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Worry Among Mexican American Caregivers of Community-Dwelling Elders

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Abstract

This mixed methods, multi-site, National Institute of Nursing Research (NINR)-funded, interdisciplinary, descriptive study aimed to identify expressions of worry in qualitative data obtained from caregiving Mexican American (MA) families assisting older adults. The purpose of this portion of the inquiry was to determine how worry is expressed, what happens to caregivers when they worry, and what adaptive strategies they used. We examined semi-structured interviews completed during six in-home visits with 116 caregivers. We identified 366 worry quotations from 639 primary documents in ATLAS.ti, entered them into matrices, and organized findings under thematic statements. Caregivers expressed cultural and contextual worries, worried about transitions and turning points in care, and identified adaptive strategies. Despite these strategies, worry persisted. Constant worry may be an allied, important aspect of caregiver burden. We need additional longitudinal research to better understand the experience of MA caregivers for older adults and to provide empirically supported interventions, programs, and services that reduce worry.

Keywords

Mexican American; caregivers; worry; life course perspective

The family affair of caregiving is so deeply embedded in the Latino culture that there is no separate Spanish word for it. When pressed, some call it “*cuidado de viejitos*” (to care for the old), but they still see care recipients primarily as reciprocal family members (Borrayo, Goldwater, Vacha-Haase, & Hepburn, 2007). Also, religiosity is integral to caregiving; caregivers believe God protects them and gives them special assistance (Rehm, 1999). They say, “*Que Dios te lo pague*” (“God will reward you for it”; Aleman, 2000, p. 14, explicated by Crist, Garcia-Smith, & Phillips, 2006, p. 120). If home care workers are used, families expect them to have “the gift” (“*el don*”) of concern; only then are they considered acceptable (Crist, Velazquez, Durnan, & Figueroa, 2006, p. 288).

Conversely, some caregivers feel “chained” (*encadenada*; Herrera, Lee, Palos, & Torres-Vigil, 2008) to care recipients, and Alzheimer’s caregivers may describe the “battle” (*la*

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lucha; Gelman, 2010) associated with the illness. Still, these families are in the minority because even acknowledging the burden of caregiving responsibilities, much less using the word “burden,” can be seen as culturally inappropriate (Gallagher-Thompson, Solano, Coon, & Arean, 2003).

Caregiver burden is often defined as the emotional, psychological, physical, and financial weight assumed by caregivers, along with their subjective appraisals of how caregiving affects their lives (Zarit, Todd, & Zarit, 1986). Burden is complicated by the constant vigilance involved in safe, timely care, lack of preparation, and the quality of caregiving relationships (Archbold, Stewart, Greenlick, & Harvath, 1990; Mahoney et al., 2003). Also, burden is interwoven with acculturation, determined by language preference, length of residence in the United States, preferred circle of friends, and cultural pride (Castro, Cota, & Vega, 1999).

In earlier work, Coon et al. (2004) cited two qualitative reports suggesting that Hispanic caregivers may find the term “burden” unacceptable, and therefore use alternative terms for burden, such as “frustration,” “worry,” and “being overwhelmed” (Calderon & Tennstedt, 1998; John & McMillian, 1998). One of the reports used a Puerto Rican sample, so findings may not be transferable to our Mexican American (MA) border population, and the suggestion of substitute terminology has not been clearly confirmed by more recent research. A different notion might be that caregivers are attempting to express something in addition to burden. For example, there may be a component of worry that is allied with, yet separate from, burden. If there is a separate worry component, how can it be conceptualized and systematically studied?

What Does Worry Look Like?

Worry in the daily life of a MA caregiving family is mentioned only incidentally throughout the literature. Indirectly, the California site of the initial National Institutes of Health (NIH)-funded REACH (Resources for Enhancing Alzheimer Caregivers' Health) project addresses “bother” or “upset” that caregivers feel when exposed to disturbing behaviors of care recipients with Alzheimer's (Gallagher-Thompson, Coon, et al., 2003) and “anxiety” associated with depression (Coon et al., 2004). Dilworth-Anderson and Gibson (2002) choose the term “pressure” to characterize illness definitions and meanings of dementia, in relation to experiences of “stress, worry, anxiety, trauma, or family discord” (p. S59). More directly, some researchers report that elders worry about being institutionalized by children who no longer adhere to *la familia*, and that caregivers fear the stigma of dementia disclosure (Mahoney, Cloutterbuck, Neary, & Zhan, 2005). Other researchers (Crist et al., 2006) continue to grapple with the concept of worry as they refine questionnaire subscales for caregiving families.

