

COMPARING DEMENTIA CAREGIVERS AND  
HEALTHY CONTROLS IN MENTAL HEALTH  
AND HEALTH RELATED QUALITY OF LIFE  
IN CALI, COLOMBIA

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Estudio sobre la salud mental y la calidad de  
vida de un grupo de cuidadores de personas con  
demencia y un grupo control en Cali, Colombia

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*Abstract*

Dementia caregivers are at risk for stress, depression, and a multitude of negative health outcomes, yet little research has examined the extent of these issues in caregivers from Latin America. The purpose of this study was to compare the mental health and health-related quality of life (HRQOL) of dementia caregivers to healthy controls in Cali, Colombia. Ninety dementia caregivers and 51 healthy controls completed measures of depression, satisfaction with life, stress, and HRQOL. Although it was hypothesized that dementia caregivers would report lower levels of mental health and HRQOL than controls, caregivers only reported higher depression levels. This finding suggests that dementia caregivers in this region, even when they have access to health care, are in need of mental health services and other caregiving resources. Such interventions would likely improve the mental health of caregivers and quality of care that caregivers are able to provide for individuals facing dementia.

**Palabras clave:** Dementia caregivers; mental health; health related quality of life; Latin America.

*Resumen*

A pesar de que los cuidadores de personas con demencia están en riesgo de sufrir estrés, depresión y múltiples consecuencias negativas para la salud, en América Latina se han realizado pocos estudios que hayan investigado el alcance de estos problemas. El propósito de este estudio fue comparar la salud mental y la calidad de vida relacionada con la salud (CVRS) de un grupo de cuidadores de personas con demencia con un grupo de personas sanas de Cali (Colombia). Noventa cuidadores de personas con demencia y 51 personas sanas completaron una serie de cuestionarios que medía depresión, satisfacción con la vida, estrés y CVRS. A pesar de que se planteó la hipótesis de que los cuidadores de personas con demencia obtendrían niveles más bajos de salud mental y CVRS en comparación con el grupo de personas sanas, los cuidadores sólo reportaron mayores índices de depresión. Estos resultados sugieren que los cuidadores de demencia de esta región, a pesar tener acceso a los servicios de salud, necesitan servicios de salud mental y otros recursos de cuidado. Este tipo de ayudas e intervenciones probablemente ayudarían a mejorar su salud mental y la calidad de cuidado que pueden ofrecer a las personas que sufren demencia.

**Keywords:** Cuidadores de personas con demencia, salud mental, calidad de vida relacionada con la salud, América Latina.

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## INTRODUCTION

### Epidemiology of Dementia

The World Health Organization estimates that 18 million people worldwide have been diagnosed with Alzheimer's disease, the most common cause of dementia (World Health Organization, 2012). The prevalence is projected to nearly double to 34 million people by the year 2025 (World Health Organization, 2012). Much of this increase will occur in developing countries, and is due to population aging. Currently, more than 50% of people with dementia live in developing countries, and by the year 2025, this prevalence will be over 70% (World Health Organization, 2012). An estimated 5.4 million people in the United States alone experience Alzheimer's disease (AD; Alzheimer's Association, 2012). This includes one in eight people age 65 and older and nearly half of people age 85 and older (Alzheimer's Association, 2012). AD ranks sixth among the ten-leading causes of death in the United States and is the only one of these ten causes that cannot be prevented, cured, or slowed (Alzheimer's Association, 2012).

Due to demographic changes in many Latin American countries, a significant increase in the representation of elderly individuals is occurring in the population (Nitrini et al., 2009). An increase of the prevalence of chronic medical conditions, including dementia, has been a natural consequence of this demographic trend when coupled with low socioeconomic and educational levels in comparison to many other global regions (Nitrini et al., 2009). In a study of the prevalence of dementia in Latin America, AD was the most frequent cause of dementia, ranging from 49.9% in Maracaibo, Venezuela, to 84.5% in Concepcion, Chile (Nitrini et al., 2009). The prevalence of dementia in individuals aged 65-69 was significantly higher than the prevalence in developed countries (Nitrini et al., 2009). Conversely, the prevalence of dementia in the oldest adults was lower than in the developed world, which may be due to higher mortality from dementia (Nitrini et al, 2009). However, wide ranges of dementia rates have been reported in Latin America, making it difficult to know exact prevalence rates for specific countries.

