%)
Early-middle	23 (74.2%)	64 (75.3%)
Late		

Table 2

Comparison of 32 Care Recipients (Initial Wave) With Remainder of 119 Total Care Recipients

	1st wave care recipients <i>N</i> = 32	Remainder of care recipients <i>N</i> = 87
Age		
Range	60–98	60–110
Mean	<i>M</i> = 79.5	<i>M</i> = 78.35
Acculturation		
Low level	25 (78.1%)	47 (54%)
Bicultural/bilingual	7 (21.9%)	37 (42.5%)
High level	0 (0%)	3 (3.5%)
Gender		
Male	11 (34.4%)	20 (23%)
Female	21 (65.6%)	67 (77%)
Education level		
No formal education	5 (15.6%)	10 (11.5%)
Primary school	21 (65.6%)	49 (56.3%)
Secondary school	4 (12.5%)	20 (23%)
Years of community college	2 (6.3%)	7 (8%)
Graduate degree	0 (0%)	1 (1.2%)
Socioeconomic group		
Executive and high-level	0 (0%)	0 (0%)
Manager and technical	0 (0%)	1 (1.1%)
Mid-level management	0 (0%)	2 (2.3%)
Skilled/semi-skilled worker	5 (15.6%)	34 (39.1%)
Unskilled worker	9 (28.1%)	27 (31.0%)
Other	18 (56.3%)	23 (26.4%)