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Family Caregiver Role and Burden Related to Gender and Family Relationships

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Abstract

This study described and contrasted family caregivers and explored the effect of gender and family relationship on the caregiver's role perception, workload, burden, and family help. Home care agencies and community organizations assisted with the recruitment of 533 multicultural, predominantly Latino caregivers who were interviewed at home. The Caregiver Identity Theory guided the study. Survey instruments were standardized tools or were constructed and pretested for this study. Descriptive statistics and t-test analyses assisted in describing the sample and multivariate analyses were used to contrast the caregiver groups. Findings suggested a gendered approach to self-appraisal and coping. Men in this predominantly Latino and Caribbean sample felt less burden and depression than women who believed caregiving is a female duty. Family nurses should pay attention to the most vulnerable groups: older spouses resistant to using family and community resources and hard-working female adult children, and assess each family situation individually.

Keywords

elderly; family caregivers; gender roles; adult children; spouse caregivers; multicultural; quantitative research

According to a 2010 survey of the Pew Research Center, 30% of the U.S. population perform the role of family caregiver (Fox & Brenner, 2012). As the life span of seniors increases with better medical care, families are increasingly forced into the caregiver role, and since the number of available siblings in families has become smaller, many of these family caregivers have to carry the responsibilities alone or with little help.

As of today, the majority of caregivers worldwide are women (American Psychological Association, 2009). Nevertheless, in the United States, the proportion of male caregivers has recently grown to 45% (Fox & Brenner, 2012), and the responsibilities males assume have

expanded (Baker, Robertson, & Connelly, 2010). Yet, researchers have long discovered significant differences in caring patterns and responses to caregiving between men and women caregivers (Gibbons et al., 2014; McDonnell & Ryan, 2013), as well as between spouses and other family members. Understanding coping of caregivers of older relatives and their families, and differences based on gender or relationship are critical for researchers and clinicians. This study is the first to describe and contrast caregiver, care recipient, and family variables in a multicultural sample from the greater Miami area of South Florida, addressing the following research questions:

1. How do male and female spouses and male and female adult children differ in demographic, care recipient, caregiver, and family variables?
2. What variables are associated with the caregivers' perception of burden and the culturally defined caregiver role in each of the four groups?
3. What variables influence the workload of caregivers and help from the family in each of the four groups?

Male and Female Caregivers

The decision to take care of a relative is often driven by necessity for both genders and thus not a voluntary act (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). Such a decision may lead to extensive changes in the organization of the household, roles and functions of family members, ability to work outside the home, or social engagements (Pinquart & Sörenson, 2006). Studies show that with increasing demands, caregiving responsibilities compete with time and energy for the family, outside work, and personal health (Dolan & Thien, 2008; Scharlach, Gustavson, & Dal Santo, 2007).

Stress and burden induced by such changes affect women more than men. Papastavrou and colleagues (2007) explain that many women in their study in Cyprus did not have the necessary knowledge or preparation for the caregiving role, but were expected to perform in this capacity because they were female. The success of mastering caregiving stress depends on the use of available physical resources and ways of coping with emotional demands. Calasanti and King (2007) observed that women perceived their work as an extension of their usual role. Their caregiving work was part of their self-definition and an expectation by family and society, but many challenges became at times difficult.

A general thread throughout comparative studies seems to be the conclusion that care is structured along gender roles and values (Calasanti & King, 2007; Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014). Prior to the turn of the century, researchers suggested that gender roles were necessary for healthy family functioning and that women were naturally drawn to care, because they were best suited for the work (Campbell, 2010). Campbell (2010) then explained a shift in theoretical thinking to viewing societal pressure as a considerable force dictating women's caring behavior according to their gender. Since women learn their gender role as they grow up, their sense of obligation feels to them as if it were an inborn trait and caregiving a source of fulfillment of their natural role. Nevertheless, they feel societal pressure when they decide against offering their caregiving services and often respond with guilt, because the world around them considers them morally deficient

(Kittay, 2001; Sanders & Power, 2009). The socialization process (Robinson et al., 2014) and, therefore, the type and extent of moral obligation differ between men and women (Sanders, 2007; Sanders & Power, 2009). Even when filial obligation is high, a choice to decline giving care is easier for men who feel free to use outside resources without guilt (Calasanti & King, 2007).

Authors (Calasanti & King, 2007; Robinson et al., 2014) explain that male caregivers experience societal pressure to uphold masculinity. In the U.S., the world of work presents a way to practice masculinity. In the family caregiving context, therefore, men convert the caregiving role into a work situation with challenging problems to be solved and feel proud of their achievements (Phinney, Dahlke, & Purves, 2013). Doing that, they can escape into the masculine world (Calasanti & King, 2007). Accordingly, researchers (Calasanti & King, 2007; Robinson et al., 2014; Russell, 2007) found that male caregivers of Alzheimer's patients focused closely on necessary tasks, by avoiding disruption and distractions, and blocked their emotional reactions.