## Symptoms of Dementia and Caregiving Responsibilities

Dementia is a syndrome caused by disease of the brain (World Health Organization, 2012). It often involves impairments in memory, judgment, and abstract thinking (Serrano-Aguilar et al., 2006), and when caused by AD, it eventually impairs an individual's ability to carry out basic bodily functions, such as walking and swallowing, ultimately causing death (Alzheimer's Association, 2012). The symptoms of dementia are classified into three categories (World Health Organization, 2012). The early stage involves forgetfulness, difficulty finding words, becoming lost in familiar places, losing track of time, difficulty making decisions, and changes in mood and behavior. The middle stage involves becoming very forgetful, especially of recent events and people's names, difficulty comprehending time, difficulty with communication (speech and comprehension), needing help with personal care, inability to live at home safely without considerable support, and significant behavior changes such as wandering, repeated questioning, hallucinations, disinhibition, and aggression. Symptoms of the late stage include unawareness of place and time, inability to recognize relatives and friends, inability to eat without assistance, trouble swallowing, bladder and bowel incontinence, change in mobility, and aggression toward caregivers. This last stage is characterized by nearly total dependence and inactivity (World Health Organization, 2012).

Because of these impairments, dementia caregivers often spend many physically and emotionally demanding hours providing care. In Latin America and the Caribbean specifically, caregivers spend a median of 6 hours per day with the person with dementia which is higher than the 3-4 hours per day provided by caregivers in Asia (The 10/66 Dementia Research Group, 2004). These hours are filled with caregiving tasks that may include assisting with personal care, toileting, feeding, household maintenance, shopping, transportation, financial management, and emotional support (Dupuis, Epp, & Smale, 2004). Caregivers must also supervise prescribed treatment, evaluate changes in the person with dementia, and provide structure to the person's daily routine (Dupuis, Epp, & Smale, 2004). Caregiving tasks are numerous and varied, and at later stages, require constant vigilance by the caregiver (World Health Organization, 2012).

## **Dementia Caregiver Physical and Mental Health**

The challenging effects of dementia begin with the patient and extend to the primary caregiver, family, and friends (Henderson, Alexander, & Mayka, 1989). The majority of dementia caregivers are family members (70%), making dementia known as a “family disease” (Zucchella et al., 2012). Due to the nature of dementia, caregiver burden becomes more pronounced as symptoms increase, and caregiving has been associated with chronic fatigue, anger, depression, and increased mental health problems (Cox & Monk, 1990). Over time, the manifestations of dementia can lower the health related quality of life (HRQOL) of caregivers. HRQOL is multidimensional and includes domains related to physical, mental, emotional, and social functioning (Healthy People, 2010). Certain factors related to caregiving, such as behavioral problems of individuals with dementia can lower a caregiver’s overall quality of life (Vellone et al., 2012), which is associated with increased depression and anxiety, both of which can reduce HRQOL (Serrano-Aguilar et al., 2006).

Research suggests that caregivers are at risk for a multitude of poor physical health outcomes such as cardiovascular disease, decreased immune and metabolic function, and diverse physiological symptoms (Roepke et al., 2010). One study found that caregivers experience higher allostatic load (the cumulative damage that multiple physiological systems endure over time while adapting to stressors) than non-caregivers, indicating that allostatic load may represent a way that caregiving stress is related to poor health outcomes (Roepke et al., 2010). Caregivers with high depression and burden may be less able to handle stressors and thus experience worse physical outcomes (Roepke et al., 2010). And notably, Serrano-Aguilar and colleagues (2006) compared the HRQOL of dementia caregivers to that of controls using the EuroQol-5D (EQ 5D), finding that caregivers had a higher frequency of problems for each EQ-5D dimension (mobility, personal care, daily activities, pain, discomfort, and anxiety/depression). The authors noted the largest differences in the dimensions of pain/discomfort and anxiety/depression, with 66.7% and 78.5% of caregivers reporting problems in these dimensions, respectively (Serrano-Aguilar et al., 2006).

In terms of mental health, dementia caregivers typically experience significantly higher levels of psychological morbidity, depression, and stress than their non-caregiver counterparts (Mahoney et al., 2005). In a meta-analysis, Pinquart and Sörensen (2003) found that caregivers of older adults experience more stress and depression, and have lower levels of subjective well-being, physical health, and self-efficacy than non-caregivers. Differences between caregivers and non-caregivers were larger in studies of dementia caregivers than in studies with a combination of caregivers for older adults with and without dementia, suggesting that caring for an individual with dementia is especially stressful (Pinquart & Sörensen, 2003). Dementia family caregivers in particular have been shown to experience social, emotional, physical, and financial problems, which become more pronounced as the disease progresses (Serrano-Aguilar et al., 2006), as well as loneliness and depression (Beeson, 2003). Mahoney and colleagues (2005) found that nearly a quarter of dementia caregivers screened positive for anxiety, and 10% screened positive for depression. Caregiver anxiety and depression have been linked to greater cognitive impairment in the individual with dementia (Aguglia et al., 2004), and many factors have been linked to decreased caregiver quality of life, including strained finances, poor family functioning, difficult patient behavior, and the amount of time spent caring for family members with dementia (Vellone, Piras, Talucci, & Cohen, 2007).

