Comparisons Between Hispanic and Non-Hispanic White Informal Caregivers

Nancy J. Karlin¹, Joyce Weil¹, and James Gould¹

Abstract

This study focuses on understanding similarities and differences between non-Hispanic White and Hispanic informal caregivers of those with Alzheimer’s disease. Comparisons take place between caregivers reporting high levels of burden as indicated by the Zarit Burden Inventory. Data suggest similarities and differences between Hispanic (n = 17) and non-Hispanic White (n = 17) caregivers in this study in several areas. Hispanic caregivers indicated fewer sources of income, had less investment money for family member’s treatment, reported caregiving as a greater interference with life’s accomplishments, and indicated a lesser percentage of the total care cost provided by the family member. Non-Hispanic White caregivers reported having completed a higher level of formal education and that organized religion’s importance prior to becoming a caregiver was not quite as important as compared with the Hispanic care provider. With current trends, of demographic and cultural changes, it is crucial to fully understand the changing role and needs of both Hispanic and non-Hispanic White caregivers.

Keywords

Alzheimer’s disease, burden, Hispanic caregivers, social support

Studies are only beginning to examine the effect that cultural differences play in both caregiving role and burden (Hughes, Tyler, Danner, & Carter 2009; Losada et al., 2006; Montoro-Rodriguez & Gallagher-Thompson, 2009). Much has been studied about the caregiver role and related burden of non-Hispanic Whites (Baronet, 1999; Connell, Janevic, & Gallant, 2001), whereas much less is known about the effect of racial and ethnic differences in caregiving for Hispanic family members. As Hispanic elders are predicted to be the fastest growing group of persons 65 years of age and older over the next 40 years—from 7% of those 65 and older in 2008 to 20% in 2050—understanding the experience of Hispanic caregivers is vital (Federal Interagency Forum on Aging-Related Statistics, 2010). “Hispanics will comprise 20% of the next generation of older adults, representing the largest minority population aged 65 years and older” (Villa, Wallace, Bagdasaryan, & Aranda, 2012, p. 166). Very little research comparing ethnic group differences in caregiving has been done in this region of the United States (Coon et al., 2004; Crist, Garcia-Smith, & Phillips, 2006; Navia-Waliser et al., 2001; Radina & Barber, 2004; Valle, Yamada, & Barrio, 2004). Recent articles cite this lack or scarcity of research specifically focusing on Hispanic caregivers and caregiver burden in Latino families and call for additional empirical research focused on this group (Evans, Crogan, Belyea, & Coon, 2009; Fruhauf, Gomez, & Barber, 2005; Fruhauf, Vega, & Barber, 2004; Gelman, 2010; Simpson, 2010; Weitzman, Neal, Chen, & Levkoff, 2008).

Drawing attention to the lack of empirical research on Hispanic caregivers for those with Alzheimer’s disease (AD), the Alzheimer’s Association’s 2010 Facts and Figures included a special report, “Race, Ethnicity, and Alzheimer’s Disease.” Findings included the fact that the disease has different rates of prevalence by race; specifically, Hispanic elders are 1½ to 2 times more likely than non-Hispanic Whites to have the disease. Hispanics have the disease earlier and remain undiagnosed longer. Literature suggests that caregiving dominates the additional roles of the caregiver and requires adaptation to adjust to this new demanding position (Cantor, 1983; Cohen & Eis dorfer, 1986; Mace & Rabins, 1999; Powell & Courtice, 1983). Clearly, the caregiving role tends to increase the stress experienced (Pearlin, Mullan, Semple, & Skaff, 1990). Understanding the role of stress as related to informal caregiving is vital to support the increasing number of Hispanic caregivers within the United States. Pearl in, Lieberman, Menaghan, and Mullan (1981), in their Stress Process Model stated that the understanding of social stress must focus on sources of stress, mediators of stress, and outcomes of stress. Research on the stress process suggests stress affects all aspects of the care provider’s life. In fact, “Persistent role strains can confront people with dogged evidence of their own failures—or lack of success—and with inescapable proof of their inability to alter the unwanted circumstances of their lives” (Pearlin et al., 1981, p. 470108).
p. 339). In considering the sources of stress, the authors looked at life events and chronic life strains. The role of informal caregiver can be one of the most stress producing experiences an individual can encounter.