The finding of many studies that women perceive more stress and burden than men (e.g. Hong & Kim, 2008; Thompson et al., 2004) or men less than women (Sander, 2007; Stewart et al., 2014) is consistent with gender role theory. Authors have reported that female caregivers are more emotionally connected to the patient than men, sacrifice their social life (Beeber & Zimmerman, 2012), and ask for little help from others, even if they are available (Bédard et al., 2005; Brank & Wylie, 2014).

Other authors suggest that women are more affected by problematic behaviors of the care recipient and therefore suffer more depression than men (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010; Papastavrou et al., 2007). They explain this by female coping methods. Women resort to emotional coping strategies, and since such strategies are related to a higher sense of burden (Papastavrou et al., 2007), emotional coping can also lead to depression (Etters, Goodall, & Harrison, 2008). Nevertheless, men also suffer burden, watching the condition of their loved one deteriorate. In fact, Akpınar, Küçükgüçlü, and Yener (2011) found emotional burden to be similar in both genders, but men were less likely to admit their negative feelings (Baker, Robertson, & Connelly, 2010). Sanders and Power (2009) reported that men processed their emotions individually, without sharing them.

Assessing burden was also challenging in research with Mexican caregivers of both genders who had strong family commitment and could not admit to negative feelings since acknowledgement of burden was culturally unacceptable (Evans, Belyea, Coon, & Ume, 2012). Since most research was done with White samples, much is unknown about the response of ethnic caregivers about their role and responsibilities, a reason to conduct this study with minority participants.

Spouse and Adult Child Caregivers

Researchers in caregiving have long recognized that spouses represent a group with characteristics distinct from adult children and other family members and warn against

generalizing research findings from mixed samples (Savundranayagam, Montgomery, & Kosloski, 2011). Spousal caregivers experience more burden and depression than other family members, and their well-being and self-efficacy are lower (Pinquart & Sörenson, 2003). Across all ethnicities, spouses give care for more hours and perform more tasks than other family members (Marks, Lambert, & Choi, 2002). In spite of receiving the least help from family and friends (Bédard et al., 2005), spouses are most reluctant to hire professional helpers or use community services, especially if they are women (Seltzer & Li, 2000). Consequently, male and female spouses report more serious issues around their ability to fulfill their caregiving role and the most negative health effects (Bédard et al., 2005).

Many other studies also document the ill effects of caregiving on physical and mental health (e.g. Pinquart & Sörenson, 2007; Schulz & Martire, 2004) without looking at group differences. Explaining why spousal caregivers differ, Beeson (2003) reported that for them, the marriage is the most significant relationship in their lives. Distress evolves from subjective interpretations of the caregiving situation rather than from the caregiving workload (Savundranayagam et al., 2011). Consequently, for caregiving spouses, emotional burden involves anxiety about the possible loss of the relationship with their spouse (Savundranayagam et al., 2011). Spouses are reluctant to turn care over to others and, when employing services, they use them for as short a time as possible (Robinson, Buckwalter, & Reed, 2005). Robinson and colleagues (2005) proposed that spouse caregivers of Alzheimer patients in their sample may have felt that using services was betraying the spousal relationship.

With this study, we explored whether such differences also exist in a multiethnic sample. The literature is not clear about the issue. Savundranayagam et al. (2011), for example, report that older, very committed spouses who have cared for their partner for many years tend to be a rather homogeneous group across ethnicities. Family-centered values often turn caregiving into a positive experience for Hispanics (Scharlach et al., 2006) and perhaps for other groups as well. Mausbach and colleagues (2006), however, claim that young and more acculturated caregivers are less able to perceive the positive aspects of caregiving.

Clearer differences were reported relative to the caregivers' willingness to accept help from the family or the community. African American caregivers were found to have the strongest communal view of caregiving of all racial groups, in that they were able to line up most family assistance (Feld, Dunkle, & Schroepfer, 2004). Beeber and Zimmerman (2012) describe diverse and complex arrangements of sharing work and making decisions in the family. In contrast, recent research suggested that Hispanic caregivers considered it inappropriate to acknowledge burden or admit the need for help (Evans et al., 2012). Reluctant to delegate tasks or use outside services rendered them vulnerable to exhaustion and distress (Crist, Garcia-Smith, & Phillips, 2006; Escandón, 2006; Neary & Mahoney, 2005). It is unclear, however, if this reluctance also applies to younger adult child caregivers whose filial piety may have weakened with acculturation (Pang, Jordan-Marsh, Silverstein, & Cody, 2003). In particular, there is little known about the caregiving role of sons (McDonnell & Ryan, 2013).

Conceptual Model

We adopted Montgomery and Kosloski's (2013) Caregiver Identity Theory as the basis for interpretation. According to this theory, caregivers, interacting with the care recipients, undergo a self-appraisal and determine to what extent their caregiver role agrees with their understanding of self. If the caregiving responsibilities are incongruent with their belief about what a caregiver should do, caregivers experience distress. As demands of caregiving increase over time, the role norm discrepancy tends to become more intense. As pressure mounts, caregivers have two choices, to either change their role norm or their situation. Ways to keep their role norm unchanged are to engage the family, use services, or in the extreme case, institutionalize the patient. In contrast, adjusting the role norm to the situation is a psychological process. Caregivers need to justify why they should give more care than bargained for. Possible reasons may be that the caregivers perceive they owe it to the patient, or they cannot trust anyone else to care for the patient.