### **Culture and Caregiving**

Latino caregivers have been shown to have a number of cultural characteristics that influence the ways in which they provide care, such as strong filial responsibility beliefs and traditional caregiving ideologies (Pinquart & Sörensen, 2005). The term *familismo* (familism) is a cultural value held among many Latinos and embodies feelings of loyalty, reciprocity, and solidarity among family members (Arevalo-Flechas, 2008). The familism and collectivism in Latino cultures often surface through a tendency to place significant value on the well-being of the group and to support sick family members both in the nuclear and extended family (Delgado & Tennstedt, 1977; Sánchez-Ayendez, 1998; Villarreal, Blozis, & Widaman, 2005; Zea, Quezada, & Belgrace, 1994; Zsembik & Bonilla, 2000). These values may also surface in the cultural unacceptability of nursing home placement (Pinquart & Sörensen, 2005) and in the high

status and respect that older adults garner within Latino families (Cox & Monk, 1990). Additionally, Latino caregivers are more likely to perceive positive aspects of caregiving such as pride in fulfilling filial or spousal responsibilities, enhanced closeness with the care recipient, and satisfaction with one's competence as a caregiver (Pinquart & Sörensen, 2005).

In the context of mental and physical health, Latino caregivers have been shown to be more depressed than their White non-Latino counterparts (Covinsky et al., 2003; Mintzer et al., 1992; Pinquart & Sörensen, 2005), and in a study specifically of Latino dementia caregivers, participants' average depression scores exceeded the clinical cutoff for depression (Cox & Monk, 1990). With respect to HRQOL, a study by Arango-Lasprilla et al. (2010) found that dementia caregivers in Colombia had higher scores than controls on all eight dimensions of the Short Form-36, a measure of HRQOL, including physical function, role physical, role emotional, vitality, mental health, social function, bodily pain, and general health. The authors suggested that these findings may be due to Latino caregivers often having the mindset that their own personal and physical comfort comes second to the care-recipient's needs (Arango-Lasprilla et al., 2010). Thus, Latino caregivers may put off such things as medical care for themselves until the need becomes desperate (Arango-Lasprilla et al., 2010).

Latino caregivers have been found to be exposed to more stressors than White caregivers (Pinquart & Sörensen, 2005). For example, due to culture-specific beliefs, many Latino caregivers are concerned that their community will perceive the unusual behavior of individuals with dementia as representative of "craziness in the family" (Henderson, Alexander, & Mayka, 1989). In some areas of Latin America, mental illness is still perceived as a condition akin to "mal de sangre" or "bad blood" (Henderson, Alexander, & Mayka, 1989), garnering significant levels of stigma. Other stressors faced by Latino caregivers may include elevated patient deficits in comparison to other racial/ethnic groups, including cognitive, behavioral, and physical impairments (Pinquart & Sörensen, 2005). Latino caregivers also tend to provide more hours of care and use less formal support than White caregivers, perhaps because caring for an older family member is considered more normal for Latino than White caregivers (Pinquart & Sörensen, 2005). Also, the double-



jeopardy hypothesis postulates that caregivers from communities with few financial resources may experience higher levels of stressors and therefore be at greater risk for poor health (Carreon & Noymer, 2011).

### **The current study**

Although the research literature has identified unique cultural features of caregiving in Latino populations as well as documented the aging demographic shifts in Latin America, very little research has examined the mental and physical health of dementia caregivers in this global region; the research that has (e.g., Arango-Lasprilla et al., 2010), has focused primarily on physical health. As a result, the purpose of this study is to compare the mental health (depression, satisfaction with life, and stress) and HRQOL (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, mental health, and role-emotional) between dementia caregivers and healthy controls from Cali, Colombia.

## **METHOD**

### **Participants**

This study recruited 90 family caregivers for persons with dementia and 51 non-caregiving controls. Of the caregiver participants, 82 were caregivers for individuals with Alzheimer's dementia, 4 for individuals with vascular dementia, 2 for individuals with Parkinson's disease with dementia, and 2 for individuals with mixed dementia. Inclusion/exclusion criteria were that the caregiver (a) had to be related to the care-recipient, (b) had to be the primary caregiver, (c) had been providing for at least 3 months, (d) was informed about the patient's family and medical history, and (e) had no history of neurological and psychiatric disorders or learning disabilities. Control participants (a) could not be currently providing informal care for an individual with a disability, and (b) had no history of neurological and psychiatric disorders or learning disabilities. Caregivers participating in existing psycho-educational workshops at Alzheimer Foundation of Cali, Colombia were recruited, between February 2011 and June 2012, and control participants were recruited from the same community using flyers and word of mouth via family and friends of individuals at the Foundation.



