

Cross Cult Gerontol. Author manuscript; available in PMC 2013 October 22.

Published in final edited form as:

J Cross Cult Gerontol. 2013 June; 28(2): 137–152. doi:10.1007/s10823-013-9193-6.

# Patterns of Caregiving of Cuban, Other Hispanic, Caribbean Black, and White Elders in South Florida

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#### **Abstract**

Caregivers in Miami, Florida (185 Cubans, 108 other Hispanics, 229 non-Hispanic Whites, and 73 Caribbean Blacks) were described and compared along demographic and health variables, cultural attitudes, and caregiving behaviors. Participants were recruited at random through Home Health Services (61 %) and convenience sampling in the community (39 %), and interviewed at their home. Standardized instruments and measures constructed for this study were pretested. Multivariate analyses showed that the ethnic groups differed in age, education, income, and number of persons giving care, while caregiver health and patient functioning were similar. Controlling for demographics, differences in cultural variables were small. The sense of obligation, emotional attachment, openness about who should give care, spirituality, use of family help or community services were comparable in all groups. Commitment to caregiving was high, driven mainly by patient needs. Cubans had the greatest family stability, and worked the hardest, with the lowest sense of burden. Caribbean Black caregivers lived in bigger families, were youngest, and their patients had the lowest cognitive status. Burden was felt most by White caregivers who were older than the others. Professionals need to understand complex belief systems and behavior patterns to assist caregivers in mobilizing appropriate resources.

#### **Keywords**

Family caregiving; Ethnic differences; Culture; Family stability; Family growth; Cuban; Hispanic; Caribbean Black

As a result of their study of ethnic differences in caregiver service use, Scharlach et al. (2008) concluded that research was needed to focus on patterns of caregiving relative to cultural values and attitudes in order to better understand how culture affects decision

making about using resources. Knowledge about the caregivers' perception of their role can help inform and reform local and national health services and is critical for the development of programs and policies to ease the burden of family caregivers. The correlational study presented here explored differences between ethnic groups of caregivers on demographic, health, and cultural attitude variables, as well as care recipient and relationship factors, the caregivers' workload, and the use of family help and community services.

# **Culture and Caregiving Families**

The framework underlying our study is the Framework of Systemic Organization (Friedemann 1995). We used this theoretical basis to select and categorize variables that seemed the best indicators of cultural processes in the family, to choose appropriate instruments for measuring the concepts and, thus, to interpret the findings in a broader sense than most research offers. The framework allowed us to make the connection between single variables and cultural processes occurring when individuals interact in families. According to the Framework of Systemic Organization, culture as an individual or family process has two functions of 1) maintaining stability (**Culture Maintenance**) through a firm set of values and traditions passed down from previous generations and 2) changing traditions (**Culture Transformation**) through the adjustment of values, beliefs, and consequently behaviors. Individuals and families balance these two seemingly opposing cultural processes in order to achieve well-being and health (Friedemann 1995). Accordingly, families of all ethnic groups use their cultural beliefs to guide them in utilizing the resources available to them within their families and in their communities.

Understanding the life of caregivers, particularly those of diverse racial and ethnic backgrounds, required a thorough comprehension of cultural aspects of caregiving, and definitions of the caregiving role. Therefore, the aim of this study was to describe and compare four groups of caregivers in the Miami-Dade area (Cuban, other Hispanic, non-Hispanic White, and Black Caribbean) with regard to their cultural attitudes and behavior patterns in maintaining stability and changing traditions in response to their caregiving situation.

In caregiving, the first process of culture maintenance is rooted in family values, in variables such as a sense of obligation or affection for the elderly relative and can be observed in the extent of work the caregivers are willing to perform. As part of their cultural belief system and family values, caregivers form an opinion about the appropriateness and meaning of their role. The extent to which their culturally defined role agrees with their actual caregiving activities determines family stability and health. The perception of burden arises when the actual work of the caregiver exceeds the culturally defined role norm. Thus, burden suggests conflict or difficulties in the caregiving operation and interferes with family stability.

The second process of culture transformation refers to coping, adjusting values, and changing behaviors (Friedemann 1995). An indicator of such flexibility in caregiving is the caregivers' attitude about the appropriateness of family members of different gender and family relationships to perform certain caregiving tasks. A flexible attitude is also reflected in the caregivers' willingness to accept help from a variety of helpers and actually ask for family help or use community services. Such behaviors will allow change in the family operation. Finally, the integration of spirituality in the coping process is relevant for family adjustment to difficult situations and plays a prominent role in the Afro-American and Hispanic experience of life (Morano and King 2005; Karlin et al. 2009).

## Caregiver differences between ethnic groups

Ongoing immigration trends have transformed the racial, ethnic, and therefore cultural, composition of the United States. In recent decades, the percentage of the population of Hispanic or Asian origin has more than doubled (Family Caregiver Alliance 2006). According to the U.S. Census Bureau (2009), the population segment of individuals aged 65 or older is projected to increase from 13 % in 2010 to 19.3 % by the year 2030. At the present time, 44 million Americans take care of ailing elderly family members or friends (Family Caregiver Alliance 2006). Better understanding of how these caregivers conduct their challenging work and still maintain their families is necessary to determine needed resources and support.

The literature points out that African American and Hispanic caregivers are younger and more likely to be working outside the home (Siefert et al. 2008) compared to older Whites among whom the percentage of spouses is larger (Roth et al. 2007). Younger caregivers, especially African Americans, who work full or part-time, report having more unmet needs than their counterparts (Drapalski et al. 2008; Scharlach et al. 2007). Employed younger caregivers are therefore more likely to pay for services than others who do not have paid jobs (Scharlach et al. 2007). Nevertheless, the overall use of community services is extremely low in all ethnic groups (Robinson et al. 2005), and ethnic differences in attitudes and behaviors related to service use are still unclear (Dilworth-Anderson et al. 2002). For example, Kosloski et al. (2002) report higher use of respite services by Hispanics, whereas other researchers cite that underuse of services by Hispanics is greater than by other ethnic groups (Min and Barrio 2009).