The operational definition of worry for our study with MA caregivers was “understanding that caregiving has negatively impacted [one's own] emotional well-being.” We identified participant statements about “suffering worry” as a recurring theme and a key component of caregiver strain, defined as “*lasting* emotional, psychological, physical, and financial problems from caregiving that potentially harm the caregiver.” During the 5 years of the

study, the theme recurred so frequently and with such vividness that it demanded additional exploration. To do that, we used qualitative data collected as part of a larger mixed methods, multi-site, National Institute of Nursing Research (NINR)-funded, interdisciplinary, descriptive project in which 116 MA caregivers were interviewed about their caregiving experiences. The parent project relied on *life course perspective* to examine cultural and contextual differences, transitions, turning points, and *adaptive strategies* in caregiving (Evans, Crogan, Belyea, & Coon, 2009; George, 2003; Wethington, 2005). Additional details about the theoretical framework, the methodological approach, and methods used in this study are available else-where (Evans, Coon, & Ume, 2011).

Importantly, the MA caregivers in the current study persisted in caregiving until the death of the family member, and only 2 of 116 caregivers relinquished care of the older person permanently to formal services. In one case of placement, the 24-hour complete care became physically impossible and in the other, the caregiver suffered an incapacitating stroke. Essentially, these MA caregivers provided assistance across the continuum of care including palliative and end-of-life care, a phenomenon about which little is known in this population (Carrion & Nedjat-Haiem, 2012; Cruz-Oliver, Talamantes, & Sanchez-Reilly, 2013; NIH, NINR, 2013). Given the sparse literature addressing MA caregiving families and, in particular, their involvement in palliative and end-of-life care, a significant knowledge gap stymies interventionists in conceptualizing effective strategies for family support during this time. In an effort to bridge this gap, we returned to our data and singled out the demanding theme of “worry” as a potential means of illuminating more clearly the MA caregiving experience. Although the MA caregivers in our study never used the word “burden” during the interviews, they described aspects of burden, strain, and rewards of caring for older family members, and frequently described “worry.” The purpose of this portion of the inquiry became exploration of the phenomenon of worry in such families, using the research question: “How are worries expressed in MA caregiving families, what happens to caregivers when they worry, and what adaptive strategies do they use to calm their worries?”

Method

Overview of the Larger Study

After approval by the University Human Subjects Review Board, we recruited 116 caregivers, primarily through word of mouth using bilingual research technicians (RTs) who were trusted by the MA community. A stratified purposeful sampling plan ensured case variation in acculturation, the nature of the caregiving relationship, the functional and cognitive status of the caregiver, and the elapsed time of the caregiving trajectory. A telephone screen identified caregivers who were family members, at least 18 years of age, with no self-reported psychiatric history other than depression, who provided continuous assistance for a community-dwelling care recipient (60 years of age or older, of any cognitive ability). The screen also included the widely accepted Generalized Acculturation Index (scored as low, moderate, and high; Balcazar, Castro, & Krull, 1995) and the CLOX: An Executive Clock Drawing Task (cognitive function; valid with community-based Hispanic elders regardless of education or acculturation; Royall et al., 2003) to determine their ability to participate. In addition to the telephone screen, the interview protocol was

completed at each of six visits in the interviewee's preferred language. Following the work of Lawton, Moss, Hoffman, and Perkinson (2000), we defined "early caregiving" as 0 to 12 months and the transitional period (for which there is no clear demarcation; Lawton et al.) between early stage and late stage caregiving as 13 to 24 months, calling this period "middle stage caregiving." "Late stage caregiving" was defined as 25 months or greater.

Caregiver interview protocol—A semi-structured interview protocol explored the caregiving trajectory, reflecting *life course perspective*. Interview questions, derived from caregiving literature, included open-ended items such as "What are the roles and responsibilities of the people in your family concerning caregiving?" We also asked about the caregiver's physical and mental health and self-care activities. Questions took about 60 minutes to administer, with 10-week follow-up interviews requiring slightly less time.

Digitally recorded interviews were transcribed and verified by bilingual personnel for accuracy. Trained RTs coded instances of worry in relation to the strain of caregiving, using a coding manual (Gerring, 2004) developed from *life course perspective* and constructs identified in initial interviews, and validated against 60 interviews, at which time no new codes appeared. The RTs were culturally and linguistically congruent with the study sample so that they could accurately identify participant meaning.

Codes were reconciled by RTs, based on an initial 90% interrater reliability, and entered into ATLAS.ti, a computerized program for qualitative data management. Interrater reliability was periodically re-checked to minimize conceptual drift, and each interview was actively searched for negative evidence that contravened established themes and categories.