The sample of 90 caregivers was made up of mostly females (64.4%) with an average age of 54.12 ( $SD = 11.50$ ) and 15.18 ( $SD = 4.69$ ) years of education. Most of the individuals in the sample were siblings of the care-recipient (60%), while 22.2% were children, 15.6% were spouses, and 2.2% were a live-in romantic partner. The majority of caregivers were married (30%) or single (30%). In addition, 18.9% were divorced, 12.2% were widowed, 4.4% were in a common law marriage, and 4.4% were separated. The majority of the caregivers in the sample made over five times the minimum wage (45.6%), 23.3% made between four and five times the minimum wage, 20.0% made between two and three times the minimum wage, 7.8% made between one and two times the minimum wage and 3.3% made less than minimum wage. Caregivers had been a caregiver for an average of 43.91 months ( $SD = 38.24$ ) and spent 63.84 ( $SD = 27.67$ ) hours per week providing care.

The sample of 51 controls was made up of mostly females (58.8%) with an average age of 55.82 ( $SD = 13.41$ ) and 14.20 ( $SD = 4.45$ ) years of education. In addition, 47.0% were married, 9.8% were divorced, 7.8% were widowed, 5.9% were in a common law marriage, and 2.0% were separated. Of the controls, 5.9% made less than minimum wage, 15.7% made between 1 and 2 times minimum wage, 15.7% made between 1 and 2 times minimum wage, 33.3% made between 2 and 3 times minimum wage, 33.3% made between 3 and 4 times minimum wage, and 11.8% made over 5 times minimum wage.

## Measures

**Satisfaction with Life Scale (SWLS).** A Spanish version of the SWLS (Pavot & Diener, 1993) was used to measure global life satisfaction. This self-report scale contains 5 items, and response options range from 1 (strongly disagree) to 7 (strongly agree). Higher total scores represent higher life satisfaction, and the Spanish version has been shown to have strong psychometric properties (Atienza, Pons, Balaguer, & Garcia-Merita, 2000).

**Patient Health Questionnaire-9 (PHQ-9).** The PHQ-9 (Kroenke, Spitzer, & Williams, 2001) is a nine-item self-report measure of depression. Participants indicate how often each item has bothered them in the past two weeks on a scale of 0 (not at all) to 3 (nearly every day). Total

scores range from 0 to 27, and higher scores indicate more depressive symptoms. The Spanish version of the scale (Wulsin, Somoza, & Heck, 2002) has been demonstrated as reliable and valid in Spanish speakers (Diez-Quevado, Rangil, Sanchez-Planell, Kroenke, & Spitzer, 2001; Donlan & Lee, 2010).

**Perceived Stress Scale (PSS).** The PSS (Cohen, Kamarck, & Mermelstein, 1983) is a 14-item self-report measure of the degree to which situations in one's life are stressful. The items on the scale ask about the thoughts and feelings of the participant during the past month. Participants rate the items using a 5-point response scale ranging from 0 (Never) to 4 (always). The PSS has been demonstrated as reliable and valid (Cohen, Kamarck, & Mermelstein, 1983).

**Short Form-36 (SF-36).** The SF-36 (Ware & Sherbourne, 1992) is a self-report questionnaire used to assess health related quality of life (HRQOL). This instrument consists of 36 items on eight different health dimensions: physical functioning, role-physical (role limitations due to physical problems), bodily pain, general health, vitality, social functioning, mental health, and role-emotional (role limitations due to emotional problems). Subscale scores range from 0 to 100, with higher scores representing higher HRQOL. The Spanish version of the SF-36 has been established as reliable and valid (Alonso, Prieto, & Anto, 1995).

## Procedure

All participants were scheduled for a 1.5- to 2-hour meeting with a psychologist during which demographic information was collected before the above questionnaires were administered. The study was reviewed and approved by the Institutional Review Board of the Alzheimer Foundation of Cali. This IRB does not produce protocol numbers. All participants received an explanation of the study and signed an informed consent form.

## Analyses

In order to determine whether the data were normally distributed, normality tests were run on the eight subscales of the SF-36, as well as on the PHQ-9, SWLS, and the PSS. Critical ratios of 2.0 were used to identify

variables that were skewed or kurtotic. If a variable was significantly skewed or kurtotic, square root transformations were used to normalize participants' scores on that variable.