Since prior socialization into gender roles seems crucial in the process of developing caregiver role norms (Montgomery & Kosloski, 2013) we expected women and men caregivers to differ and, since gender socialization has changed from one generation cohort to the next, we also expected spouses to differ from adult children. We therefore explored caregiver role norms and evidence of gendered care in our multicultural sample by focusing on differences between male and female caregivers and between adult children and spouses.

Methods

Sample and Characteristics

A total sample of 613 caregivers of frail older relatives was recruited. Of these, 533 were either spouses or adult child caregivers and could be used for this analysis; 147 were female spouses, 277 female adult children, 61 male spouses, and 48 male adult children. An estimation of sample size for the analysis using multivariate models with a less than pure random sample required an a priori specification of the number of parameters in the models (Wood & Ross-Kerr, 2005). Since 5 to 10 subjects per parameters are recommended (Wood & Ross-Kerr, 2005) with no more than 6 parameters in our models (see Results section), the male groups of 61 and 48 were sufficient in size.

In this sample, all care recipients needed help in at least one activity of daily living and lived with the caregiver or at a distance of no more than 30 minutes by car. The caregivers were the persons in charge of care decisions. All participants spoke either English or Spanish. Five local home health nursing services, all serving mixed ethnic communities, assisted in the random selection of two thirds of these caregivers and their patients. From the list of patients who had family caregivers, agency administrators selected 5 to 10 cases per month according to random numbers provided by the researchers. After being carefully trained, visiting staff recruited the caregivers and referred interested participants to the researchers. About 20% of the caregivers declined participation. Since those declining were mostly Black, additional minority participants, mainly from the Caribbean Islands, had to be added with the help of community leaders active in neighborhood organizations. This necessitated a breaking of random procedures for one third of the sample. The study was approved by the

Florida International University Internal Review Board to protect participant rights and by the Board of the agencies that had one.

The final sample included 38.6% White non-Hispanic caregivers; 12.2% Blacks, predominantly from the Caribbean; 30.6% Cubans; and 18.6% caregivers from other Hispanic countries in Central and South America, Mexico and Puerto Rico, and their aged relatives who suffered from many types of ailments. The dementia rate of these relatives was approximately 60%. Only 6% of the care recipients lived alone, 48% in two-person households, 22% with two other people, and the remainder with 3 to 8 persons, including children.

Data Collection

Two trained interviewers collected the data in the participants' homes from 2006 to 2009. They visited in pairs for reasons of safety and mutual supervision. Before the survey, the caregivers signed an Informed Consent form, and the care recipients also signed a form consenting to a quick mental status exam. Care recipients unable to sign were not tested.

Measures—In addition to recording gender, marital status, education, age, ethnicity, and income of caregivers and care recipients, the survey schedule included data on household constellation, and the relationship between caregiver and patient. Other caregiver, care recipient, and family variables were derived from standardized instruments or were measures constructed and pre-tested for this study. All standardized instruments had been subjected to factor and reliability analyses that yielded acceptable validity information.

The instruments with their reliability data are listed in Table 1. The *Caregiver Health Index* consists of the sum of four self-report items described in Montgomery and Borgotta's (1985) research: Health in consideration of age and gender, satisfaction with health, health in comparison with others in the same age range, and interference with daily activities. The instrument assessing Caregiver Depression, the *Patient Health Questionnaire* (PHQ-9), is widely accepted as a diagnostic screen (Hueng, Chung, Kroenke, Delucchi, & Spitzer, 2006), and the *Mini Mental Status Exam* (Folstein, Folstein, & McHugh, 1975) is well known as a screen for cognitive status. The *Spiritual Perspective Scale* (Reed, 1986), an instrument previously tested with Hispanics, was used to measure Spirituality.

The Montgomery *Activities of Daily Living/Instrumental Activities of Daily Living (ADL/IADL) Scale* measures physical and instrumental ability as reported by the caregiver (Montgomery & Borgotta, 1985; Montgomery & Kosloski, 2001). The *Caregiver-Elder Relationship Scale* developed and tested by Montgomery and Borgotta (1985) provides a subscale of six items for Caregiver Obligation. Other instruments previously used and tested in Montgomery's research are the *Problematic Behavior Scale* and the *Subjective Burden Scale* (Montgomery & Borgotta, 1989; Savundranayagam et al., 2011) of which five items measure stress burden or the effect on the caregivers' emotions such as worry, anxiety, and depression, and the other five items measure relationship burden that addresses the caregivers' perception of being taken advantage of or manipulated.

Since a very short list of possible caregiving tasks was needed, the *Caregiving Tasks Instrument* was developed and pretested for this study. The eight items were derived from the results of factor analyses of caregiving tasks in Montgomery's Support Project (Montgomery & Borgotta, 1989) and modified for the purpose of family caregiving at home. The items express possible tasks family caregivers do: (a) Visits and rides, (b) walks and exercise, (c) transportation, errands, (d) laundry and meals, (e) bathing, dressing, (f) cleaning up after accidental urine and bowel movements, (g) medical procedures, (h) handling of a confused patient. To compute the caregivers' workload (Caregiver # Tasks), the respondents reported which of the tasks they performed. For Family Help in Number Tasks, caregivers indicated on the Caregiving Tasks Instrument the tasks they received help with, and for Family Help in Hours, they reported how many hours of help they received for each task.