Among immigrant caregivers, the level of acculturation (Angel et al. 2004) and education (Scharlach et al. 2008), or the time caregivers have lived in the U.S. (Calderón-Rosado et al. 2002) significantly determine resource acquisition (Radina and Barber 2004). Less acculturated and often less educated immigrants seem to feel a sense of abandonment (Siefert et al. 2008) and social isolation (Angel et al. 2004), and try to accomplish too much due to cultural commitment, guilt (Scharlach et al. 2008) and strong sense of obligation (Savundranayagam and Montgomery 2010).

Since many minority caregivers are younger and carry a job, they would necessarily need services to assist with caregiving. This has been shown to hold true only for caregivers with higher education and a higher income who also tend to be more acculturated and accepting of the local healthcare system (Scharlach et al. 2008). Through acculturation, these caregivers reduce their sense of obligation, accept outside resources and allow themselves more personal time (Kutner et al. 2009). Educated ethnic caregivers also suffer from less burden and depression (Mausbach et al. 2004).

In summary, education acts as a facilitator of the acculturation process. Nevertheless, certain groups seem to maintain their cultural values and strong commitment to giving care. African Americans and Hispanic caregivers have been observed to spend more hours in the caregiving role (Dilworth-Anderson et al. 2005) than Whites. Whether the significant factor here is age, education, religion, a lack of resources, or a combination of the above is not clear. This seems to suggest that cultural processes include highly complex interactions of background, cultural values, economic and family variables.

In terms of maintaining their families, minority caregivers live more often than Whites with family members other than the patient (Adams et al. 2006; Hinojosa et al. 2009). Other researchers report that African American spouse caregivers request the assistance of family members most often (Feld et al. 2004), suggesting a stronger communal view of caregiving

than other ethnic groups. Nevertheless, whether minority caregivers generally have more help available than Whites has not been clearly confirmed in research (Kaufman et al. 2010).

Few differences related to factors other than demographics are cited in the literature. One such finding is that the sense of burden and depression is higher among White caregivers than among African Americans (Roth et al. 2008), yet the intensity level of care is higher among African Americans who also report more unmet needs (Navaie-Waliser et al. 2001; Casado et al. 2011). Nevertheless, even this finding may be influenced by demographics in that White caregivers may feel more burden because more of them are spouses and therefore older (Pinquart and Sorensen 2005) and less physically fit to give care (Fredman et al. 2008).

Researchers have looked at religion as a possible way of coping with caregiving responsibilities. African American caregivers report the highest level of religiosity and self-acceptance (Morano and King 2005). Compared to White caregivers, they are more likely to seek prayer and religious practices as a moral compass to make everyday decisions (Nelson-Becker 2005). Similarly, studying Hispanic caregivers of stroke patients, Clark et al. (2010) report that Hispanics believe that health is affected by external factors and that they need to pray to God who has the sole power to heal their loved ones.

Considering the complexity of these cultural processes together, these studies represent only a beginning exploration of the impact of cultural factors on caregiving and caregivers. Consequently, in this study we focused on family and cultural patterns to shed light on the process of caregiving and differences among ethnic groups. Since, to our knowledge, no other study had distinguished between different Hispanic groups, we examined Miami-Dade Cubans as a distinct group from more recent immigrants from other Latin American countries in terms of immigration history and acculturation. Finally, we explored Caribbean Black caregivers, a group that, to our knowledge, has not been studied as of yet.

#### **Methods**

# Sample and characteristics

A sample of 595 caregivers of frail elderly was recruited. Five local home health nursing services, all serving mixed ethnic communities, assisted in the random selection and recruitment of 429 patients and their caregivers. Managers pulled 5 to 10 cases from their active patient list using random numbers provided weekly by the researchers. Fieldworkers then recruited the caregivers and patients during their service visit and referred the participants to the researchers. About 20 % of the caregivers declined participation. Since those declining were mainly Black, 166 minority participants were added to the study by community leaders in neighborhood organizations who had a trusting relationship with caregivers, by using convenience methods.

The sample included 229 (38.5 %) White non-Hispanic caregivers, 73 (12.3 %) Blacks, predominantly from the Caribbean; 185 (31 %) Cubans; and 108 (18.2 %) caregivers from other Hispanic countries in Central and South America, Mexico and Puerto Rico. Demographic and health data from caregivers and their patients in all four groups are listed on Tables 3 and 4. The patients were 65 years or older and required assistance due to a variety of conditions, such as effects of accidents, stroke, cardiac problems, cancer, or simply frailty of old age. Their dementia rate ranged from 18 to 20 %. Caregivers not sharing the home with the patients lived closer than 30 min driving.

#### **Data collection**

Two trained interviewers collected the data, in English or Spanish, in the participants' homes. They visited in pairs for reasons of safety and mutual supervision. Before the interview, the caregivers signed an Informed Consent form, and the elderly persons also signed a form consenting to a quick mental status exam. Elders unable to sign were not tested. The study was approved by the University Review Board, as well as by the Ethics Committees of the participating agencies that had one.

#### Measures

The measures relative to variable categories in the caregiving literature and their relationship to the theoretical concepts are listed in Table 1. The theoretically justified variables and measures relative to culture maintenance and transformation used in this study of multiethnic caregivers were intended to reach beyond the literature about caregiver responses to their situation and to focus on complex cultural processes. The framework assisted us in categorizing variables that were found significant in the literature according to the role they play in the two theoretical dimensions.

Demographic variables were included to describe the caregiving context. In addition to recording gender, marital status, education, age, and income of caregivers and patients, the survey included data on household constellation, and the relationship between caregiver and patient, as shown on Table 1. Table 2 lists the instruments and scales used in relation to the relative concepts and measures. Reliability data are indicated on the same table.

All standardized instruments had been subjected to factor and reliability analyses that yielded acceptable validity information. 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), has nine items and is widely accepted as a diagnostic screen. The Montgomery *ADL/IADL Scale* measures physical and instrumental ability as reported by the caregiver (Montgomery and Borgotta 1985; Montgomery and Kosloski 2001); and the *Mini Mental Status Exam* (Folstein et al. 1975) is well known as a screen for cognitive status.

The Assessment of Strategies in Families-Effectiveness (ASF-E) (Friedemann 1991) has 20 items with three response options expressing family patterns. The options are assigned a score from 1 to 3, depending on their level of effectiveness. Scale and sub-scales (stability with 12 items; growth with 8 items) have documented content and construct validity, tested repeatedly with multicultural samples (Friedemann 1991).