Mediating resources of stress have been discussed in the literature for a number of years (Lieberman & Mullan, 1978). Mediators that appear throughout the literature include social support, formal and informal spiritual issues, education, and financial sources of support. For the purposes of this article, these mediators listed are the variables of interest for the current study.

The outcomes of stress have implicated a number of potential variables including poorer immune system functioning, poorer response to vaccines, greater incidences of respiratory tract infections (Vitaliano, Schulz, Koeelglaser, & Grant, 1997), physical stress, fatigue, exhaustion, increased use of prescription medications and a host of medical conditions (Haug, Ford, Stange, Noeker, & Gaines, 1999), more chronic illness, self-ratings of poor health (Schulz & Williamson, 1994), burden (Karlin, Bell, & Noah, 2001), negative emotional reactions like anxiety and depression (Schulz & Salthouse, 1999) as well as other variables. The present study focuses on the possibility that caregivers with less support report greater burden, more financial strain, and demands of the role (Alzheimer's Association of America, 2010; Zarit, Anthony, & Boutselis, 1987). Clearly, the caregiving role tends to increase the stress experienced (Pearlin et al., 1990).

Prior work done by various members of the current research team found spiritual life, satisfaction with social support, desire to gain knowledge and skills or task mastery, increased burden as assessed on the Zarit Burden Interview, and same-language preference are important factors for Hispanic families caring for someone with AD (Karlin, Eguigure, & Torres, 2009). Considering these findings along with the stress process models of caregiving (Aneshensel, Pearl, Mullan, Zarit, & Whitlatch, 1995; Pearl et al., 1981; Zarit, 2008), the current study focuses on understanding the disparities and similarities for high-burden caregivers in caregiving for Hispanic and non-Hispanic White households. The following research questions were addressed:

**Research Question 1**: What are the sources of stress for Hispanic and non-Hispanic White caregivers?

**Research Question 2**: What are the reported mediators of stress for Hispanic and non-Hispanic White caregivers?

**Research Question 3**: What is the impact of caregiving for those identified as high-burden caregivers?

**Family**

Within Hispanic culture, the family is often cited as providing primary care to a member with AD. Familism has been reported to be a key issue in Hispanic culture (Losada et al., 2006). The idea of a strong sense of familial roles and obligations place group needs over individual needs (Cox & Monk, 1993; Radina, Gibb, & Lim, 2009). It has been suggested that Hispanic caregiving has an intergenerational aspect with day-to-day care supplied to elders reciprocated by elders' care of younger family members (Cox & Monk, 1993; Ory, Hoffman, Yee, Tenstedt, & Schulz, 1999). Studies have linked the strong kinship ties to buffering and reducing the level of caregiver stress and more individual reward and satisfaction from caregiving (Barber & Vega, 2004; Coon et al., 2004).

Recently literature has also referred to the process of Hispanic families providing care as la lucha or “the struggle” (to both provide care and maintain other familial and social roles) (Gelman, 2010). Caregiving burden among Hispanic care providers may arise when caregivers feel they cannot meet these obligations (Cruz-Lopez & Pearson, 1985). Burden was shown to have severe health costs to the caregivers and generate concern about their ability to adequately care for elders over the long term (Bernard & Guarnaccia, 2003; Pinquart & Sorensen, 2007; Sparks, Farran, Donner, & Keane-Hagerty, 1998; Wilcox, O’Sullivan, & King, 2001). Karlin et al. (2009) reported Hispanic care providers desire greater knowledge of AD, have high levels of burden, are satisfied with support provided, and, at the same time, desire more emotional support, all of which may impact the caregiving process as a possible source or suggested mediator of stress experienced.

**Religiosity**

Another factor that has been reported to influence the caregiver role is religion. Although religiosity can have many definitions and be assessed in various forms, it has traditionally been associated as having a beneficial impact on the caregiving relationship (Griffith & Griffith, 2002; Irwin, 2002; Karlin, 2004; Schulte, Skinner, & Claiborn, 2002; Stolley, Buckwalter, & Koenig, 1999; Stuckey, 2001; Whitlatch, Meddaugh, & Langhout, 1992; Wright, Pratt, & Schmalt, 1985). Frueauf et al. (2005) found, although not significant, Hispanic caregivers used religiosity (service attendance and prayer) as a way of coping with caregiving duties and improved overall well-being. Connell and Gibson (1997) stated compared with White caregivers, non-White caregivers were more likely to use prayer, faith, or religion as a way to cope. Previous data suggest that older Mexican Americans who attend worship services more often tend to look for something positive in the face of suffering, but they are not more likely to suffer in silence. Second, the results indicate that searching for something positive in suffering is associated with developing a perceived close relationship with God, but similar findings failed to emerge with respect to suffering in silence. Third, the
Impact of Caregiving