The "Worry" Inquiry

The sample—Fifty-three (45.7%) of 116 caregivers used the word "worry" in describing their caregiving experiences. Of the 53, the vast majority were women (92.5%) providing late stage caregiving. More specifically, 9.6% ($n = 5$) of the worried caregivers were involved in early stage caregiving (age range = 54-63, $M = 58$ years), another 9.6% ($n = 5$; age range = 51-77, $M = 62.4$ years) in middle stage caregiving, and 81.1% ($n = 43$; age range = 24-75, $M = 51.9$ years) in late stage caregiving. A greater percentage of "worried" caregivers were late stage, compared to the entire sample of 116 caregivers where 74.1% ($n = 86$) were engaged in late caregiving. More than 58% ($n = 31$) of the 53 worried caregivers were moderately or highly acculturated, with the remainder being of lower acculturation. Of the four male caregivers expressing worry, three were moderately acculturated and one was highly acculturated.

Use of ATLAS.ti and data matrices—For this portion of the inquiry, we queried the ATLAS.ti data base (Scientific Software, v. 6.1.1, 2012) for the word "worry" during six in-home visits to caregiving MA families at 10-week intervals over the 15-month course of their participation (639 primary documents). We then examined those quotations within- and across-cases for patterns of similarity or dissimilarity to assist us in the drawing of inferences during the analytic and interpretive phases of the study (Creswell & Plano Clark, 2007; Morgan, 1998).

Data matrices (Miles & Huberman, 1994) were constructed to facilitate within-case examination of the worry query and to juxtapose data across interviews. We sorted the data by length of caregiving, gender, and acculturation of the caregiver. Working back and forth across the matrices, we looked for patterns associated with worry and caregiver adaptive strategies. During data interpretation, we used Sandelowski and Leeman's (2012) strategy of creating thematic sentences to summarize key ideas, preserve complexity, and increase the accessibility and utility of findings. Such sentences are used here as section headers for findings and discussion, which are presented together to explore meaning in detail and produce a credible storyline for the reader (Holloway & Wheeler, 2009).

Worry: "[The worry] is there, it's always there, always, always there."

(Jakinda, caregiving daughter)

MA caregivers across the caregiving trajectory and at all levels of acculturation experience worry—Much of the vast caregiving literature is based on cross-sectional analyses; only recently have the longitudinal implications of informal caregiving been considered (Gaugler & Teaster, 2006). In our recently completed longitudinal work, we used a series of data matrices (previously described; Miles & Huberman, 1994) to compare worry across caregivers. In an effort to identify similarities or differences, one large matrix juxtaposed worry exemplars from early, middle, and late stage caregivers with their corresponding acculturation levels. Although we were unable to pinpoint major differences in content or means of expression across various stages and acculturation levels of caregivers, the matrix revealed that caregivers of any acculturation and across all stages of caregiving describe feeling worried (Table 1). As noted above, however, a great percentage of worried caregivers were late stage, lending support to the "wear and tear" hypothesis that the demands of caregiving may accumulate over time (Townsend, Noelker, Deiling, & Bass, 1989).

Previous studies with female caregivers of loved ones with Alzheimer's note that more acculturated Hispanic/Latino caregivers reported fewer benefits or positive aspects from caregiving than their less acculturated counterparts (Coon et al., 2004; Mausbach et al., 2004). In one of these reports, lower levels of positive aspects of caregiving were associated with greater rates of care recipient placement into long-term care (Mausbach et al., 2004). In the current project's inquiry on "worry," however, all the caregivers expressed, and all but two carried out, a continuing commitment to care at home (Table 1). Still, we do not know how acculturation, gender, and family network changes, as well as "worry," affect caregiver choices and needs, all of which point to significant gaps in the literature (Cagle, Wells, Hollen, & Bradley, 2007).

Most MA caregivers provide care for a lengthy period of time, express worries related to cultural and contextual issues and transitions in care, experience concurrent physical and emotional conditions, and utilize a variety of adaptive strategies to address their worries.

Table 2 displays the type and focus of worries for caregivers in this study, along with verbatim exemplars of these worries. In the table, late stage worries are considered first,

since those worriers comprise our largest group, progressing through middle and early stage worries.

As shown in Table 2, similar worries plagued caregivers across all stages. They all expressed worry in relation to changes in care recipient cognitive status, safety issues, progression of care recipient health problems, and balancing caregiving with other activities, as well as their own affective disruptions and physical problems. Unsurprisingly, all caregivers worried about the future.