The Caregiver–Elder Relationship Scale developed and tested by Montgomery and Borgotta (1985) provides subscales of 6 items each for Caregiver Obligation and Caregiver Affection for the care recipient. Another instrument previously used in Montgomery's research is the Subjective Burden Scale (Montgomery et al. 1985; Savundranayagam et al. 2011). The 5 items of stress burden measure the effect on care-givers' emotions such as worry, anxiety, and depression. The other 5 items of relationship burden address the caregivers' perception of being taken advantage of or manipulated.

The *Caregiving Tasks Instrument* was developed for this study to measure several variables and pretested for reliability. It consists of eight items expressing types of tasks: (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 Caregiver Workload, the respondents reported how many of the tasks they performed and how many hours they spent with each task. Similarly, for Family Help in Hours caregivers indicated on the Caregiving Tasks Instrument how many hours of help they received for each task from family or friends. To measure the variable Agreement with Role Norm with the Caregiving Tasks Instrument, we first asked participants for each task whether a relative like themselves should or should not do the task. Then, we deducted the actual number of tasks performed by the caregiver (Caregiver Workload). Finally, we squared and summed the discrepancies to eliminate negative values.

The Caregiving Tasks Instrument served for two more scores expressing the participants' cultural attitude about the caregiver role. This time, we asked participants for each task whether a relative like a daughter, daughter-in-law, son, granddaughter, grandson/brother, sister, wife, husband, other relative/friend, or a paid helper (total 10 persons) should do the task, assuming all were available. (1) The score for Openness to Accept Help With Tasks was the sum of the tasks that, according to the caregiver's cultural belief, could be done by all 10 possible helpers. (2)The score for Openness to Accept Helpers was the sum of the relations/friends/paid helpers who should help with all the tasks listed, assuming they were available.

The 10-item Reed Spiritual Perspective Scale (SPS) measured spirituality as practicing religion and integrating spirituality in everyday life (Reed 1986). Finally, we assessed the actual Use of (Community) Services with a *List of 17 Services* known to be available in the area. The caregivers marked the services they actually used during the last month, and we summed up the services checked.

## **Analysis**

**Preliminary analyses**—Due to the ethnically diverse sample, we confirmed the reliability and factor structures of all the published and unpublished instruments and inspected the measures for univariate and multivariate normality.

**Descriptive analyses**—The first step of the analysis consisted of describing the sample and each ethnic group in terms of demographic and health factors, and the variables of culture maintenance and transformation using frequencies or measures of central tendency. Next, we compared the groups along the same variables, using cross-tabulations with Chi-Square test or one-way analysis of variance with Scheffe multiple comparisons. Finally, using multivariate analyses, we examined main effects of ethnicity and interaction effects of ethnicity with demographic and health variables on culture maintenance and culture transformation variables.

## Results

## Ethnic group differences in caregiver demographics and health variables

Black Caribbean caregivers were predominantly adult children and differed from Whites and Cubans in younger age [F (3,590) = 14.51, p<.001] and a greater number of people living in the household [F (3,591) = 14.05, p<.001]. (See also Table 3.) Related to the younger age, there were significantly fewer spouses among Black Caribbean caregivers [ $x^2$ (3) = 11.34, p=.01] and significantly more single caregivers. The Black group had the most divorced caregivers and the other Hispanic group the fewest [ $x^2$ (12) = 40.34, p<.001]. (See also Table 3.)

Considering all educational categories, Whites were best educated, followed by Cubans, other Hispanics, and Caribbean Blacks [ $x^2(21) = 77.92$ , p < .001]. Similarly, income was

highest for White caregivers, with most in the highest annual income category of \$60,000 and more and fewest in the lowest income category of less than \$15,000. The opposite was true for other Hispanics. Cuban and Black Caribbean caregivers were comparable and fell between the White and other Hispanic groups [ $x^2(6) = 47.19$  (6), p < .001]. (See Table 3)

There were no significant differences in the gender ratio of the four groups or the status of physical health of the caregivers. The average depression score of the caregivers in all four groups was well below the 10 points signifying clinical significance and ranged from 3.54 to 6.38. Cubans had slightly higher scores than the other groups (see Table 4), but Scheffe comparisons yielded no significant differences.

### Ethnic group differences in patient age and functional status

Similar to the caregivers' age, the age of the patients was also lower in the other Hispanic and Black Caribbean groups. The two groups differed significantly from Whites [F(3,591) = 6.79, p < .001]. In spite of the younger age of the Black Caribbean patients, their cognitive status was, on average, the lowest of the four groups and differed significantly from that of White patients [F(3,521) = 3.83, p = .01]. Their functional level (ADL and IADL) was comparable to most other groups; only Cuban patients scored lower than the others [F(3,591) = 4.35, p = .005]. (See Table 4).

## Effect of ethnicity on culture maintenance variables

Variables tested (see Table 5 for descriptives by ethnic group) were Family Stability, Obligation, Caregiver Workload in hours, Agreement with Role Norm (congruence between the caregivers' role norm and actual work performed), Caregiver (subjective) Burden, and Affection for the patient. With multivariate analysis, we explored the main effects of Ethnicity on these culture maintenance variables as well as possible interactions with the variables: Caregiver Age (2 levels: up to 60 and 61+), Gender, Income (2 levels: up to \$20,000 and \$21,000+), Relationship to Patient (Spouse or Other), Patient ADL/IADL (high-low), and Patient Cognitive Status (high-low). The analysis yielded a significant but small main effect of Ethnicity on the culture maintenance variables taken together [F(21) = 1.96, p<.01; Eta Sq.=.043], meaning that Ethnicity served as relatively weak but significant predictor of overall culture maintenance (Table 5).

Two between-subject effects of Ethnicity explained the specifics about the above overall main effect in that Ethnicity had a small effect on Family Stability [F(3) = 3.39, p=.05; Eta Sq.=.032] and Caregiver Workload [F(3) = 4.60, p=.01; Eta Sq.=.042]. Table 5 assisted in clarifying that mainly Cubans were responsible for this finding, since Cuban caregivers distinguished themselves with higher Family Stability and the heaviest Workload of all groups.