In order to determine whether caregivers and controls differ on demographic variables, a series of analyses of variance (ANOVAs) and chi-square tests were run with participant group (caregiver vs. control) as the independent variable. The demographic of interest was the dependent variable in each analysis. ANOVAs were used for continuous variables such as education level, socioeconomic status, and age. Chi-squares were used for gender and relationship status (with partnered = 1 and not partnered = 0). All demographic variables on which there were significant differences between caregivers and controls were entered into the following analyses as covariates in order to control for these differences.

The first principal analysis was a multivariate analysis of covariance (MANCOVA) in which the independent variable was participant group and the dependent variables were the three mental health variables: depression, satisfaction with life, and stress. The covariates were any demographic variables found to differ between caregivers and controls. If an overall omnibus effect of participant group was found, follow-up analyses of covariance (ANCOVAs) were run to identify the precise location of effects, again controlling for any demographic differences. These follow-up ANCOVAs included participant group as the independent variable and each of the three mental health variables as the dependent variable.

The second principal analysis was a MANCOVA in which the independent variable was participant group and the dependent variables were the eight subscales of the SF-36. Again, if an overall omnibus effect of participant group were found, follow-up ANCOVAs were run to identify the precise location of effects in which the independent variable was participant group and the dependent variable was each of the eight SF-36 subscales.

## RESULTS

### Normality assumptions

Normality assumptions were checked prior to running the principal analyses. Assumptions were met for the Vitality, Mental Health, and General Health subscales of the Short Form-36 (SF-36), as well as the Perceived Stress Scale (PSS) and Satisfaction with Life Scale (SWLS). The Patient Health Questionnaire-9 (PHQ-9) was non-normal, with skewness of 1.98 and kurtosis of 4.55, and the following SF-36 subscales were also non-normal: Physical Functioning had skewness of -2.51 and kurtosis of 6.81, Role-Physical had skewness of -2.28 and kurtosis of 4.40, Role-Emotional had skewness of -2.01 and kurtosis of 2.73, Pain had a skewness of -1.61 and kurtosis of 2.47, and Social Functioning had a skewness of -1.62 and kurtosis of 2.41. Depression was transformed with a square root transformation, and the negatively skewed variables were reflected and transformed using a square root transformation, which adjusted the skewness appropriately.

### Demographic differences between caregivers and controls

ANOVAs were conducted to determine whether caregivers and controls differed significantly on education, income, and age. There were no significant differences between caregivers and controls in education,  $F(1, 139) = 1.48, p = .226$ , or in age,  $F(1, 139) = .63, p = .428$ . However, caregivers reported higher levels of income ( $M = 4.00, SD = 1.13$ ) than controls ( $M = 3.29, SD = 1.06$ ),  $F(1, 139) = 13.22, p < .001$ .

Chi-squares were conducted to determine if caregivers and controls differed in gender and relationship status. There was no significant difference in gender,  $\chi^2(1, N=141) = .44, p = .508$ . However, there was a significant difference between caregivers and controls in relationship status,  $\chi^2(1, N=141) = 4.60, p = .032$ , such that a lower percentage of caregivers were partnered (34.4%) than controls (52.9%). Because significant differences between caregivers and controls emerged for income and relationship status, these two variables were entered as covariates in all of the following analyses.

## Differences between Caregivers and Controls in Mental Health and HRQOL

For the mental health variables entered as dependent variables into the first MANCOVA, a statistically non-significant *Bax-M* test for homogeneity of the variance-covariance matrices across design cells,  $Bax-M = 5.67$ ,  $F(6, 72512.60) = .92$ ,  $p = .479$ , with three non-significant Levene's tests (all  $ps > .268$ ) provided multivariate and univariate support for the homogeneity of variance assumption, suggesting that a more liberal estimate of the  $F$ -statistic should be used, such as Wilk's lambda. The overall omnibus MANCOVA revealed a statistically significant effect for participant status (caregiver vs. control), Wilk's lambda = .889,  $F(3, 132) = 5.50$ ,  $p < .002$ ,  $\eta^2 = .111$ . As a result, three follow-up univariate analyses of covariance (ANCOVAs), again controlling for demographic differences, were run to identify the location of the significant differences between caregivers and controls on the mental health variables. In each of these ANCOVAs, the independent variable was participant status (caregiver vs. control), and the dependent variables were each of the three mental health scores in the omnibus MANCOVA. The results of these ANCOVAs appear in Table 1. Caregivers had higher covariate-adjusted depression scores than controls (Figure 1).