Some differences in worry could be identified across stages of caregiving. Like other Hispanic caregivers (Uebelacker et al., 2012), our late and middle stage caregivers expressed worries about finances and health insurance (Table 2). Late stage caregivers worried about the increase in caregiving as their family members' conditions deteriorated, and noted that they needed to remain in good health to care for everyone. Middle stage caregivers expressed little worry about the need for auxiliary caregivers, neighborhood safety, or sound sleep. The absence of this expression could have been a function of the low numbers in this category, although one caregiver clearly voiced the need for self-care. Early caregivers, also a small group, did not yet verbalize worries about finances or health insurance. Instead, they focused on the constant monitoring required of their new role and the tasks associated with caregiving.

Cultural and contextual worries—Despite *la familia*, caregivers worried when they were obliged to leave their aging charges in someone else's hands and compared their care to that of children: "I really worried about them ... like when you have a child. You don't trust anybody ... you want to make sure"; "She is like a baby, whatever she wants, she gets. I have the privilege of being able to take care of them, I consider it a responsibility."

Caregivers worried about others' competence, even extending those worries to health providers. They also worried about the absence of other family caregivers, underscoring the relatively new finding that Latino family support may not be as common as previously thought (e.g., Coon et al., 2004; Gelman, 2010; Phillips & Crist, 2008). Although some families relied on one another, others lamented the lack of banding together to provide day-to-day care. "It is very hard, my son is so little. My mom's health worries me, her medication, and even if I am stressed out I have to do it all by myself." Caregivers also worried about neighborhood safety or support and their worries were magnified by children with emotional or legal issues.

Transitions and turning points—Some worries were associated with *transitions*, defined as gradual alterations in personal, social, financial, job, or family roles and responsibilities, which could be incorporated into caregiving. Worries about progressively more difficult behaviors connected to care recipients' memory loss sapped caregivers' strength; cognitive impairment underlying such behaviors is often viewed as normal aging by Latinos but some describe it as "losing" one's parents (Gelman, 2010, p. 185). Because MA families often are not well informed about dementia and may be reluctant to discuss the gradual transition into impairment with health providers, diagnosis and treatment can be delayed, offering virtually no assistance with adaptive strategies. By the time treatment is

sought, caregivers' mental health can be negatively affected (Dilworth-Anderson & Gibson, 2002; Hinton, Haan, Geller, & Mungas, 2003), an ongoing worry for these caregivers: "I worry more than anything about getting forgetful."

Some of these caregivers were "sandwiched" between the multigenerational responsibilities of caring for aging parents, while raising a child or providing support to a grown-up child (Pew Research Center, 2010). They engaged in constant vigilance and felt the weight of caregiving deeply. Deterioration in family members' health was a constant concern (also noted by Borrayo et al., 2007) and, given these circumstances, caregivers were often wakeful. Their wakefulness seemed to reflect their view of parental caregiving as caring for aging children; they often sounded like parents listening for small children rather than sleeping.

Balancing responsibilities over the long haul took its toll. At work, caregivers often were distracted by responsibilities awaiting them at home and struggled to focus on assigned tasks. None, however, reported the need to leave their jobs as did Borrayo et al.'s participants (2007), perhaps because the income was imperative for adequate provision of care. At home, they were overwhelmed with household tasks, all the while caring for their older family members.

Middle caregivers worked to balance caregiving with work responsibilities, asking for time off from work when needed for caregiving, and displayed a future-focused, behavioral adaptive strategy also noted in the literature, that of self-care (Borrayo et al., 2007; Uebelacker et al., 2012). Although other researchers (Wells, Cagle, Marshall, & Hollen, 2009) report that caregivers do not change self-care practices in the face of poor health, some of our participants strove to maintain their own health—not as a personal indulgence, but as a means to ensure their ability to continue family caregiving. They still worried about the future, including the death of the family member, yet they reported no *turning points* in care.

Balancing caregiving with other responsibilities had not yet become an issue for early caregivers. Instead, they worried about caregiving tasks and the monitoring or vigilance required for safe care. Both permanent nursing home admissions in the entire cohort of 116 caregivers occurred in this group. In the first case of permanent nursing home placement (Table 1), the *turning point* was when the caregiver could no longer meet the 24 hour a day needs of his invalid mother. For the other, the turning point in care was related to safety concerns and, ultimately, to the physical collapse of the caregiver in an effort to keep an older parent at home.

Nursing home placement by early stage caregivers may suggest the "adaptation" effect (Table 1; Gaugler, Kane, Kane, Clay, & Newcomer, 2005), rather than the "wear and tear" hypothesis (Townsend et al., 1989). These caregivers may not yet have adapted to the demands of their new role, whereas middle and late stage caregiving families have progressed to the point in the trajectory where they effectively manage caregiving stressors.