Ethnicity in interaction with one or two variables as covariates also yielded significant results. Together with Caregiver Income, Ethnicity had a significant but small effect on Caregiver Workload [F(3) = 2.31, p < .05; Eta Sq. = .043]. In other words, the influence of income on the caregivers' workload was different for the four ethnic groups. In addition, a three-way interaction of Ethnicity with Caregiver Age and Patient ADL/IADL on Family Stability [F(3) = 3.55, p = .05; Eta Sq. = .033] showed that the caregivers' Age and the patient's ADL/IADL, interacting with each other and Ethnicity, also predicted Family Stability. This suggested that negative effects on Family Stability differed with age of the caregivers and the functional level of their patients, but the effects of caregiver age and patient function were not the same for all ethnic groups.

Finally, two three-way interactions of Ethnicity 1) together with Caregiver Age and Gender [F(2) = 6.00, p < .01; Eta Sq.=.037] and 2) with Caregiver Income and Gender [F(5) = 2.84,

p=.05; Eta Sq.=.044] had a significant but small effect on the caregivers' Obligation. In other words, the caregivers of different age, income, and gender experienced obligation toward the older relative differently, depending on their ethnic group. In addition, Table 5 shows that Cuban and Black Caribbean caregivers reported a slightly higher obligation toward their relatives, a finding that seemed to explain why ethnicity became part of the equation.

## Effect of ethnicity on culture transformation variables

We tested the variables (see Table 6 for descriptives by ethnic group) Family Growth, Spirituality, Openness to Accept Helpers, Openness to Accept Help with Tasks, Use of Family Help, and Use of Services in a multivariate analysis and entered the variables listed above as fixed effects. Ethnicity yielded no significant main effects in this multivariate test. Instead, Caregiver Age, Income, and Education affected the Culture Transformation variables in a small interaction effect, meaning that, instead of Ethnicity, it was the caregivers' younger age, higher income and higher education that enhanced culture transformation.

The analysis yielded no between-subjects main effects. Nevertheless, the variable Family Growth was slightly influenced by significant interactions between Ethnicity and Caregiver Income [F(6) = 2.41, p=.05; Eta Sq.=.045], and Ethnicity and Gender [F(3) = 3.46, p=.05; Eta Sq.=.033]. Whereas caregivers with higher incomes reported more family growth, this relationship was not consistent across ethnic groups, and Gender without an apparent effect on Family Growth seemed to influence Family Growth when interacting with Ethnicity.

Finally, a small three-way interaction effect of Ethnicity, Caregiver Age, and Patient Cognitive Status influenced the variable Openness to Accept Helpers [F(3) = 3.20, p=.05; Eta Sq.=.030]. Caregiver Age or Cognitive Status of the patients were similar in all ethnic groups, but in an interaction with Ethnicity, these variables did serve as a combined predictor of the caregivers' Openness to Accept Helpers. Neither Spirituality nor Openness to Accept Help with Tasks, nor Use of Services was involved in main effects or interactions with Ethnicity.

In summary, differences among ethnic groups were mainly related to demographics, health and functional status of the patient. Differences between ethnic groups along culture maintenance and transformation variables were much less than expected. Interactions of ethnicity with some demographic, health and functional variables suggested culture-based reaction patterns, but their effect was small.

## **Discussion**

In this study, we compared four ethnically different groups, as diverse as the population in the Miami area. The most homogeneous was the Cuban group with 95 % of the caregivers born in Cuba. These caregivers had either immigrated to the U.S. with their parents in the first wave of immigration in the 1960s, or arrived in the 1980s or later and had their parents follow them. Only 5 % were born in the U.S. The group of White caregivers was more diverse in that 14 % had emigrated from other countries, the majority from Europe, and most others had moved to the area from diverse states across the nation. Of the other two groups, about 91 % of the caregivers were immigrants from Latin America or the Caribbean, the majority of whom arrived later than 1980.

Consequently, differences in education, income levels, age or gender were likely to be related to conditions in the home countries and immigration history. Having lived in the U.S. the longest, Cubans were most comparable to White caregivers on all measured variables. In

both groups, the percentage of spouse caregivers was higher; thus, their average age was older and the number of men taking care of their wives was higher. The average age of the patients was also older in both groups, but only in the Cuban group did the patients have lower functional ability. Perhaps, White caregivers were more inclined to admit patients with significant functional decline to nursing homes than ethnic caregivers (Mausbach et al. 2004). The two groups also had similar education levels with the exception of a greater number of caregivers without a high school diploma in the Cuban group. In spite of similar education levels, White caregivers enjoyed higher incomes on the average than all the other groups. This fact may speak to the struggle many immigrants face with acculturation and difficulties with the English language (Pinquart and Sorensen 2005).

With a few exceptions, the other Hispanic caregiver data were comparable to the Caribbean Black group. Among Black Caribbean caregivers, the percentage of adult children and other family members was considerably higher than in all other groups. Consequently, this group tended to live in relatively large families. The patients were not older than those in other groups, but their cognitive status was lower on average. This may reflect a greater tolerance of dementia and disruptive behaviors within the Black Caribbean population similar to other African American caregivers (Anderson and Turner 2010; Cooper et al. 2010). In summary, in this study, demographic, family, and health differences seemed related mainly to immigration history and socio-economic differences apparent in the population at large.

## Ethnic group differences in culture maintenance and transformation variables

The analysis attempted to control for the inherent differences discussed above by treating the demographic variables as fixed effects in the multivariate analysis. These factors accounted for, we found very few group differences based on ethnicity in the way the caregivers felt about their role, took care of patients, and reacted to their situation.

All groups reported high family stability, sense of obligation, and affection for the patient. Nevertheless, the analysis showed that Cubans reported significantly higher family stability and worked longer hours taking care of the patients. Table 5 also shows that Cubans felt the least burden in connection with their work and the highest family obligation. Whereas these means were not significantly different from those of other groups, they helped to gain a fuller picture of the Cuban caregivers. Many were elderly spouses who emigrated from a country to which they could never return. Over the years, these couples had to jointly overcome many hurdles while learning to live in a strange country. Such a history may have led to a strong feeling of obligation to care for each other. Considering the interaction of ethnicity with age, gender, and income on the caregivers' workload and the sense of obligation, as well as research cited in the literature, such dynamics may be especially strong in older women of lower income levels (Napoles et al. 2010; Scharlach et al. 2006). The finding that these same caregivers also used fewer services was consistent with research indicating that foreign-born Hispanic caregivers are less likely to use outside resources than those born in the U.S. (Scharlach et al. 2008).