For the HRQOL variables entered as dependent variables into the second MANCOVA, a statistically significant *Bax-M* test for homogeneity of the variance-covariance matrices across design cells,  $Bax-M = 94.93$ ,  $F(36, 37658.48) = 2.46$ ,  $p < .001$ , with eight non-significant Levene's tests (all  $ps > .111$ ) generally provided multivariate and univariate support for the homogeneity of variance assumption, suggesting that a more liberal estimate of the  $F$ -statistic should be used, such as Wilk's lambda. The overall omnibus MANCOVA did not reveal a statistically significant effect for participant status (caregiver vs. control), Wilk's lambda = .907,  $F(8, 128) = 1.65$ ,  $p = .117$ ,  $\eta^2 = 0.93$ . As a result, no follow-up tests were conducted.

**Table 1.**  
Means and standard deviations of mental health  
scores for caregivers and controls

Variables	Caregivers	Controls	F-statistic	p-value	Partial $\eta^2$
Depression	4.41 (4.96)	2.71 (2.69)	5.44	.021	.04
Stress	9.03 (7.38)	11.35 (5.81)	.55	.460	.00
Satisfaction with life	26.98 (6.52)	26.69 (5.45)	.62	.431	.01

**Note.** Partial  $\eta^2$  effect size: .01 = small, .10 = medium, .15 = large; *p*-values are two-tailed. Unadjusted means and standard deviations are presented above. Although, the *F*, *p*, and partial  $\eta^2$  are based on the covariate adjusted means.

### Exploratory analyses

In order to determine whether number of months as a caregiver and number of hours per week spent caregiving were associated with caregiver HRQOL and mental health, a series of bivariate correlations were conducted. The only statistically significant correlation was between months spent caregiving and caregiver social functioning,  $r = -.23$ ,  $p = .029$ , such that participants who had spent more months as a caregiver reported lower social functioning.

### DISCUSSION

The purpose of this study was to compare mental health and health related quality of life (HRQOL) between dementia caregivers and controls from Cali, Colombia. Although it was hypothesized that dementia caregivers would report lower levels of mental health and HRQOL than controls, caregivers only reported higher depression levels, but not stress, satisfaction with life, or HRQOL. Differences in depression were present even after controlling for differences between the two groups in income and relationship status.

### Normality assumptions

Although the majority of scales used in the study had normally distributed data, several did not, which could have contributed to the non-significant findings. The non-normal data were transformed using

a square-root transformation, but the resulting distributions were still fairly skewed. The PHQ-9 was non-normal, as well as the following SF-36 subscales: Physical Functioning, Role Physical, Role Emotional, Pain, and Social Functioning. Generally, participants' scores clustered at the high end of the SF-36, suggesting a ceiling effect such that the vast majority of participants, both caregivers and controls, had very high HRQOL. The distribution of the SWLS similarly had moderate left skew, although it did not reach the 2.0 cutoff for requiring its transformation. So a similar ceiling effect may have emerged on that measure. Skewness on both of these scales could have eclipsed true differences between groups on the constructs, although skew cannot solely account for this lack of differences, as differences did emerge on the PHQ-9, which also had moderate skew, even after transformation. Additionally, the PSS had a more normal distribution, yet no significant differences emerged.

### **Demographic Differences between Caregivers and Controls**

Caregivers were generally matched to controls, although caregivers reported higher income levels such that the percentage of caregivers who earned over five times the minimum wage was about four times higher than the percentage of controls who earned over five times the minimum wage. It is unlikely that the income level of caregivers in this study reflects the income level of the larger community. Another study of HRQOL of caregivers in Cali, Colombia, found that the majority of caregivers were on the lower end of the socioeconomic spectrum (Arango-Lasprilla et al., 2010). One potential source of the income difference in this study is that in Colombia, caregiving resources are scarce and typically reserved for caregivers with greater resources who are better able to access care. Because this sample of caregivers was recruited from a facility providing resources to dementia caregivers, the sample may have had a generally higher income because they had access to this facility. Access to this facility may be nested with access to other resources to help alleviate the burden of caregiving, and this possibility may have played a role in some of the lack of differences in mental health and HRQOL between caregivers and controls. Additionally, because of the higher income in this sample, caregivers may have had extra help at home, like paid caregivers or maids, which could reduce burden.



Caregivers were also less likely to be in a romantic relationship than controls. The fact that most of the caregivers were siblings or children of the care recipient perhaps indicates that children or siblings may have been the ones within their family who were more available (i.e., not in a romantic relationship) to take on the time-consuming role of caregiving, thus may have had less competing roles to negotiate. This finding could suggest that the current sample of caregivers had more time to spend caregiving, which may fulfill a sense of familial responsibility to older adults and traditional caregiving ideologies prevalent in Latino cultures (Delgado & Tennstedt, 1977; Sánchez-Ayendez, 1998; Villarreal, Blozis, & Widamen, 2005; Zea, Quezada, & Belgrace, 1994; Zsembik & Bonilla, 2000), reducing negative effects of caregiving duties. This interpretation may garner support from the finding in the current study that generally, hours per week spent caregiving and length of time being a caregiver were not associated with mental health or HRQOL variables, except for social functioning. Perhaps because of these distinct cultural values, caregiving may not have been as much of a burden on caregivers from this sample in comparison to previous studies from other less-collectivistic global regions.