Physical and mental health—As caregivers themselves grew older, their own mental and physical health problems disturbed their ability to balance the demands of care. Caregivers' worries occurred concurrently with "nerves," depression, anxiety, stress, heart palpitations, concentration problems; overeating; feeling hurt; and angry while watching the loved ones' deterioration or others' lack of care, and feeling guilty despite the care being provided.

In addition to a broad range of chronic diseases such as fibromyalgia, hypertension, diabetes mellitus, elevated cholesterol, and arthritis, many of them stress-related, caregivers struggled with fatigue and insomnia related to worry or constant monitoring of care recipients. Many caregivers reported "being a worrier" or feeling worried or anxious all the time, especially at night. Such reports align with the concept of vigilance (Mahoney et al., 2003), where caregivers see themselves as "responsible for the care recipient even when they were not engaged in specific caregiving tasks" (p. 40).

Late stage caregivers reported health problems that presaged turning points where the caregiving trajectory was at risk, posing their worries about the future as questions reflecting their battle with role engulfment and role strain (Dilworth-Anderson, Williams, & Gibson, 2002). Remarkably, however, there was only one actual *turning point* in this group: When a caregiver needed surgery, her sister stepped in to help. Meanwhile, the care recipient went to the hospital and temporarily to rehabilitation, but then returned home for care.

Adaptive strategies—Caregivers turned to *adaptive strategies* to ease the worry. They looked for work, taking temporary positions if necessary, but tried to arrange flexible schedules and take a few days off when they approached a caregiving crisis. They learned to keep busy and engage in positive self-talk, recognizing that they might be "worriers." They "looked for therapy through exercise" that helped them generate more energy for caregiving. One caregiver even had lap-band surgery that enabled her to keep caregiving long-term.

One caregiving spouse lived out her vow to "take care of my husband during the good times and the bad times, make sure he is very clean every day; we are never alone without each other." Caregivers "tricked" reluctant care recipients into going to vital physician appointments, requested medications and got sons to coax their moms into taking them, found sources for inexpensive incontinence pads, and searched online for caregiving assistance. They identified allies such as social workers and used them to facilitate the process of care, but if health care providers did not respond to their concerns, families got medications from Mexico and used herbs and teas along with Western biomedicine to manage both their own illnesses and those of family members. They went to each other's houses for breaks if other family caregivers were available and made overtures toward their neighbors if there were no other family members.

They "jumped through the hoops," hunting down death certificates, and opening a checking account so the family could apply for caregiver assistance. In addition, some caregivers coped through their relationships with God, offering up their worries to His care. This orientation toward acceptance of God's will may have facilitated coping and positive

physical and mental outcomes across the caregiving experience (Cagle et al., 2007; Coon et al., 2004).

Persistent Worry Across the Acculturation Continuum

“Worry” may not be the only term used to express the understanding that caregiving has negatively impacted [one’s own] emotional well-being. Although we queried only the term “worry” in this initial inquiry to increase conceptual clarity, MA caregivers may choose alternate terms such as “concern” or may express their distress in other terms. For example, one caregiver vividly described her insomnia as “The thing is, I go to bed but my mind keeps going ... the body wants to rest but the mind can’t.” Another ruefully described her monitoring of her mother at night: “Even though I know my dad is in there, I check on her several times—I get very tense and nervous.” Being at work also occasioned distress: “I am thinking the entire day if she is fine or not, because she can die when she chokes.” Given these expressions of something that sounds very much like worry also occurred across the acculturation continuum, future inquiries may need to broaden how worry is conceptualized to capture the full extent of the phenomenon.

Worried MA caregivers actively engage in adaptive strategies aimed at mitigating their worries but still experience an undercurrent of worry. Caregivers in this portion of the inquiry were not helpless in the face of worry. Their engagement in care resembled the larger sample, where adaptive strategies were creative and tailored to each circumstance and caregiving relationship. Both permanent nursing home admissions in this study, however, occurred in worried caregivers, perhaps suggesting that worry could be a harbinger of decreased ability or commitment to provide care. Most caregivers continued to worry, suggesting that adaptive strategies were not completely successful: “[The worry] is there, it’s always there, always, always there.” Also, the sheer number of worries expressed by late stage caregivers may suggest further investigation to determine if worries accumulate across the caregiving years because adaptive strategies are lacking or because the chosen strategies prove ineffective over time.

Conclusion

Need for Future Research

Using the theoretical framework of *life course perspective*, we examined the worries of family caregivers in this descriptive study, staying close to the data and working at lower levels of interpretation (Sandelowski, 2000). We enhanced transferability through congruency with our theoretical framework, specific descriptions of our data collection and analytic procedures, and verbatim exemplars, so that other researchers could evaluate the trustworthiness of our conclusions for themselves (Evans et al., 2011; Miles & Huberman, 1994).