Ethnic differences in the group of culture transformation variables depended on an interaction of ethnicity with the caregivers' age and education. Specifically, family growth was reported somewhat higher by White caregivers (see Table 6). This effect was significant due to the interaction of ethnicity with income and with gender, meaning that persons with higher incomes and women were better able to adjust to necessary changes than others. This finding may be related to a greater availability of resources (Sorensen and Pinquart 2005) and the willingness to go beyond the household to search for solutions (Dilworth-Anderson et al. 2005).

Finally, the openness to involve all 10 possible relatives/friends in the care of the frail family member was greatest in Caribbean Black families (see Table 6), but this difference became significant only with cognitively impaired patients and younger caregivers. It seems logical that the need for more helpers is greater with cognitively impaired patients, and the effect of age may be based on the fact that many younger caregivers were still in the workforce and needed assistance in watching the elders during the time they were absent.

Variables that were similar in all groups are also of interest. Significantly, all groups acted out of a strong affection for the elderly patient. Their family obligation was high and their sense of burden relatively low in spite of considerable responsibilities. There were even greater similarities in the culture transformation variables that capture the family's ability to cope with the caregiving situation. Contrary to the findings of Nelson-Becker (2005), in our study, spirituality or religious practices were equally important for all ethnic groups, including White caregivers. All caregivers expressed a willingness to engage other family members or friends in the care if they were available. In reality, however, the share of work done by family members was relatively small, leaving the major tasks to the primary caregivers. As reported in other research (Mausbach et al. 2004; Dilworth-Anderson et al. 2002; Dunlop et al. 2002), the use of services was minimal. White caregivers used services slightly more, but even they used on the average only 1.5 services during the previous month from a list of 17. According to verbal statements recorded in field notes of the data collectors, many caregivers did not know about services, did not qualify, or could not afford them.

The ethnic mix in this study is unique and so is the theoretical framework, leading to a selection of variables not usually chosen for ethnic comparisons. The framework directed us toward seeing caregiving as a family process, in which all caregivers mobilize resources within or outside the family; but the framework should also allow for cultural variation as families use different ways to balance the two processes. Our variables addressed basic cultural values, emotional reactions and actual strategies such as using family help or services. Even though we did not find substantial cultural differences, it is possible that differences existed within specific thought processes, reaction patterns, emotional responses, and belief-based actions. Our study is important in that it points to the need to explore differences on a deeper and more personal level that can only be achieved with qualitative studies. The clear distinction between Cubans and other Hispanics resulting from the analysis also shows the importance of analyzing cultural groups not simply along skin color or language spoken, but also along their past and present economic status, immigration and acculturation history.

#### **Practice implications**

Our findings show that the needs of the chronically impaired family member first and foremost drive the process of mobilizing caregiver and family to provide care. This implies that the kind of services available could be adequate to meet ethnic care-givers' needs, provided that all caregivers could meet qualifications for the services they need, received clear information about how to access the programs, and felt understood and supported by empathetic health care professionals. The fact that immigrants do not use services as much as other caregivers shows that existing conditions are not ideal for all.

Multicultural providers ought to facilitate the use of their services with the aim of mitigating personal and family burden caused by disease and disability. To make services available to ethnic groups, it is necessary to connect to these groups. This entails knowledge of the family context and preferred caregiving patterns. Considering that the care recipient's health affects relationships, roles, and responsibilities in the whole family (Schubart et al. 2007), all professionals concerned with the empowerment of caregiving families need to provide

information not only about the patient's progress and treatments but also about resources that ease coping with giving care (Bee et al. 2009; Drapalski et al. 2008). Caregiver needs are extensive and include assistance with logistical tasks, emotional support, and high quality communication with health staff (Kutner et al. 2009).

In working with all ethnic groups, a focus on culture means respecting the family process, in which cultural patterns are executed (Friedemann 1995). Professionals are truly helpful if they allow themselves time to fully understand family situations.

## Limitations of the study and recommendations for further research

Studying ethnic group characteristics is a formidable task and the challenges of minority recruitment in research are well acknowledged by social science researchers (Segre et al. 2011). In spite of involving home health agencies serving a sizable Caribbean Black client population in recruitment, these caregivers did not volunteer to participate. Only by engaging the help of community liaisons and neighborhood services and by compromising randomness of the sample were we able to obtain enough participants. The chance of bias is therefore a possibility in spite of an adequate sample size for a comparative analysis.

Studying minority groups in an area like Miami-Dade constantly reminds researchers of tremendous within-group diversity that often makes results difficult to interpret. For example, since the sample size did not allow us to further break down the "other Hispanic" group, we could not determine whether there were cultural variations among immigrants from different countries or continents. These difficulties clearly show that future research of minorities needs to focus not simply on three or four racial/ethnic groups but demands an indepth look at cultures of immigrants from various geographic regions and educational/economic levels.

We suggest qualitative studies that illuminate the phenomenon of caregiving as part of acculturation and coping with an unfamiliar healthcare system. Still other studies ought to examine ways to overcome barriers to accessing community programs, perhaps by looking at the methods of neighborhoods and organizations that are successful at enrolling minorities in service programs. Results from these studies would lead to the next step of developing and offer culture-congruent interventions.

# Acknowledgments

This study was supported by Florida International University MBRS grant, SCORE Project NIHSO6GM08205, National Institutes of Health, National Institute of General Medical Sciences.

#### References

Adams CE, Horn K, Bader J. Hispanic access to hospice services in a predominantly Hispanic community. The American Journal of Hospice & Palliative Care. 2006; 22(1):9–16. [PubMed: 16450658]

Anderson JR, Turner WL. When caregivers are in need of care: African-American caregivers' preferences for their own later life care. Journal of Aging Studies. 2010; 24:65–73.