### **Mental Health and Health Related Quality of Life**

Caregivers reported higher levels of depression than controls, a small-sized effect. This finding is consistent with previous literature identifying that dementia caregivers experience higher depression than non-caregivers, which is especially true in some Latino populations in the United States (Covinsky et al., 2003; Cox & Monk, 1990; Mintzer et al., 1992; Pinquart & Sörensen, 2005). This finding from the current study is novel in that it is the first documentation of higher depression levels in dementia caregivers from Latin America in comparison to controls. Despite the meaning derived from taking care of a family member with dementia in many Latino cultures (Delgado & Tennstedt, 1977; Sánchez-Ayendez, 1998; Villarreal, Blozis, & Widamen, 2005), the process of caregiving likely resulted in higher depression among caregivers in this study. A reason for the depression finding in the absence of other significant mental health or HRQOL findings may be due to the general societal perception of depression in Latin America. A review by Peluso and Blay

(2004) suggested that depression is not often seen as a mental illness in Latin America, perhaps making it less likely that caregivers would seek depression treatment from health care providers. Additionally, mental health issues often garner substantial levels of stigma in Latino cultures (Henderson, Alexander, & Mayka, 1989), perhaps making it less likely that caregivers in this study would seek depression treatment, even if they had access to it and realized they were depressed. Because of this mental health stigma, caregivers may have been willing to take care of their physical health problems, but not their mental health.

The finding that there was no difference in stress between caregivers and controls was inconsistent with previous literature. At least in comparison to White caregivers, Latino caregivers have been found to be exposed to more stressors such as elevated patient deficits including cognitive, behavioral, and physical impairments and as a result, experience high levels of stress (Pinquart & Sörensen, 2005). Perhaps the current findings are inconsistent with Pinquart and Sörensen's (2005) study because the caregivers in this study had access to health care and more financial resources than controls, and therefore likely had more resources than some other Latino caregiver populations studied in previous research (e.g., Arango-Lasprilla et al., 2010). Research on the double-jeopardy hypothesis suggests that individuals from communities with fewer financial resources may experience higher levels of stressors (Carreon & Noymer, 2011), but because this sample of caregivers was well-resourced in terms of finances and health care, they may have been exposed to fewer stressors than controls or than other caregiving populations, and therefore did not experience elevated stress levels.

Similarly, no differences emerged between caregivers and controls in satisfaction with life, a finding that may have been due to the fact that Latino caregivers are more likely to perceive positive aspects of caregiving such as pride in fulfilling filial or spousal responsibilities, enhanced closeness with the care recipient, and satisfaction with one's competence as a caregiver (Pinquart & Sörensen, 2005). The cultural value of familism held among many Latinos encompasses values such as loyalty, reciprocity, and solidarity among family members (Arevalo-Flechas, 2008). A natural consequence of this familism is the tendency

to value the well-being of not just the individual but the group. This tendency is evident in the support of sick family members in both the nuclear and extended family as well as in the high status and respect older adults garner within Latino families (Cox & Monk, 1990, Delgado & Tennstedt, 1977; Sánchez-Ayendez, 1998; Villarreal, Blozis, & Widamen, 2005; Zea, Quezada, & Belgrace, 1994; Zsembik & Bonilla, 2000). Thus, it is possible that caregivers experienced no lower satisfaction with life than non-caregivers because they perceived caregiving as a mechanism through which they could embody the cultural value of familism.

There were no differences between caregivers and controls on the eight dimensions of the SF-36 used to measure HRQOL. This finding is inconsistent with previous literature documenting that dementia caregivers in Colombia had higher scores than controls on all eight dimensions of the SF-36 (Arango-Lasprilla et al., 2010). This inconsistency may again be due to the fact that this particular sample of caregivers had greater access to health services through the Alzheimer Foundation where they had been recruited to participate, which buffered the HRQOL effects found in previous studies.

### **Exploratory Analyses**

A series of correlations were run to examine whether number of months as a caregiver and number of hours per week spent caregiving were associated with caregiver mental health and HRQOL. The only statistically significant correlation was between months spent caregiving and caregiver social functioning, such that participants who had been a caregiver for a longer period of time experienced lower social functioning. Caregivers who spent more time caregiving could have had less time to engage in their own social activities and thus had lower social functioning. The lack of associations between these two caregiving variables and caregiver mental health and HRQOL is different from previous research, which has found that caregivers who spend more than 20 hours per week caregiving are at risk for compromised health (Taylor, Ford, & Dunbar, 1995). This lack of associations may be due to the previously mentioned high levels of resources that caregivers in this sample likely had.