Caregivers, as well as other family members, may need to adapt to these complex changing roles (Cantor, 1983; Cohen & Eis dorfer, 1986; Mace & Rabins, 1999; Powell & Courtice, 1983). In the caregiver role, primary caregivers are more likely to report greater burden and less support (Nicolaoou, Egan, Gasson, & Kane, 2010). Feelings of burden may increase because of financial strain and the physical exertion required for the care of an individual with AD (Zarit et al., 1987). Perceived burden may also increase as the result of a decrease in the number of outside social contacts experienced because the caregiver feels a need to stay at home with the relative who has dementia. For all care providers, social isolation may be a source of emotional distress. Many of the factors that encourage social isolation (higher age, lower socioeconomic status [SES], and lower levels of informal support) are related to poorer caregiver health (Pinquart & Sorensen, 2007).

For a few informal providers, caregiving experiences demonstrate a period that may be advantageous. Benefits of family caregiving may include cost savings when institutionalization can be postponed or avoided. The costs of institutionalization in a nursing home for someone with AD have been estimated to average US$72,270 or more per year in some geographic areas (Alzheimer’s Association of America, 2010). Even so, literature on the impact of caregivers of those with AD has found caregivers typically experience role change or even reversal (Brown, 2000; Carruth, 1996; Daire, 2001; Raschick & Ingersoll-Dayton, 2004) with caregivers struggling to adapt to these changing roles (Adams, Pilstrom, Joseph, & Brunner, 2003; Boss, 1999).

The present study explores whether there will be similar as well as different sources of stress for Hispanic and non-Hispanic White caregivers. It will also consider whether Hispanic care providers will report comparable plus diverse elements of stress as reported by non-Hispanic White providers. In relation to the impact of caregiving, it is believed that providing care will be reported to have been experienced differently.

Method

Sample

A smaller than expected Hispanic sample size was obtained as a result of issues at the time of data collection. Recent events such as Immigration and Customs Enforcement (ICE) raids and linking universities with governmental agencies made it difficult to collect data from Hispanic caregivers in this area. The current sample included Hispanic (n = 17) and non-Hispanic White (n = 17) caregivers with AD in a county in northern Colorado with just over 27% of the population self-identifying as Hispanic (U.S. Census, 2010). To be eligible, caregivers had to be age 18 or older, self-identify as Hispanic or non-Hispanic White, speak English or Spanish, and have served as an informal caregiver within the past 6 months. Informal caregivers surveyed were primarily responsible for treatment decisions for the individual for whom care was being provided and were not paid for any care given. After Institutional Review Board (IRB) approval, initial fliers and newspaper advertisements about the study were posted in both the Hispanic and non-Hispanic White communities.

A broader data collection strategy was needed to include Hispanic caregivers as participants. In the local area, agencies report having difficulty obtaining Hispanics in services and programs, such as Alzheimer’s support groups (Bonnie Wacker, personal communication, August 2, 2010). Initially, flyers were posted at laundromats, clinics, restaurants, grocery stores, churches, retail stores, recreation centers and clubs, cultural centers, hairdressers, and libraries that are recognized as having Hispanic clientele (n = 26 locations) and three announcements were placed for 1 week in a newspaper that serves the Hispanic community (i.e., La Tribuna).

Only 3 Hispanic participants were gathered from these initial data collection methods. As a result, telephone calls were made to every Hispanic surname listed in the regional telephone directory. Hispanic surnames were selected based on agreement by a panel of three Hispanic research consultants. A similar surname approach has been used by American Association of Retired Persons (AARP) to include a greater number of Hispanic caregivers who are difficult to obtain in surveys (Alzheimer’s Association of America, 2010). Sweeney et al. (2007) reported that surname search efficiently identifies Hispanics and is a valid method. In all, 731 telephone calls were made resulting in 14 additional participants self-identifying as a Hispanic informal caregiver. Thus, these participants were included via this snowball sampling technique where these additional participants were obtained by directly calling Hispanics in the region. An attempt to control sampling bias was adopted by calling every Hispanic surname in the regional directory. A sample of 17 non-Hispanic...
White caregivers was obtained from the group of 60 White participants obtained using fliers and newspaper advertisements.