Angel JL, Angel RJ, Aranda MP, Miles TP. Can the family still cope? Social support and health as determinants of nursing home use in the older Mexican-origin population. Journal of Aging and Health. 2004; 16(3):338–354. [PubMed: 15155066]

Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. Journal of Clinical Nursing. 2009; 18:1379–1393. [PubMed: 18624779]

Calderón-Rosado V, Morrill A, Chang BH, Tennstedt S. Service utilization among disabled Puerto Rican elders and their caregivers: does acculturation play a role? Journal of Aging and Health. 2002; 14:3–23. [PubMed: 11892759]

- Casado BL, van Vulpen KS, Davis SL. Unmet needs for home and community-based services among frail older Americans and their caregivers. Journal of Aging and Health. 2011; 23:529–533. [PubMed: 21084723]
- Clark AN, Sander AM, Pappadis MR, Evans GL, Struchen MA, Chiou-Tan FY. Caregiver characteristics and their relationship to health service utilization in minority patients with first episode stroke. NeuroRehabilitation. 2010; 27:95–104. [PubMed: 20634604]
- Cooper C, Tandy AR, Balamurali TB, Livingston G. A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. The American Journal of Geriatric Psychiatry. 2010; 18(3):193–203. [PubMed: 20224516]
- Dilworth-Anderson P, Williams I, Gibson B. Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980–2000). The Gerontologist. 2002; 42(2):237–272. [PubMed: 11914467]
- Dilworth-Anderson P, Brummett BH, Goodwin P, Wallace Williams S, Williams RB, Siegler IC. Effect of race on cultural justifications for caregiving. Journal of Gerontology: Social Sciences. 2005; 60B:S257–S262.
- Drapalski AL, Marshall T, Seybolt D, Medoff D, Peer J, Leith J, et al. Unmet needs of families of adults with mental illness and preferences regarding family services. Psychiatric Services. 2008; 59:655–662. [PubMed: 18511586]
- Dunlop D, Manheim L, Song J, Chang R. Gender and ethnic/racial disparities in health care utilization among older adults. Journal of Gerontology: Social Sciences. 2002; 57B(3):S221–S233.
- Family Caregiver Alliance, National Center on Caregiving. Fact Sheet: Caregiver Health; 2006. http://www.caregiver.org/caregiver/jsp/print\_friendly.jsp?nodeid=1822
- Feld S, Dunkle RE, Schroepfer T. Race/ethnicity and marital status in IADL caregiver network. Research on Aging. 2004; 26:531–558.
- Folstein MF, Folstein SE, McHugh PR. Mini-mental state. Journal of Psychiatric Research. 1975; 12:189–198. [PubMed: 1202204]
- Fredman L, Cauley JA, Satterfield S, Simonsick E, Spencer SM, Ayonayon HN, et al. Caregiving, mortality, and mobility decline: the health, aging, and body composition (Health ABC) study. Archives of Internal Medicine. 2008; 168:2154–2162. [PubMed: 18955646]
- Friedemann ML. An instrument to evaluate effectiveness of family functioning. Western Journal of Nursing Research. 1991; 13(2):220–236. [PubMed: 2048313]
- Friedemann, ML. The framework of systemic organization: A conceptual approach to families and nursing. Thousand Oaks: Sage Publications, Inc; 1995.
- Hinojosa MS, Rittman M, Hinojosa R. Informal caregivers and racial/ethnic variation in health service use of stroke survivors. Journal of Rehabilitation Research and Development. 2009; 46(2):233–242. [PubMed: 19533537]
- Huang FY, Chung H, Kroenke K, Deluchi KL, Spitzer RL. Using the Patient Health Questionnaire-9 to measure depression among racially and ethnically diverse primary care patients. Journal of General Internal Medicine. 2006; 21:547–552. [PubMed: 16808734]
- Karlin NJ, Eguigure A, Torres A. Hispanic family members and caring for those with Alzheimer's Disease. Alzheimer's Care Today. 2009; 10(4):191–203.
- Kaufman AV, Kosberg JI, Leeper JD, Tang M. Social support, caregiver burden, and life satisfaction in a sample of rural African-American and White caregivers of older persons with dementia. Journal of Gerontological Social Work. 2010; 53:251–269. [PubMed: 20336572]
- Kosloski K, Schaefer JP, Allwardt D, Montgomery RJ, Karner TX. The role of cultural factors on clients' attitudes toward caregiving, perceptions of service delivery, and service utilization. Home Health Care Services Quarterly. 2002; 21(3/4):65–88. [PubMed: 12665072]
- Kutner J, Kilbourn KM, Costerano A, Lee CA, Nowels C, Vancura JL, et al. Support needs of informal hospice caregivers: a qualitative study. Journal of Palliative Medicine. 2009; 12:1101–1104. [PubMed: 19764830]

Mausbach BT, Coon DW, Depp C, Rabinowitz YG, Wilson-Arias E, Kraemer HC, et al. Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers. Journal of American Geriatrics Society. 2004; 52(7):1077–1084.