Few studies consider contextual features of caregiving or use longitudinal designs, including life course perspective to examine phenomena over time. Both are included in this study and our initial consideration of the unexplored phenomenon of worry adds to the limited knowledge base about MA caregiving families. Our participants describe worry as an

anticipatory repetitive process that feels relatively uncontrollable (Borkovec, Robinson, Pruzinsky, & DuPree, 1983; Suarez-Morales & Bell, 2006). Caregivers often seemed unable to terminate it unless distracted, and they returned to it throughout the day or night.

Worry may in part encompass a problem-solving activity aimed to prevent unwelcome future events or identify potential adaptive strategies. Because worry is accompanied by a negative affect, it may influence reactions to events when they finally occur. In children, it may provide a backdrop for interpretation of, and response to, problems (Suarez-Morales & Bell, 2006). Suarez and Bell found that socioeconomic disadvantage may influence worry in African American, Caucasian, and Hispanic children; that daily hassles are related to emotional distress; and that ethnicity interacts with worry to impact problem-solving confidence. This finding may provide at least a partial explanation for much of the distress in our MA caregiving sample because daily hassles, such as dealing with rambunctious pets, routinely occurred during the trajectory of informal family caregiving. These hassles are reflected in caregiver reports; caregivers describe occasional crises but are primarily concerned with everyday worries.

MA families may be less likely to seek formal caregiving support than Anglos (Crist, Garcia-Smith, & Phillips, 2006; Crist, Velazquez, et al., 2006); cultural aspects of these decisions may be confounded by social class and financial status (Phelan, Link, & Tehranifar, 2010). For example, Medicaid coverage may affect reliance on informal caregivers (Min & Barrio, 2009). Although not all MAs are socially or economically disadvantaged, MA caregivers who come from such backgrounds (more than 54% of our overall sample earned less than US\$20,000 per year) may have diminished confidence in their ability to problem solve their way through the hassle-filled days of informal family care but still fear relinquishing care to strangers. It is possible that the patterns of worry described in this article as well as family caregivers' anticipation of negative outcomes associated with worry further impede help-seeking behavior.

Limitations of this study include the possibility that conclusions may be more congruent and representative than they really are and that cultural nuances may be missed, despite the involvement of MA RTs. These limitations, however, will be addressed by generating propositions for further mixed methods testing, such as "Worry affects MA caregivers' ability to recognize the positive aspects of caregiving" (Creswell & Plano Clark, 2007; Miles & Huberman, 1994). Relying on standards for the quality of conclusions set forth in Miles and Huberman, we used a stratified purposeful sampling plan, a conceptual framework with temporal aspects to guide the longitudinal study (Evans et al., 2011), a semi-structured interview protocol to enhance quality control and consistency, prolonged engagement with caregivers (15 months), and a single RT interacting with each family to increase credibility of the findings. We also utilized team review and consensus of coding decisions (based on a coding manual), careful attention to interrater reliability, periodic checks for conceptual drift, and verification of themes and categories across multiple interviews along with a corresponding active search for negative evidence to increase robustness of findings. We looked for congruency of findings with theoretical constructs and the literature, and presented verbatim exemplars and sufficiently "thick description" for the reader to assess verisimilitude of findings and transferability, although interpretation stays close to the data,

as befits a qualitative descriptive study (Sandelowski, 2000). Finally, as one investigator generated findings, coinvestigators reviewed them in relation to the data for congruency.

There is little known about worry, which may be an allied and important aspect of burden in the caregiving trajectory, and we need to further consider its interactions with acculturation, gender, and family caregiving roles (Cagle et al., 2007; Hinton et al., 2003). We need to look further at its relationship to institutionalization, and to examine the validity and reliability of existing scales or develop new scales that successfully capture the construct of worry for MA family caregivers, such as those under development by Crist's team (Crist et al., 2006).