To compute the variable Caregiver Role Norm Discrepancy with the Caregiving Tasks Instrument, we first asked participants for each of the eight tasks, whether a relative like themselves (i.e. a daughter) should (score 1) or should not (score 0) do the task. Then, we deducted the parallel items on the caregiver workload application of the Caregiving Task Instrument mentioned above. For a total score, we squared the discrepancies to eliminate negative values and summed the items.

Finally, we assessed the actual Use of (Community) Services with a *List of 14 Discretionary Services* known to be available in the area. The caregivers marked the discretionary services they actually used in the preceding month and we summed the services. We did not include home care service that most participants had received, based on the findings of Kosloski, Montgomery, and Karner (1999) that medical and home care services are assigned to patients, do not vary in different populations, and therefore are not considered discretionary.

Analysis

Due to the ethnically diverse sample, we confirmed the reliability and factor structures of all the published and unpublished instruments. The first step of the analysis consisted of describing the characteristics of the four caregiver subgroups: male spouses, female spouses, male adult children, and female adult children, using frequencies or measures of central tendency. Next, we compared the means of demographic, caregiver, and patient variables relative to gender and relationship, using t-test analysis for independent samples, followed by multivariate analyses to explore what variables may influence caregiver role norm discrepancy and burden, and caregiver workload and family help.

Results

Sample Description

Demographic variables are listed in Table 2 for all caregiver subgroups: male spouses, female spouses, male adult children, and female adult children. The spouse groups included six unmarried couples in a long-term relationship. Compared to adult children, spouses had lower incomes. Cuban and White caregivers had the highest percentage of male spouses and Black caregivers the lowest. White caregivers had the highest percentage of male adult children of all groups. The relative's primary condition requiring care was reported by the

caregivers. Table 2 shows only the 5 most frequent conditions; 15 additional conditions were mentioned in the “other” category. Spouses cared for more stroke patients than adult children and for fewer patients who had nothing but physical disabilities. The numbers in the caregiver subgroups, however, were not large enough to allow statistical comparisons. Of note in the group of male adult children was the high number of single men taking care of their parents (almost 65% of the male adult children).

Sample Differences

Table 3 contrasts the sample means, standard deviations, and score ranges of the study variables. T-tests estimated the significance of the differences in means between males and females, spouse and adult children. Spouses were older than adult child caregivers ($t = 129.79, p < .001$) and male spouse caregivers were older than female spouses ($t = 3.96, p < .001$). Male caregivers were involved in fewer caregiving tasks ($t = 1.94, p = .05$) than women. Most notable were the male adult child caregivers who spent the least time giving care of all groups (see Table 3), while the caregiving work of female adult children was comparable to the harder working spouses. The same male adult child caregivers also reported a smaller role norm discrepancy than female adult children ($t = -4.85, p < .001$) and both spouse groups. Male caregivers in general were less spiritual than females ($t = 5.50, p < .001$).

In terms of obligation to care, male spouses scored significantly higher than female spouses ($t = 3.29, p = .001$), but both spouse groups felt more obligation than adult children of both genders ($t = 3.26, p = .001$). In spite of their high obligation, male spouses scored less burden than female spouses ($t = 2.52, p = .01$) and less than the adult child groups. Female adult child caregivers received the most family help followed by male adult children. In general, spouses received significantly less help than adult children ($t = -.603, p < .001$) and males less than females ($t = -2.62, p < .01$), in spite of their advanced age. The relatives taken care of by male adult children had fewer functional limitations than those of female adult children ($t = 2.99, p < .01$) and the patients of female adult children were significantly more cognitively impaired than those in all other groups ($t = 2.11, p < .05$). Finally, the use of community services was negligible across the sample with little over 1 service on the average of a total of 14 possible services. The difference in the number of services was not significant between men and women or between spouses and adult child caregivers. Likewise, differences in caregiver health and the care recipients' problem behaviors were not significant.

Variables Influencing Caregiver Burden and Role Norm Discrepancy

In order to explore which of the variables affected the caregivers, we conducted multivariate analyses (Pillai's Trace) for each group (Adult Child Females, Adult Child Males, Spouse Females, and Spouse Males), entering caregiver demographics (Age and Ethnicity) as fixed factors, caregiver and patient variables (Caregiver Health, Spirituality) as co-variants, and the caregivers' Burden and Role Norm Discrepancy as dependent variables. In the models with Burden as dependent variable, Caregiver Health and the intercept of all model variables yielded main and between-subjects effects in all four groups. These factors explained the largest proportion of Burden among Adult Child Males and Spouse Females ($R^2 = .24$

compared with R^2 .07 for Adult Child Females and .04 for Spouse Males). In the models with Role Norm Discrepancy as dependent variables, effects were also significant but much smaller ($R^2 = .04 - .09$). In addition to the model intercepts, other variables yielded small between-subjects effects: Spirituality had a significant between-subjects effect in both Adult Child and Spouse Female groups; Caregiver Age became a contributing factor in Spouse Male and Female groups; Ethnicity alone and in combination with Age had a significant between-subjects effect in the Spouse Female group.