- Min JW, Barrio C. Cultural values and caregiver preference for Mexican-American and non-Latino White elders. Journal of Cross-Cultural Gerontology. 2009; 24:225–239. [PubMed: 19127418]
- Montgomery, RJ.; Borgotta, EF. Family Support Project. Final report to the Administration on Aging. Seattle, WA: University of Washington, Institute on Aging/Long-term Care Center; 1985.
- Montgomery RJ, Borgotta EF. The effects of alternative support strategies on family caregiving. The Gerontologist. 1989; 29:457–464. [PubMed: 2521103]
- Montgomery, RJ.; Kosloski, C. Executive summary: AOA further analysis and evaluation of the ADDGS project. Lawrence: Gerontology Center, University of Kansas; 2001.
- Montgomery RJ, Stull DE, Borgotta EF. Measurement and the analysis of burden. Research on Aging. 1985; 7:137–152. [PubMed: 4059631]
- Morano CL, King D. Religiosity as a mediator of caregiver well-being. Journal of Gerontological Social Work. 2005; 45(1–2):69–84. [PubMed: 16172063]
- Napoles AM, Chadiha L, Eversley R, Moreno J. Developing culturally sensitive dementia caregiver interventions: are we there yet? American Journal of Alzheimer's Disease and Other Dementias. 2010; 25(5):389–406.
- Navaie-Waliser M, Feldman PH, Gould DA, Levine C, Kuerbis AN, Doneland K. The experiences and challenges of informal caregivers. The Gerontologist. 2001; 41:733–741. [PubMed: 11723341]
- Nelson-Becker H. Religion and coping in older adults: a social work perspective. Journal of Gerontological Social Work. 2005; 45(1/2):51–67. [PubMed: 16172062]
- Pinquart M, Sorensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. The Gerontologist. 2005; 45(1):90–106. [PubMed: 15695420]
- Radina ME, Barber CE. Utilization of formal support services among Hispanic Americans caring for aging parents. Journal of Gerontological Social Work. 2004; 43(2–3):5–23.
- Reed PG. Religiousness among terminally ill and healthy adults. Research in Nursing & Health. 1986; 9:35–41. [PubMed: 3634417]
- Robinson KM, Buckwalter KC, Reed D. Predictors of use of services among dementia caregivers. Western Journal of Nursing Research. 2005; 27(2):126–140. [PubMed: 15695566]
- Roth DL, Haley WE, Wadley VG, Clay OJ, Howard G. Race and gender differences in perceived availability for community-dwelling middle-aged and older adults. The Gerontologist. 2007; 47:721–729. [PubMed: 18192626]
- Roth DL, Ackerman ML, Okonkwo OC, Burgio LD. The four-factor model of depressive symptoms in dementia caregivers: a structural equation model of ethnic differences. Psychological Aging. 2008; 23:567–576.
- Savundranayagam MY, Montgomery RJ. Impact of role discrepancies on caregiver burden among spouses. Research on Aging. 2010; 32(2):175–199.
- Savundranayagam MY, Montgomery RJ, Kosloski K. A dimensional analysis of caregiver burden amoung spouses and adult children. The Gerontologist. 2011; 51:321–331. [PubMed: 21135026]
- Scharlach AE, Kellam R, Ong N, Baskin A, Goldstein C, Fox PJ. Cultural attitudes and caregiver resource use: lessons from focus groups with racially and ethnically diverse family caregivers. Journal of Gerontological Social Work. 2006; 47(1/2):133–156. [PubMed: 16901881]
- Scharlach AE, Gustavson K, Dal Santo TS. Assistance received by employed caregivers and their care recipients: who helps care recipients when caregivers work full time? The Gerontologist. 2007; 47(6):752–762. [PubMed: 18192629]
- Scharlach AE, Giunta N, Chun-Chung Chow J, Lehning A. Racial and ethnic variations in caregiver service use. Journal of Aging and Health. 2008; 20(3):326–346. [PubMed: 18332187]
- Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: family caregiver burden and unmet needs. Neuro-Oncology. 2007; 10:61–72. [PubMed: 17993635]
- Segre LS, Buckwalter KC, Friedemann ML. Strategies to engage clinical staff in subject recruitment. Journal of Research in Nursing. 2011; 16:321–332. [PubMed: 21869904]

Siefert ML, Williams A, Dowd MF, Chappel-Aiken L, McCorkle R. The caregiver experience in a racially diverse sample of cancer family caregivers. Cancer Nursing. 2008; 31(5):399–407. [PubMed: 18772665]

- Sorensen S, Pinquart M. Racial and ethnic differences in the relationship of caregiver stressors, resources, and sociodemographic variables to caregiver depression and perceived physical health. Aging & Mental Health. 2005; 9(5):482–495. [PubMed: 16024408]
- U. S. Census Bureau. Summary Table: Projections of the Population by Selected Age Groups and Sex for the United States: 2010 to 2050. 2009. http://www.census.gov/population/www/projections/ summarytables.html

# Table 1

# Variables and concepts

Variable categories	Concept	Measures
Caregiver demographics	Context	Age
		Gender
		Relationship to patient
		Living/not living with patient
		Marital status
		Education
		Birth place- U.S./foreign born
		Family income
Care recipient demographics		Age
		Gender
Caregiver health	Health context	Physical health
		Depression
Care recipient health		Functioning (ADL/IADL)
		Cognitive status
Caregiver values/perceptions	Culture maintenance	Obligation
		Affection for patient
		Burden
		Agreement with role norm
	Culture transformation	Openness to accept helper
		Openness to let others do tasks
		Use of spirituality
Caregiver behaviors	Culture maintenance	Caregiver workload
	Culture transformation	Use of family help
		Use of services
Family functioning	Culture maintenance	Family stability
	Culture transformation	Family growth

Table 2

Summary of measurements

Concept	Measure	Instrument	# Items	Reliability
Health	CG physical health	Health Index (Montgomery and Borgotta 1985)	4	=.82 =.78 <sup>a</sup>
	CG depression	Patient Health Questionnaire (PHQ-9) (Huang et al. 2006)	9	=.7989
	CR functioning	ADL/IADL Scale (Montgomery and Borgotta 1985)	12	=.83 =.96 <sup>a</sup>
	CR cognitive status	Mini Mental Status Exam (Folstein et al. 1975)	30	=.5496 =.92 <sup>a</sup>
Culture maintenance	Family stability	Assessment of Strategies in Families (ASF-E) (Friedemann 1991)	12	=.78 =.83 <sup>a</sup>
	Obligation	Caregiver–Elder Relationship Scale (Montgomery and Borgotta 1985)	6	=.89 =.88 <sup>a</sup>
	Affection	Caregiver–Elder Relationship Scale (Montgomery and Borgotta 1985)	6	=.89 =.76 <sup>a</sup>
	CG Workload	Caregiving Task Instrument	8	=.82 <sup>a</sup>
	Agreement with role norm	Caregiving Task Instrument	8	
	CG burden	Subjective Burden Scale (Montgomery and Borgotta 1989)	10	=.7880
Culture transformation	Family growth	Assessment of Strategies in Families (Friedemann 1991)	8	=.72 =.62 <sup>a</sup>
	CG spritiuality	Spiritual Perspective Scale (SPS) (Reed 1986)	10	=.9295
	CG openness	Caregiving Task Instrument		
	- To accept helpers		# Helpers 8	=.9399 <sup>a</sup>
	- To accept help with tasks		# Tasks 8×10	
	Family help	Caregiving Task Instrument	Hrs. family help 8	=.82 <sup>a</sup>
	Services used	List of Community Services	#Services used 17	

Key

 $<sup>^{\</sup>it a}$  Pre-test in Miami Dade area;  $\it CG$  caregiver;  $\it CR$  care recipient