### **Implications for Interventions**

Developing interventions to help dementia caregivers in Colombia and Latin America cope with the demands of caregiving may target the depression that caregivers in this study were found to experience, a process that could even reduce the likelihood of institutionalization for the individual with dementia (Brodaty & Donkin, 2009). The number of caregivers in Latin America has been increasing (Ferri et al., 2005), and the resources for dementia caregivers may not have kept up with this trend since the obligation of family caregiving is inherent in many Latino cultures and not necessarily viewed as a burden for caregivers requiring additional services (Arango-Lasprilla et al., 2010). However, needed services could include support groups, cognitive behavioral therapy, nursing home services, and health care facilities that provide low-cost and accessible basic care to caregivers. Without these services, the increased levels of caregiver depression found in this study would be likely to remain high, reducing the quality of care that caregivers can provide to individuals with dementia and affecting patient outcomes.

The Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) intervention is a multicomponent psychosocial training for dementia caregivers (NREPP, 2013). The intervention is designed to (a) reduce caregiver burden (b) reduce caregiver depression (c) improve caregivers' ability to provide self-care, and (d) provide caregivers with social support and help caregivers learn how to manage difficult behaviors in individuals with dementia (NREPP, 2013). A study conducted by Elliot, Burgio, and DeCoster (2010) found that after the intervention, caregivers reported better self-rated health, sleep quality, physical health, and emotional health. Further, decreases in depression were mediated by these variables such that better caregiver health led to less depression, which in turn led to lower caregiver burden (Elliot et al., 2010). The REACH II intervention unfortunately has only been systematically evaluated in the United States, and the positive results of the intervention in helping to assuage the psychosocial effects of caregiving indicate that this intervention, or one like it, should be implemented in other global regions such as Latin America where dementia is highly prevalent.

Certain characteristics of dementia interventions are important to note which may influence the efficacy of an intervention for caregivers in Latin America. According to a study by Pinquart and Sorensen (2006), longer interventions were more successful at reducing depression than shorter interventions, and a meta-analysis by Brodaty, Green, and Koschera (2003) identified that the strongest predictor of success for an intervention was the involvement of the dementia patient in addition to the caregiver in a structured program. Due to the cultural importance of caregiving and familism in Latin America (Zea, Quezada, & Belgrace, 1994; Zsembik & Bonilla, 2000), interventions that draw on the cultural strengths and positive aspects of caregiving, such as the fulfillment of family roles and values, coping through spiritual or religious practices, and the creation of meaning through caregiving, might also be a very effective way of culturally tailoring dementia caregiver interventions for this global region.

### **Limitations and Future Directions**

The current study had several limitations, which could help identify directions for future research. This first limitation is potential sample bias in that caregivers were recruited from only one medical facility, which presupposed that caregivers had access to care, and likely therefore had higher income levels than the control group or perhaps than other dementia caregiving samples in the region. However, it is important to note that income of the group of dementia caregivers was statistically controlled for, and differences between groups cannot be due to income. Recruitment from this particular facility is very likely to have resulted in well-resourced caregivers who did not experience the same burden of care as those who do not have access to a similar medical facility. Future research should recruit broader community samples in order to achieve a more representative sample. A second limitation to this study is its lack of data on the length of time the patient had had dementia or on level of dementia impairment. As a result, specific impairments or disease progression could not be linked to particular aspects of caregiver mental health or HRQOL. Future studies should examine these potential associations, especially in Latin America where dementia impairments may produce a different type or level of caregiver burden than in other

global regions. The current caregiver sample included a majority of sibling caregivers. Given the lack of attention on sibling caregivers in previous research, this is a strength of the current study (e.g., Zucchella et al., 2012, Serrano-Aguilar et al., 2006); however, it limits the generalizability of the findings to other caregiving groups. Finally, this study may not be immediately generalizable to other countries in Latin America or to surrounding rural and suburban areas because participants were only recruited from one city in Colombia. Future studies should recruit from different regions in Latin America including rural and suburban areas, as well as within communities that do not have good access to medical facilities.

## CONCLUSION

Despite these limitations, this was one of the first studies to compare the mental health and HRQOL between dementia caregivers and controls in Latin America. The finding that caregivers had higher depression levels than controls points to a need for mental health services and other caregiving resources among dementia caregivers in this region. Such interventions would likely not only improve the mental health of caregivers, but also improve the quality of care that caregivers are able to provide for individuals facing one of the region's most prevalent and debilitating medical conditions in older adults.

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