Mailed surveys were used to obtain data from all caregivers no matter how the caregiver name was obtained. Prior to sending the survey, participant eligibility was determined by phone (i.e., ethnicity, care provider status, willingness, and ability to participate). All participants spoke either English or Spanish. Participants could choose a Spanish or English version of the survey and an IRB-approved consent form that were subsequently mailed. A self-addressed envelope with postage was provided for return of the surveys. All Spanish translations had gone through both forward and backward translation using two separate translators. Following forward and backward translations, a third translator completed grammar checks. The translators for the research team were raised in Spanish-speaking homes and each had four years of formal training in college with regard to speaking, reading, and writing the Spanish language.

**Participants’ Characteristics**

For both groups of caregivers, the majority were women (94% for Hispanic participants, 88% for White participants). Hispanic caregivers indicated that five were spouses, two were daughters, six were daughter-in-laws, two were friends, and two were nieces. The non-Hispanic White care providers stated that six were spouses, eight were daughters, two were daughter-in-laws, and one was a grandchild. The average age for a Hispanic caregiver was 53.3 (SD = 18.8 years, range = 21-79) as compared with the non-Hispanic White caregivers’ average age of 58.1 (SD = 16.2, range = 35-86). The majority of caregivers in both groups indicated they lived with the family member suffering with AD.

One third of Hispanic care providers did not report their immigration status. Two of the care providers were self-reported undocumented immigrants, three were documented immigrants, five were citizens of the United States, and five did not report his or her status. Of the 10 reporting nationality, 5 indicated being a citizen of Mexico and 5 were citizens of the United States. For those reporting being a U.S. citizen, various countries of origin from Central and South America were indicated. All of the non-Hispanic White participants reported being U.S. citizens.

**Instrumentation**

**Demographic characteristics.** Basic demographic data (e.g., age, marital status, educational level attained, housing, income, etc.) were collected from 34 informal caregivers (nonpaid helpers, self-defining as providing care) for individuals with AD (17 Hispanic and 17 non-Hispanic White). In addition, questions were asked about impact of caregiving on the caregiver’s life (e.g., Do caregivers attribute physical or emotional problems to their caregiver role? Did caregivers have to reduce other activities, like work or recreation, because of the caregiver role?), types of caregiver’s support (e.g., financial help, help with personal care), religious practice (importance of religion, involvement with organized/public religion for both the family member and the caregiver), and support group information (e.g., attendance, physician-recommended support group attendance).

**Deterioration.** The Functional Assessment Staging Test (FAST)/Global Deterioration Scale (GDS) was utilized so as to assess the progression of the disease. The GDS is a 16-step sequence scale ranging from no decrement to consciousness lost with scoring based on the highest level of disability (Sclan & Reisberg, 1992). The FAST was derived from the original GDS and comprises seven major levels of functioning with respect to AD. Reliability and validity structures were confirmed for all published and unpublished instruments. Concurrent validity for the FAST, including the GDS and 10 independent psychometric measures, ranged from 0.59 to 0.73 (Reisberg et al., 1984). The coefficient of ordinality was reported to be 0.9933.

**Burden assessment.** The 22-item Zarit Burden Inventory (ZBI) is often used to measure perceived burden and is the most common instrument used with caregivers of family members who suffer from dementia (Bedard, Pedlar, Martin, Malott, & Stones, 2000). Bedard et al. (2001) introduced a 12-item version. Correlations between the 12-item and 22-item version range from .92 to .97. The current study used the 12-item ZBI because of its shortened length and ease of administration (α = .88; Bedard et al., 2001). The ZBI 12 item was included for participation completion with the survey packet. Based on the research of Bedard et al. (2001), the current study worked from the premise that a score of 17 or higher on the short form reflects high burden. As a result of data collection methods using the Zarit Burden Interview, short form, 17 Hispanic (M = 20.9, SD = 9.24) and 17 non-Hispanic, White caregivers (M = 28.0, SD = 4.23) comprise the sample for the current study. Overall, both groups of caregivers on average report high levels of burden.