Variables Influencing Caregiver Workload and Family Help

We repeated the above multivariate analyses, this time entering caregiver demographics (Age and Ethnicity) as fixed factors, patient variables (ADL/IADL and Problem Behaviors) as co-variants, and the caregivers' Workload and Family Help as dependent variables. The models predicted considerable portions of the Workload variance ($R^2 = .35$ to $.46$) in all groups. Clearly, the strongest predictor in all models was Patient ADL/IADL. In addition, but only in the female groups, Patient Problem Behaviors and the intercept ADL/IADL and Patient Problem Behaviors yielded main and between-subjects effects on the caregivers' Workload. In predicting Family Help, the Patient ADL/IADL variable had a small between-subjects effect only in the Adult Child Female group ($R^2 = .04$) and Patient Problem Behaviors had no effect. The model for Adult Child Males was unique in that Ethnicity with and without the added effect of Caregiver Age was a strong predictor of Family Help. In that group, the overall model, Ethnicity, and Age predicted 40 % of the variance of Family Help.

Discussion

In this study, we explored individual and family characteristics in a multicultural sample of caregivers. These 533 caregivers carried the responsibility of making care-related decisions and were involved in an average of three to four of eight caregiving tasks (bathing and dressing; cleaning up urine and BM accidents; medical procedures; laundry; transportation; walking and exercising; taking on rides and visits; supervising a confused patient). In spite of these challenging tasks, the average caregiver was relatively healthy. Most caregivers did not have clinical depression, felt a strong obligation to care for the relative in need, were highly religious, did not feel excessive burden, and perceived that their caregiving work was what anyone in their family position should do. Thus, the majority seemed to have adjusted their role norm successfully to the present situation without receiving much help from the family or engaging community services.

Over two thirds of the caregivers in our sample were minorities, of which about half were Cubans. Most of the Cubans had immigrated to Florida between the 1960s and 1980s. The other half of the minority group was composed of more recent immigrants from the Caribbean and other Latin American countries and a small number of southern-born African Americans. Of the White group (39%), few were born in Florida; most had moved from northern states and 14% had emigrated from other countries.

Differences Between Male and Female Caregivers—This study addressed three research questions. The first was related to differences between male and female caregivers

and between spouses and adult child caregivers. Male caregivers made up 20% of the entire sample and among Black caregivers only 15%. Male caregivers were similar to female caregivers in age, health, education, and use of community services. Other variables, however, suggest that the definition of a role norm and therefore the caregiving process was structured along cultural and gender rules (Calasanti & King, 2007; Robinson et al., 2014). Unlike women, men are said to experience little social pressure to care for relatives (Campbell, 2010). In this study, men had a higher obligation score, but lower burden, depression, and role norm discrepancy than women. Therefore, one would expect male caregivers to have entered their job voluntarily for personal, perhaps religious reasons. Rather than being highly burdened by added responsibilities, literature reports that men accept their caregiving role as a challenge, focus on necessary tasks (McDonnell & Ryan, 2013; Robinson et al., 2014), and keep emotions apart (Calasanti & King, 2007).

Among male adult children the proportion of unmarried caregivers was highest. This supports Campbell's (2010) observation that being single is a decisive factor for men, determining willingness to become involved in hands-on care. Nevertheless, in this study, even single men were involved in fewer caregiving tasks than women, and the relatives they cared for had fewer functional limitations and less dementia. These findings serve as evidence that men's caregiver role norm was more flexible. Perhaps, men were also more willing to change their situation. Being that their relatives were less physically and mentally impaired, we question if we may have lost male caregivers with patients who needed a higher level of care, because they had made the decision to institutionalize the relative or turn over the care to outside help (Ducharme et al., 2007). These patterns of coping seem to act as a mechanism to protect their own emotional and consequently physical health. They do not, however, serve as a measure of quality of care.

The literature reports that women, unlike men, see their caregiving function as an extension of their usual role and their caregiving follows the expectation of the family and the society (Calasanti & King, 2007). They may feel obligated to give more of themselves and guilty if they do not, therefore experiencing more stress and burden than men (Gallicchio et al., 2002). Our findings support this notion, demonstrating that women did more caregiving work than men, possibly because they were more emotionally involved with the patient (Bédard et al., 2005; Pinquart & Sörensen, 2003), and suffered more depression than men (Papastavrou et al., 2007). Even though they received more family help than men, the level of family help was not extensive and did not significantly reduce their caregiving workload or their burden.

Female spouses were the most vulnerable group of all. Our study supports the findings of Savunranayagam et al. (2011) that female spouses, like all women caregivers, rather than feeling burdened because of a heavy workload, reacted emotionally to their situation. Spouses of both genders had a very high obligation score, signifying strong emotional attachment, but female spouses, in spite of being the most spiritually focused, had the highest depression scores, felt more burden than male spouses, and, even if not significantly different, reported less optimal physical health (Seltzer & Li, 2000). Having a lower average income may also have contributed to the negative effects associated with caregiving.