Effectively decreasing burden may require attention to the added dimension of worry about both everyday and crisis situations. We need additional longitudinal research to better understand the MA caregiver experience and identify empirically supported interventions to reduce worry (Gallagher-Thompson, Solano, et al., 2003), including worry in multigenerational and multiple caregiving families (Dilworth-Anderson et al., 2002), and reasons for nursing home placement. Although the MA population may avoid the idea of "burden," they would welcome culturally sensitive education about the impact that stress, often experienced as worry, may have on health, along with attention to communication and problem-solving skills aimed at obtaining assistance from other family members and formal service providers (Borrayo et al., 2007). Recent reviews and meta-analyses of empirically supported interventions for family caregivers of older adults (e.g., Coon & Evans, 2009; Coon, Keaveny, Valverde, Dadvar, & Gallagher-Thompson, 2012; Schulz, Martire, & Klinger, 2005; Sörensen, Pinquart, & Duberstein, 2002) suggest that interventions integrating skill-building strategies that teach caregivers problem-solving, behavior management, pleasant events scheduling, stress reduction, and mood management skills demonstrate the most benefit in reducing caregiver distress. Several of these were culturally tailored and successfully implemented with Latino/Hispanic caregivers of family members with Alzheimer's disease or a related dementia (e.g., Belle et al., 2006; Gallagher-Thompson, Coon, et al., 2003; Gallagher-Thompson, Gray, Dupart, Jimenez, & Thompson, 2008); however, none investigated the impact of these interventions on worry and its impact. A very limited number of empirically supported interventions to date have focused on MA caregivers of older adults, much less older adults with chronic illnesses or disabilities beyond dementia. Given the projected increases in the decades ahead of the proportion of MA older adults, additional culturally responsive caregiver intervention research is warranted with this population. Culturally acceptable interventions could build on the existing evidence of skill-building strategies combined with positive coping through religion and spirituality, promoting good caregiver health during caregiving, sustaining cultural values concerning care of older family members, and enhancing use of both informal and formal services (e.g., Belle et al., 2006; Cagle et al., 2007; Gallagher-Thompson, Coon, et al., 2003). Such interventions, in turn, might help caregivers control worry and upsetting thoughts in order to achieve better health outcomes for themselves and their families (Montoro-Rodriguez & Gallagher-Thompson, 2009).

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Table 1Caregiving Stage, Worried Caregivers ($n = 53$), and Exemplars.

	Early stage	Middle stage	Late stage	Totals
Low acculturation	2 We're worried about what we are going to do with my father ... many, many lamentations.	1 I don't tell him but [my husband] tells me, "Sometimes you are too worried" ... I feel my heart pounding every time I worry.	19 We all worry about the way we care for her. She can't miss any meds ... that is my biggest worry. The more people involved ... the more confusion.	22
Nursing home admissions	1 I permanent: safety and relationship concerns			
Moderate acculturation	2 I'm very worried because he is forgetting; his mind is not helping him at all. He doesn't know what day is today. Just as if I were dealing with a child 4 or 5 years of age.	2 We have to have a protocol when something happens and that's one thing I've been worrying about ... it worries me a great deal. I'm worried now and I worried then.	22 I was worried. I feel more comfortable if I take her to the bathroom and take her back to sit down. Otherwise, I would be worried.	26
Nursing home admissions			3 I temporary: hospital/rehab 2 deaths: hospice	
High acculturation	1 [I have headaches] I'm worried ... [about] everything. I just worry a lot.	2 Sometimes I start worrying about things and then I stop because I really believe that God makes the best decisions.	2 I worry because she can fall ... What worries me the most is that her sugar might drop too low in the night.	5
Nursing home admissions	1 I permanent: 24 hr/day needs Total 5/17	Total 5/13	1 I temporary: hospital/rehab Total 43/86	Total 53

Table 2

, Stages of Caregiving Worries With Type of Worry, Focus of Worry, and Exemplars.