**Results**

Table 1 shows the mean and standard deviation scores on variables of interest for Hispanic and non-Hispanic White caregivers. Due to the small sample size and nonnormal distribution, a Mann–Whitney test was used. Hispanic family members are reported to have completed less education than non-Hispanic Whites (M = 8.0, Hispanic; M = 12.9, non-Hispanic; U = 72, two-tailed p < .011). In addition, Hispanic caregivers’ education level is significantly different than non-Hispanic White caregivers (M = 11.94, Hispanic; M = 14.23, non-Hispanic; U = 66.5, two-tailed p < .01).

Additional results indicate no differences on decrement with regard to the overall global deterioration for the family member with AD (M = 9.23, SD = 3.50, Hispanic; M = 7.17,
SD = 1.81, non-Hispanic, 16-step sequence; U = 99.5, p = .122). For both groups, marked signs of memory loss were reported to have occurred between 2 and 3 years prior to diagnosis (M = 2.72, Hispanic; M = 3.05, non-Hispanic White). Hispanic and non-Hispanic White caregivers report similar levels and types of physical and emotional problems since taking on the role of caregiver as indicated in the following qualitative comments.

A Hispanic informal provider stated, “I have back problems, fatigue, headaches, weight gain, and large levels of stress.” Another indicated, “The very moment I started, I became more tense, nervous, and depressed. I do not have one moment of being tranquil.” A third Hispanic provider expressed, “I feel all of the responsibility of my mother even though I have sisters and brothers who could help me.” A fourth Hispanic caregiver declared, “I have experienced about 3 years of sadness, depression, and anger.” Non-Hispanic White providers held that they had also experienced physical and emotional problems. For example, “I have had two major surgeries for cancer where they removed part of my duodenum, pancreas, and small intestine. I now have symptoms of ulcers developing.” A second non-Hispanic White caregiver stated, “I have a lot of stress because my mother is so dependent.” An additional caregiver expressed, “I have high blood pressure and stress from caring for my family member.” These are just a few example comments made by the participating caregivers.

### Caregiver Characteristics

The average number of sources of income was reported to be less for Hispanic caregivers (M = 1.58, SD = 0.79; M = 2.29, SD = 1.10; U = 87.5, two-tailed p < .04) than for non-Hispanic White providers. The sources of financial support most often reported by Hispanic carers were social security, pensions, and government programs with significantly less percentage of overall cost of care being paid by family members than non-Hispanic Whites (M = 57.17, SD = 47.10, U = 65.7, two-tailed p = .05).
Hispanic; $M = 95.2$, $SD = 19.41$, non-Hispanic White; $U = 74.5$, two-tailed $p < .005$).

**Spirituality and Organized Religion**

No significant difference was evident between groups on the overall importance of spiritual issues to the caregiver (How important has the spiritual side of life been to you during your time as a caregiver to your family member? $M = 5.58$, $SD = 2.06$, Hispanic; $M = 5.73$, $SD = 1.27$, non-Hispanic White, range = 1-7; $U = 120.5$, $p = .387$). Differences were not evident for importance of organized religion prior to taking on the role of caregiver (Before you became a caregiver, how would you describe your involvement with organized religion? $M = 5.29$, $SD = 2.39$, Hispanic; $M = 5.46$, $SD = 1.62$, non-Hispanic White, range = 1-7; $U = 118$, two-tailed $p = .342$). Nor were there differences stated on organized religion’s importance after becoming a caregiver (Since becoming a caregiver, how would you describe your involvement with organized religion? $M = 4.82$, $SD = 2.15$, Hispanic; $M = 4.01$, $SD = 1.93$, non-Hispanic White, range = 1-7; $U = 94.5$, $p = .081$). Overall, caregivers stated a moderate to above-moderate level of importance for these areas.

**Support Group Issues**

Using a scale from 1 to 7, Hispanic participants reported similar levels of benefit for attending a support group ($M = 4.7$, $SD = 2.39$) than non-Hispanic Whites ($M = 5.05$, $SD = 1.78$; $U = 141.5$, $p = .916$). Although information about formal support group attendance was requested, it appears that most of the Hispanic participants utilize primarily informal support stemming from family and friends. Therefore, caution should be used with respect to the levels of benefit received. However, having been asked if a physician had recommended support group attendance (Yes or No) about 29% to 37% indicated receiving that type of advice ($M = 0.37$, $SD = 0.50$, Hispanic; $M = 0.29$, $SD = 0.46$, non-Hispanic White) with no difference indicated ($U = 125$, $p = .628$). Support group characteristic differences were not reported. Results indicate the majority of participants in both groups felt an above-moderate level of emotional support ($M = 5.29$, Hispanic; $M = 5.35$, non-Hispanic White, range = 1-7; $U = 134$, $p = .708$) coming from some support system.