In contrast to male caregivers, like Papastavrou et al. (2007), our results suggest that women employed emotionally-based patterns of coping associated with higher burden and depression. Based on their strong emotional attachment, women did not have the same flexibility as men to adjust their caregiver role norm to rising demands. Instead, driven by commitment and obligation, they continued caring, often to the point of exhaustion. Their pattern of intimate involvement does not, however, signify a higher quality of care than the male pattern. Being less able to resolve role norm discrepancies, women caregivers may put themselves in danger of going into a crisis and consequently ceasing to be effective as caregivers.

Family help or community resources could prevent such crises. Nevertheless, male and female spouses alike were very reluctant to ask the family for help or to use community services, perhaps out of fear to betray their spouse (Robinson et al., 2005). Based on the literature about family-centered values in Hispanic caregivers (Scharlach et al., 2006), we expected, but did not find, more family help for Hispanic spouses. Thus, our results upheld the finding of Savundranayagam et al. (2011) that older spouses, highly committed to caring for their loved ones, constitute a quite homogeneous caregiver group across ethnicities.

In summary, our findings supported the Caregiver Identity Theory (Montgomery & Kosloski, 2013) and the literature, suggesting a gendered approach to caregiving identity formation and self-appraisal. Women, especially the spouses, seemed to adhere strongly to values about obligation to care for the family learned early in life. Men and, to some extent, younger women felt freer to define their role in a way congruent with their personal situation. Consequently, female spouses seem most vulnerable to emotional and physical health problems. Another group worthy of being explored in more depth is male adult children who reported the highest burden. These men, many of whom were single, dedicated themselves to the care of their parents. Perhaps, they were comparable to the women in filial duty and responsibility, and their emotional coping set them apart in the masculine world around them.

Predictors of Subjective Burden and Role Norm Discrepancy

This section refers to research question two. According to the Caregiver Identity Theory (Montgomery & Kosloski, 2013), the perception of burden and the extent of a discrepancy between role identity and actual caregiving workload are products of self appraisal. The understanding of what the role should be (role identity) supplies the basis for such an appraisal and depends on a complex interactive process of influencing factors. The caregivers' health together with the interaction of the combined group of predictors (age, ethnicity, spirituality, and the care recipients' problem behaviors) predicted the level of subjective burden in all subgroups. With ailing health, caregiving becomes increasingly burdensome; nevertheless, individual perceptions of the situation of the patient seem to add to a complex self-appraisal and influence the motivation to give care.

Given this complexity, only a small portion of the variable caregiver role norm could be predicted in the four groups with the study variables. The most significant predictors seemed to be spirituality in women and health in men, again referring to the gender differences discussed above. Ethnicity alone and in combination with age acted as a significant predictor

only in the female spouse group. This suggests that in older immigrant caregivers, cultural values most strongly directed caregiving (Scharlach et al., 2006). Since Hispanic and Black spouses also were highly spiritual, many must have accepted their role without questions.

Predictors of Caregiver Workload and Family Help

This section refers to research question three. Based on the Caregiver Identity Theory (Montgomery & Kosloski, 2013), we hypothesized that gender-based beliefs and the demands of the patient determine the amount of care given by the primary caregivers and how much families help out. Contrary to that, we found that the caregivers' workload in all groups was mainly driven by the functional status of the care recipients. Also, patients with problem behaviors seemed to demand more work from women. Why this did not hold for male caregivers can only be speculated. One factor may be the higher rate of dementia among the relatives taken care of by female adult children.

Family Help in the spouse groups was not available for most spouses. Of the couples, 77% lived independently without other family members. Even if their children lived close by, many stated verbally that they did not want to burden their children, since they were busy with jobs and their own families. As described elsewhere, such couples often took turns caring for each other (Friedemann, 2005). We expected the extent of family help to be relative to the care demands of the patients. Surprisingly, this held true only for female adult children. Like other researchers (Bédard et al., 2005; Pinquart & Sörenson, 2003), we found that male adult children received less help, and speculated along the line of Campbell (2010) that many took on the caregiving duties out of necessity, because there were no other siblings who could have helped. Nevertheless, among those who had family close by, older Hispanics, both Cubans and others, were most likely to receive assistance, suggesting that being Hispanic from an older generation was the best predictor of family help.

Practice Implications

The above discussion implies that families who care for older relatives are diverse and that their diversity goes beyond ethnicity. The most vulnerable group is couples living by themselves and not receiving sufficient help from other family members. Whereas multigenerational households may be more common in minority populations, in our sample, over three quarters of the spouses of all ethnicities lived in couple households and many did not have access to families. In fact, family help to spouses amounted only to an average of 13 minutes for women and 22 for men per week, in spite of their age (67% were over age 70). Health and social service professionals need to pay special attention to the needs of caregiving spouses who are often at the brink of exhaustion, but are reluctant to ask for help or engage community services. Before suggesting services to ease their care work, professionals need to develop a trusting relationship, especially with minority caregivers. A measure of burden and/or depression should be made part of an initial assessment. Nevertheless, family professionals need to understand that especially minorities may not admit to feeling burden (Scharlach et al., 2006). Instead of asking about burden, they may want to use other words such as "difficulties" or "worries", or they may ask the caregivers and family to describe what is most difficult for them when giving care to their loved one. A professional approach to minority caregiving families asks for creativity in overcoming

obstacles such as refusal to accept help, insufficient money to pay for services, or lack of access due to geographical location. A careful assessment of the situation therefore often involves a session with the extended family during which available resources within and outside the family can be explored together. At times, the problem rests with a couple's reluctance to ask for help from family members. In such cases, professionals may be able to secure help by explaining in convincing terms the couple's needs to the extended family. If families cannot provide physical assistance, they may be willing to help procure a service like adult day care.