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Table 3

Caregiver demographic variables: frequencies by ethnic group

Variable	Category	White Non-Hisp. f (%)	Cuban f (%)	Other Hispanics f (%)	Black Non-Hisp. f (%)
Gender	Female	173 (75.5)	148 (80.0)	92 (85.2)	62 (84.9)
	Male	56 (24.5)	37 (20.0)	16 (14.8)	11 (15.1)
Relation to patient	Spouse	87 (38.0)	71 (38.4)	37 (34.3)	13 (17.8)
	Other family	142 (62.0)	114 (61.6)	71 (65.7)	60 (82.2)
Living with patient	Yes	194 (84.7)	159 (85.9)	99 (91.7)	67 (91.8)
	No	35 (15.3)	26 (14.1)	9 (8.3)	6 (8.2)
Marital status	Single	33 (14.4)	9 (4.9)	16 (14.8)	15 (20.5)
	Married	134 (58.5)	128 (69.1)	74 (68.5)	34 (46.6)
	Divorced/Sep.	52 (22.7)	33 (17.9)	13 (12.0)	18 (24.6)
	Widowed	10 (4.4)	15 (8.1)	5 (4.6)	6 (8.2)
Education	<high school<="" td=""><td>19 (8.3)</td><td>27 (14.6)</td><td>19 (17.6)</td><td>15 (20.5)</td></high>	19 (8.3)	27 (14.6)	19 (17.6)	15 (20.5)
	High School	67 (29.3)	37 (20.0)	15 (13.9)	12 (16.4)
	Some Post HS	60 (26.2)	66 (35.7)	44 (40.7)	27 (37.1)
	College Degree	83 (36.2)	55 (29.7)	30 (27.8)	19 (26.0)
Birth place	USA	197 (86.0)	9 (4.9)	10 (9.3)	6 (8.2)
	Foreign	32 (14.0)	176 (95.1)	98 (90.7)	67 (91.8)
Family income	<15,000	22 (9.6)	60 (32.5)	40 (37.0)	17 (23.1)
	15–24,999	32 (14.0)	30 (16.2)	10 (9.3)	11 (15.1)
	25-59,000	84 (36.7)	50 (27.0)	34 (31.4)	28 (38.2)
	+00009	74 (32.3)	38 (20.5)	18 (16.7)	14 (19.5)
	Missing	17 (7.4)	7 (3.8)	6 (5.6)	3 (4.1)

Table 4

Caregiver (CG) and Patient (P) demographic and health variables: descriptives by ethnic group

Variable	White Non-Hisp. Mean (STD) range	Cuban Mean (STD) range	Other Hispanics Mean (STD) range	Black Non-Hisp. Mean (STD) range
# Persons/Hhold	1.63 (1.13) 0-7	1.94 (1.33) 0-7	2.38 (1.59) 0-8	2.63 (1.53) 0-7
CG age	64 (14.82) 20–98	63 (13.34) 22–89	57 (14.59) 19–85	53 (13.48) 27–85
CG health	2.47 (.83) 1-4.75	2.45 (.71) 1-4.50	2.49 (.90) 1-4.75	2.32 (.84) 1-4.00
CG depression	4.79 (4.35) 0-20	6.38 (5.41) 0–19	4.89 (4.05) 0–15	3.54 (3.58) 0-13
CR age	82 (8.27) 65–102	80 (8.51) 65–103	78 (8.16) 65–98	78 (9.00) 65–101
CR ADL/IADL	1.88 (.52) 1–3	1.67 (.54) 1–3	1.82 (.59) 1–3	1.83 (.60) 1–2.75
CR cognitive status	19 (10.73) 0-32	16 (11.33) 0–30	17 (11.62) 0–30	14 (11.49) 0-30

Table 5
Culture maintenance variables: descriptives by ethnic group

Variable	White Non-Hisp. Mean (STD) range	Cuban Mean (STD) range	Other Hispanics Mean (STD) range	Black Non-Hisp. Mean (STD) range
Family stability	2.53 (.35) 1.33–3	2.62 (.35) 1–3	2.57 (.34) 1.33–3	2.48 (.36) 1.45–3
Obligation	3.76 (.45) 1.83-4	3.88 (.32) 1–4	3.73 (.56) 1.17-4	3.84 (.35) 2.17–4
CG work load	5.71 (5.59) 1–33.50	9.94 (8.53) 1–29.88	7.96 (8.37) 1–28.44	5.40 (5.80) 1–26.00
CG agreement with role norm	3.67 (.41) 2.25-4	3.69 (.43) 1.75-4	3.66 (.45) 2-4	3.77 (.42) 1.64-4
CG burden	2.84 (1.08) 1-5	2.46 (1.05) 1-4.88	2.65 (1.01) 1-5	2.52 (1.00) 1-4.25
CG affection	3.85(.37) 1–4	3.92(.25) 2-4	3.92(.25) 2.60-4	3.89(.28) 2.40-4

 Table 6

 Culture transformation variables: descriptives by ethnic group

Variable	White Non-Hisp. Mean (STD) range	Cuban Mean (STD) range	Other Hispanics Mean (STD) range	Black Non-Hisp. Mean (STD) range			
Family growth	2.65 (.28) 1.63-3.00	2.58 (.26) 1.88–3	2.55 (.26) 1.75–3	2.50 (.29) 1.75–3			
Spirituality	3.67 (1.36) 0-5.00	3.98 (1.09) 0-5.00	4.34 (.75) 1.40–5	4.53 (.60) 2-5			
Openness to accept help							
# Tasks	1.63 (1.92) 0-8	1.39 (1.85) 0-8	1.35 (1.94) 0-7	1.70 (1.89) 0-7			
# Helpers	5.29 (6.20) 0-10	5.25 (3.64) 0-10	6.02 (3.61) 0-10	7.77 (2.95) 0–10			
Family help in hours	0.60 (1.11) 0-5.81	0.68 (1.34) 0-7.41	0.63 (1.46) 0-7.13	0.37 (0.63) 0-3.50			
# Services used	1.55 (2.42) 0-9	1.12 (2.02) 0-7.75	0.86 (1.86) 0-8.25	1.24 (2.06) 0-7.75			