**Caregiving Factors**

No difference was apparent between Hispanic and non-Hispanic White care providers for length of time in having cared for a family member with AD ($M = 4.07$ years, $SD = 2.45$, Hispanic; $M = 5.21$ years, $SD = 4.19$, non-Hispanic White; $U = 130$, $p = .615$). On average, Hispanic caregivers report similar years of having received help while providing care ($M = 2.24$ years, $SD = 2.24$, Hispanic; $M = 4.2$, $SD = 4.27$, non-Hispanic White; $U = 114.5$, $p = .295$) a factor presumably associated with the amount of time in the caregiving role.

In terms of attitudes toward caregiving, both Hispanic and non-Hispanic White caregivers report that caregiving interferes in achieving individual life’s accomplishments ($M = 4.64$, $SD = 1.80$, Hispanic; $M = 3.47$, $SD = 2.12$, non-Hispanic White, range = 1-7; $U = 100$, $p = .120$). Data suggest caregiving levies a heavy impact on noncaregiving aspects of life for those experiencing high levels of burden. Both Hispanic and non-Hispanic caregivers report a strong desire to increase caregiving skills ($M = 5.35$, $SD = 2.02$, Hispanic; $M = 4.93$, $SD = 2.27$, non-Hispanic White, range = 1-7; $U = 120.5$, $p = .383$). No significant differences were evident for caregiver’s desire for increased knowledge of the disease ($M = 5.52$, $SD = 2.21$, Hispanic; $M = 5.52$, $SD = 1.58$, non-Hispanic White; $U = 118$, $p = .708$).

When asked what the positive outcomes had been in providing care to your family member, the following responses were provided by both Hispanic and non-Hispanic carers. “I know my family member is well cared for.” “I feel I am fulfilling a family obligation.” “Providing care allows me to feel I have accomplished something in my life.” “I decided to give care because I wanted to and not because I had to.” “I am able to spend time with this family member.” In addition, a small number report, “the ill family member has showed me affection or appreciation for my caregiving duties.” No differences were indicated between the two groups.

When asked, “Does your ethnic background influence you as a caregiver?” 13 out of 17 Hispanic providers said “yes.” Ten out of 17 non-Hispanic White carers said yes. If a response of “no” was given, no comments followed for either group. Comments associated with the “yes” response for Hispanic providers included, “My desire to care for her comes from my Spanish background.” “I feel that our family, and my Hispanic families, do not put their family members in nursing homes as readily as other cultures do.” “Hispanics are known for taking care of their parents at home and I wanted to.” “It is a responsibility.” “Caregiving for us is a family affair.” Non-Hispanic White comments focused on, “This is something I just wanted to do.” “She is my wife and I love her.” “This is the kind of thing we have always done.” “I am obligated to do this.” “It is not as much a culture as a family thing.”

**Discussion**

Some research has suggested that because of the ethnic diversity within society, race is an obsolete scientific category (Mahoney, Cloutterbuck, Neary, & Zhan, 2005). However, the current preliminary results suggest that a greater understanding of differences between groups is warranted. The focus of this study was concerned with using the Stress Process Model as a guide with regard to the generalized experience of informal Hispanic and non-Hispanic White care providers who report high levels of burden.
Sources of Stress

The current research suggests that Hispanics as compared with the non-Hispanic White care providers report fewer sources of income during the care process, and the Hispanic care recipient provides less financially toward his or her own care. Previous research using non-Hispanic White caregivers have indicated these factors to be sources of stress during the care process (Pearlin et al., 1990). Lieberman and Mullan (1978) report lower financial sources/support may be sources of stress for some providers thereby promoting some reported differences between ethnic groups.

Potential Mediators

However, ethnic differences were smaller than expected. Both Hispanic and non-Hispanic White participants indicated an overall desire for greater knowledge, a desire to increase caregiving skills, and a moderate to slightly above-moderate level of emotional support. Providing adequate resources, increased knowledge, and support have been cited as mediators to reduce caregiver burden and improve the caregiving experience and relationship with those with AD (Elliott, Burgio, & Decoster, 2010). Current findings provide support that both groups of caregivers may be looking for avenues to reduce burden by desiring greater knowledge, caregiving skills, and support. Findings for the current study support the Stress Process Model, which states that education and social support are key mediators of caregiver stress.