Type of worry	Focus of worry	Exemplars
Late stage caregiving worries		
Cultural and contextual worries	Finances, job status, health insurance, auxiliary caregivers, neighborhood safety	That's number one. I need to get a job ... it's very bad trying to help [my mom] without work. Thinking you can lose your job, nothing is forever ... it affects your mind, your soul, your everything. I've had issues with my insurance so I can't even see my doctor. Even though she [auxiliary caregiver] goes to the bathroom with my mom when I'm not here, I feel more comfortable if I take her. She's embarrassed with other people. I was questioning the ability of the [Medical] Center. I didn't want them killing her, God forbid. Seeing graffiti that close, that worries me a lot because they [the neighbors] are more like Americans, they are vagabonds.
Transitions and turning points	Changes in CR cognitive status, safety issues, progression of CR health problems, and balancing caregiving with other responsibilities, increase in caregiving activities	Sometimes she doesn't pay attention how she's putting on her clothes or that she smells; I need to keep on top of all that. I worry about her a lot because she has fallen twice. We were worried about his blood pressure because he didn't sleep a couple of nights and he couldn't breathe, too. I My son is in Afghanistan—I try not to watch too much [on TV] of what's going on over there. I worry because my little girl is a baby still, so I have to be in good health in order to take care of her and my papa. I wait a long time to fall asleep but then I wake up thinking something is wrong with my mom or my dad. I don't go in the deep sleep because I can hear every little noise she makes. I can hear it right away. I have a nightlight on in her room but I turn one on in the hallway, so I can go check on her stomach to see if it is moving. I watch her 24/7, I'm afraid she is going to fall again.
Caregiver physical and mental health	Affective disruptions, sleep disturbances, and physical problems	I don't have friends, I don't have vacations, I don't have anything. I keep subconsciously thinking, am I going to be like this the rest of my life? How long am I going to be doing this? Who's going to take over? How much more work am I going to have to do—then I feel guilty because how can I think about that? It looks like it's quiet but I worry. If I go to my room to try to lie down, she is always calling me. About 3 months ago I went to the doctor ... my heart wasn't stopping ... I wasn't doing anything for my body. Am I going to get Alzheimer's too?
Adaptive strategies	Coping	I know I just need to relax, be quiet, even in my work at the office ... don't worry about it, everything's going to be okay. We just do what has to be done to fix it, what else can we do? I can't afford to go crazy, worrying about these things. God says, "Give me your worries," okay, here they are: I don't want to be a widow yet.
Middle stage caregiving worries		
Cultural and contextual worries	Finances, health insurance	I'm a little bit scared but I've got an appointment with the Department of Economic Security. I got a letter that they were canceling his insurance. I don't know anything about insurance—I had to call here and there and everywhere, and in my mind I am saying, "Don't freak out!" because I want to, you know.
Transitions and turning points	Changes in CR cognitive status, safety issues, progression of CR health problems, balancing caregiving with other responsibilities, the future,	There were times that I finished mopping, sweeping, cleaning ... and when I go feed my mom, she throws it to the floor. She doesn't know anymore that food doesn't go [there]. We worry that she'll slip in the shower. I feel more responsible because he's been in and out of the hospital so many times. [The worry] is there, it's always there, always, always there.

Type of worry	Focus of worry	Exemplars
	self-care	I feel very bad, do you understand? What if something happens to her? My husband says I worry too much. I feel like I have to go to the gym, because I have to stay healthy to take care of him.
Caregiver physical and mental health	Affective disruptions and physical problems	Despair ... this feeling. Not knowing what to do, having to see him sick like that... wasting away; it hurts when I think of how he used to be. I suffer depression and some anxiety and I overeat and I don't get enough exercise. [The doctor] said, "Do you know what you have? Your blood pressure is a bit high" ... she gave me a pill.
Adaptive strategies	Coping	Things revolve around what's going on in their lives and what their needs are. I have to keep telling myself, "God will help you through this. Take it a day at a time." Even though I don't have my husband any longer, my life is filled with other things. I sorted out in my mind ... I feel like he went on a trip and eventually I'm going to join him.
Early stage caregiving worries		
Cultural and contextual worries	Auxiliary caregivers, neighborhood safety	There are no relatives; that is our problem and our worry. I get all this from my sister: "Why aren't you doing this? Why aren't you talking her to the hospital?" It's so overwhelming ... there's nothing I could do. I worry about these new people [neighbors] that have arrived because I don't know them very well.
Transitions and turning points	Changes in CR cognitive status, safety issues, progression of CR health problems, balancing caregiving with other responsibilities, the future, monitoring of CR, caregiving tasks	I am very worried because now he is forgetting, he doesn't know what day is today. I'm scared that she's going to fall again and she's not going to get up. We worry about [her illnesses] ... she is feeling a lot of ovary pain, body pain ... her eyelid. All of these things are worries for us. Now my husband is also sick and I am very worried. My son is in prison. I worry what's going to happen the next day. I shouldn't worry but that's the way it is. We gave her everything in a silver spoon, we even treated her like a queen but she didn't accept anything and that hurt us a lot because she took off her crown and threw it in the garbage. Nothing was enough. We had absolutely everything ready for her and everything she rejected. One day, she took off at around 2 am; thank God, she had not gone too far. [Nursing home placement] was a very painful decision to make, and also, I was thinking to bring her back but she said no. She decided she didn't want to, so we do what she wants ...
Caregiver physical and mental health	Affective disruptions, sleep disturbances, and physical problems	I just want to cry but I don't. I'm on Prozac and something else to calm me a little bit more. They are giving me strong medicines but I am worried because when I take them, I fall asleep [and can't hear my parents]. I turn and toss in bed ... constantly listening to see what she is doing. We don't know what to do, where she would stay [if I have surgery]. It reached the point where I had to go to the hospital because I got a mini-stroke and diabetes. The stress, the lack of sleep, and the constant state of worries became a 24-hour horrific situation.
Adaptive strategies	Coping	I didn't know what to do with my mom, so I talked to the social worker. I said, "God, I am in Your hands, it's Your will. You do what You want with me." That's how it is, I gave Him my all.

Note. CR = care recipient.