An equally careful assessment of the home situation is needed for adult child caregivers. Their burden is high and depression is likely in situations, where the care recipient has moved into their home and presents problem behaviors, or where the caregiver needs to work outside the home to make ends meet. Some families have great skills in organizing their family operation around the person in need of care; especially Black families have been cited for creative approaches (Feld et al., 2004). Other family systems, however, do not have the help needed or lack the skills to mobilize others. Professionals may want to explore possibilities with the family. They should encourage family members to communicate their own needs to each other and arrive at solutions of sharing the load. Stressors are manifold and cannot be understood without looking at each situation individually and in depth. Many families are in crisis and desperately need professionals who can guide them in the right direction. The results of this study should motivate family professionals to detect vulnerabilities in male and female, spouse and adult child groups of caregivers and their families. Since differences according to ethnicity were small, professionals should drop cultural stereotypes and instead explore each family in its own right.

Limitations of the Study and Recommendations for Further Research

The findings of this study are subject to certain limitations. Our inability to recruit sufficient Black caregivers made it necessary to drop random recruitment procedures for a part of the minority sample. Consequently, conclusions about ethnic differences have to be made with caution. The number of male caregivers in the subgroups, especially adult child males, was small though sufficient to examine differences in the spouse and adult child groups. It was too small, however, for a further breakdown, for example according to family type or ethnicity variables. Finally, we interviewed the primary caregivers and the care recipients, but did not have the resources to include other family members. Therefore, in order to gain understanding of family systems, we relied on the literature for interpretation. The fact that our findings with minority caregivers were to a great extent congruent with previous findings in the literature renders validity to this study.

In spite of limitations, to the best of our knowledge, this study was the first to examine caregivers' coping in a multicultural sample, and the findings are relevant for researchers, practitioners, and policy makers. We used the Caregiver Identity Theory successfully to gain insight into family caregiving processes, an approach that may be helpful in guiding future studies.

Based on the low use of services and family help, we suspect that many caregivers cannot sufficiently meet their needs. Unmet needs over time can lead to distress. If reports of

burden and depression were relatively low at the time of the study interview, the future may show a different picture. Therefore, future investigations should use multicultural samples with larger male participation. Immigrant groups should be defined and compared according to the time the caregivers have spent in the U.S. and their degree of acculturation. Newer studies should explore challenges to family systems in greater depth, such as family-work conflict, access to resources, financial stress of caregiving families, and caregiving obligations of descendants of immigrants.

Caregivers in our study used family help when available. The lack of availability of family help may be a critical factor, leaving caregivers vulnerable and in need of community services. In this study, we neither addressed the availability, nor the degree of helpfulness of family or other outside assistance. We therefore recommend including in future studies the caregiver perspective about such assistance. Finally, future projects are recommended that explore the coping process of caregivers, including the role of spirituality, as well as intervention studies targeting improved access to community resources and rendering programs culturally congruent and consumer friendly.

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Table 1

Summary of Measurements

Variable	Instrument	# Items	Reliability
Caregiver Health	<i>Health Index</i> (Montgomery & Borgotta, 1985)	4	$\alpha = .82$ $\alpha = .78^*$
Caregiver Obligation	<i>Caregiver-Elder Relationship Scale</i> (Montgomery & Borgotta, 1985)	6	$\alpha = .89$ $\alpha = .88$
Caregiver Depression	<i>Patient Health Questionnaire (PHQ-9)</i> (Huang et al., 2006)	9	$\alpha = .79-.89$
Caregiver Spirituality	<i>Spiritual Perspective Scale (SPS)</i>	10	$\alpha = .96$
Caregiver Burden	<i>Subjective Burden Scale</i> (Montgomery & Borgotta, 1989)	10	$\alpha = .78-.80$
Care Recipient Functioning	<i>ADL/IADL Scale</i> (Montgomery & Borgotta, 1985)	12	$\alpha = .83$ $\alpha = .96$
CR Problematic Behaviors	<i>Problematic Behavior Scale</i> (Montgomery & Borgotta, 1985)	14	$\alpha = .80$ $\alpha = .87^*$
CR Cognitive Status	Mini Mental Status Exam (Folstein et al., 1975)	30	$\alpha = .54-.96$ $\alpha = .92^*$
Caregiver Number Tasks	<i>Caregiving Task Instrument</i>	8	$\alpha = .82$
Family Help Number Tasks	<i>Caregiving Task Instrument</i>	8	
Role Norm Discrepancy	<i>Caregiving Task Instrument</i>	8	

Note.