Generally, all respondents reported that the spiritual side of life, as well as religious involvement was important both prior to becoming and after becoming a caregiver. As suggested by previous research, organized and nonorganized (personal prayer/meditation) religion may serve as a mediator to stress and be used as an avenue to reduce stress and/or burden.

Impact of Caregiving

Both groups report caregiving interferes with obtaining individual life accomplishments. A common statement for all participants was that personal lives had to be put on hold while care was provided. Even though no statistically significant difference was evident between the groups for overall burden, Hispanic providers on average did fall 8 points below the average non-Hispanic White caregiver. The above findings hold up prior research (Connell & Gibson, 1997; Cox & Monk, 1993; Losada et al., 2006) suggesting continued investigation on the impact of specific cultural contexts. Thus, the findings from the current study provide some general support for the Stress Process Model of Caregiving. “As noted in the Stress Process Model, caregiver burden is largely context driven and not a straight pathway from a specific stressor to burden” (Leggett, Zarit, Taylor, & Galvin, 2011, p. 84). The varying types of stressors caregivers might have to contend with make this statement true, but this statement becomes even truer alongside demographic and cultural issues.

Future Directions and Limitations

Evident from the beginning of the study was the difference between the two groups on recruiting Hispanic care providers. Due to issues of working with a population, which may include undocumented persons, convenience sampling was necessary. The authors attempted to obtain participants throughout the Hispanic community at a time where ICE raids had occurred during the previous year. Even with diverse methods, it was difficult to recruit Hispanic participants. Attention should be brought to the fact that Hispanic sample was divided with seven of those surveyed reported being citizens of the United States from various countries of origin, five were either documented or undocumented immigrants from Mexico, and five did not report his or her status. Although the Hispanic participants within this study indicated similar characteristics, differences within a larger subset should be explored for variations contained by specific cultural contexts. To better understand the experiences of and diversity within the entire Hispanic local community, further investigation on all variables related to the care process is warranted. The current study supports further investigation into whether the reporting of less interference in life’s accomplishments and activities, and reported lesser desire for additional knowledge and skills are related to the fact that Hispanic caregivers, at least in this study, provided care for a short period of time or whether the differences are a function of cultural norms or other factors such as SES. Possible future strategy considerations might also include stronger links with well-established Hispanic networks, and a possible distorting of obvious connections with federally and state-supported institutions like a university.

Initial data collection procedures focused on soliciting participants from a broad range of organizations and facilities within the regional Hispanic culture. Few participants were obtained. This was surprising with the three data collection staff being of Hispanic background, spoke and wrote Spanish fluently, and had been raised within the local Hispanic culture. These individuals were relatively young in the Hispanic community (all 22 years of age), which may have influenced potential participants’ participation. A strong culture-specific network may need to exist to maximize data collection. As far as a possible distancing from federally and state-supported institutions, it was obvious during data collection that various participants were less at ease with the presentation of a university logo. A university logo was found at the top of each survey packet. Even though all participants were provided verbal and written instructions indicating that at no time would any information be provided to an outside person or organization, participants seemed concerned. It is the current investigators opinion that potential
participants may have created possible connections between the university and other government agencies that clearly did not exist. Concerns may have centered on increased attention from immigration authorities for self and/or family members, information going to support services within the community concerning immigration status, along with any number of negative ramifications as a result of possible information being filtered to government agencies.

As suggested by Mier (2007), extensive research into the experiences of the Hispanic caregiver is needed. Cultural contexts must be considered when taking into account the experiences of a caregiver. Specifically, the findings underscore the importance of discussing potential differences for sources of income and the amount of money available, how caregiving might impact life accomplishments for the caregiver, support group structure and availability, activity levels as impacted by caregiving, and a desire for increased knowledge and caregiving skills. Similarities and differences exist for Hispanic and non-Hispanic White care providers. Additional research needs to be completed with Hispanic informal caregivers, so that a clear picture of needs and strengths can be assessed.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research and/or authorship of this article.