* = Results of Pre-Study Pilot Testing

Table 2
Frequencies of Caregiver Demographic and Patient Variables in Relation and Gender Groups

Variable	Category	Female Spouses		Male Spouses		Female Adult Ch		Male Adult Ch	
		f (%)		f (%)		f (%)		f (%)	
Marital Status	Single/Divorced	4 (2.7)		2 (3.3)		119 (43.0)		31 (64.6)	
	Married	143 (97.3)		59 (96.7)		138 (49.8)		16 (33.3)	
	Widowed					20 (7.2)		1 (2.1)	
Education	< High School	31 (21.1)		14 (23.0)		21 (7.6)		6 (12.5)	
	High School/GED	36 (24.5)		15 (24.6)		55 (19.9)		11 (22.9)	
	Post High School Ed.	46 (31.3)		13 (21.3)		101 (36.5)		14 (29.2)	
	College Degree	34 (23.1)		19 (31.1)		100 (36.1)		17 (35.4)	
Income	< \$15,000	42 (28.6)		21 (34.5)		53 (19.2)		5 (10.4)	
	\$15 – 60,000	69 (46.9)		28 (45.9)		130 (46.9)		27 (56.3)	
	> 60,000	22 (15.0)		11 (18.0)		86 (31.0)		12 (25.0)	
	Missing	14 (9.5)		1 (1.6)		8 (2.9)		4 (8.3)	
	White Non-Hispanic	60 (40.8)		27 (44.3)		96 (34.7)		23 (47.9)	
Race/Ethnicity	White Non-Hispanic	60 (40.8)		27 (44.3)		96 (34.7)		23 (47.9)	
	White Hispanic Cuban	46 (31.3)		25 (41.0)		84 (30.3)		8 (16.7)	
	White Hispanic Other	31 (21.1)		6 (9.8)		52 (18.8)		10 (20.8)	
	Black/Afro American	10 (6.8)		3 (4.9)		45 (16.2)		7 (14.6)	
Patient Living	Alone					29 (10.5)		5 (10.4)	
Patient Living	With Caregiver	147 (100.0)		61 (100.0)		248 (89.5)		43 (89.6)	
Patient Gender	Male	147 (100.0)				39 (14.1)		9 (18.8)	
	Female			61 (100.0)		238 (85.9)		39 (81.3)	
Patient Primary Condition	Dementia	28 (19.0)		16 (26.2)		60 (21.7)		7 (14.6)	
Requiring Care	Accident/Injury	23 (15.6)		9 (14.7)		44 (15.9)		6 (12.5)	
	Heart Problem	23 (15.6)		3 (4.9)		36 (13.0)		10 (20.8)	
	ADL Difficulties	7 (4.8)		3 (4.9)		44 (15.9)		9 (18.8)	
Stroke	Stroke	17 (11.6)		11 (18.3)		18 (6.5)		2 (4.2)	
	Others	49 (33.4)		19 (31.0)		75 (27.0)		14 (29.1)	

Table 3

Descriptives for Caregiver, Family, and Relative Variables

Variable	Female Spouses Mean (SD)	Male Spouses Mean (SD)	Female Adult Ch Mean (SD)	Male Adult Ch Mean (SD)
Caregiver Age	71.73 (9.38)	76.92 (6.38)	53.88 (10.36)	50.94 (12.25)
Caregiver Health	2.64 (.79)	2.38 (.72)	2.41 (.81)	2.29 (.96)
Caregiver Burden	2.72 (1.07)	2.30 (1.10)	2.74 (1.03)	2.78 (1.02)
Caregiver Obligation	3.85 (.32)	3.97 (.19)	3.73 (.49)	3.81 (.47)
Caregiver Spirituality	4.08 (1.18)	3.33 (1.37)	4.13 (1.02)	3.65 (1.38)
CG Norm Discrepancy	3.79 (.30)	3.76 (.32)	3.74 (.35)	3.45 (.54)
Caregiver Depression	6.31 (4.99)	4.07 (4.61)	5.27 (4.76)	4.07 (4.03)
Caregiver # Tasks	3.22 (1.41)	3.21 (1.50)	3.25 (1.63)	2.29 (1.66)
Family Help # Tasks	1.03 (1.62)	.61 (1.02)	1.93 (2.08)	1.58 (1.83)
Family Help Hours	.36 (.86)	.22 (.67)	.76 (1.37)	.57 (1.06)
Community Services	1.22(1.94)	1.20 (1.89)	1.35 (2.33)	1.37 (2.55)
Relative Age	77.95 (6.99)	75.21 (6.36)	82.33 (8.46)	79.10 (9.63)
Relative ADL/IADL	1.85 (.57)	1.80 (.58)	1.75 (.55)	2.01 (.53)
Relative Cognitive Status	19.06 (11.28)	17.00 (11.88)	15.85 (11.20)	19.90 (10.61)
Relative Problem Behavior	1.69 (.55)	1.63 (.56)	1.69 (.54)	1.55 (.51)

Note. Female Spouses n = 147; Male Spouses n = 61; Female Adult Ch n = 277; Male Adult Ch n = 48