References

Adams, M. S., Pihlstrom, E., Joseph, M., & Brunner, J. (2003, November) Changes in intimacy, passion, and commitment when a parent has Alzheimer’s disease: Responses from adult-child caregivers to Sternberg’s Triangular Love Theory. Paper presented at the Annual Conference of the Gerontological Society of America, San Diego, CA.

Alzheimer’s Association of America. (2010). Alzheimer’s disease Facts and Figures. Retrieved from http://www.alz.org/alzheimers_disease_facts_figures.asp?type=homepage

Aneshensel, C., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. (1995). Profiles in caregiving: The unexpected career. New York, NY: Academic Press.

Barber, C. E., & Vega, L. D. (2004). Ethnic differences in the experience of filial caregiving: A comparison of Hispanic and non-Hispanic White caregivers in Colorado. Southwest Journal on Aging, 19, 33-54.

Baronet, A. M.(1999). Factors associated with caregiver burden in mental illness: A critical review of the research literature. Clinical Psychology Review, 19, 819-841.

Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O’Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. The Gerontologist, 41, 652-657.

Bedard, M., Pedlar, D., Martin, N., Malott, O., & Stones, M. (2000). Burden in caregivers of cognitively impaired older adults living in the community: Methodological issues and determinants. International Psychogeriatrics, 12, 307-332.

Bernard, L. L., & Guarinaccia, C. A. (2003). Two models of caregiver strain and bereavement adjustment: A comparison of husband and daughter caregivers of breast cancer hospice patients. The Gerontologist, 43, 808-816.

Boss, P. (1999). Ambiguous loss: Learning to live with unresolved grief. Cambridge, MA: Harvard University Press.

Brown, T. K. (2000). The process of becoming a caregiver to an aging parent: A qualitative study. Dissertation Abstracts International, 61, 2194.

Cantor, J. H. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23, 597-604.

Carruth, A. K. (1996). Motivating factors, exchange patterns, and reciprocity among caregivers of parents with and without dementia. Research in Nursing & Health, 19, 409-419.

Cohen, D., & Eisdorfer, C. (1986). The loss of self: A family resource for the care of Alzheimer’s disease and related disorders. New York, NY: W. W. Norton.

Connell, C. M., & Gibson, C. M. (1997). Racial, ethnic, and cultural differences in dementia caregiving: Review and analysis. The Gerontologist, 37, 355-364.

Connell, C. M., Janevic, M. R., & Gallant, M. P. (2001). The costs of caregiving: Impact of dementia on family caregivers. Journal of Geriatric Psychiatry and Neurology, 14, 179-187.

Coon, D. W., Rubert, M., Solano, N., Mausbach, B., Kraemer, H., Arguelles, T., . . .Gallagher-Thompson D. (2004). Well-being, appraisal, and coping in Latina and White non-Hispanic female dementia caregivers: Findings from the REACH study. Aging & Mental Health, 8, 330-345.

Cox, C., & Monk, A. (1993). Hispanic culture and family care of Alzheimer’s patients. Health & Social Work, 18, 92-100.

Crist, J. D., Garcia-Smith, D., & Phillips, L. R. (2006). Accommodating the stranger en casa: How Mexican American elders and caregivers decide to use formal care. Research and Theory for Nursing Practice: An International Journal, 20, 109-126.

Cruz-Lopez, M., & Pearson, R. E. (1985). The support needs and resources of Puerto Rican elders. The Gerontologist, 25, 483-487.

Daire, A. P. (2001). Parental bond, caregiver involvement, and emotional distress in sons who are the primary caregiver of a parent with dementia. Dissertation Abstracts International, 62, 2479.

Elliott, A. G., Burgio, L. D., & Decoster, J. (2010). Enhancing caregiver health: Findings from the resources for enhancing Alzheimer’s Caregiver Health II Intervention. Journal of American Geriatric Society, 58, 30-37.

Evans, B. C., Crogan, N., Belyea, M., & Coon, D. (2009). Utility of the life course perspective in research with Mexican American caregivers of older adults. Journal of Transcultural Nursing, 20, 5-14.

Federal Interagency Forum on Aging-Related Statistics. (2010, July). Older Americans 2010: Key indicators of well-being. Washington, DC: U.S. Government Printing Office.
Fruhauf, C. A., Barber, C. E., & Vega, D. L. (2004, November). The impact of acculturation on filial caregiving in Mexican American families residing in Colorado. Poster session presented at the Annual Meeting of the Gerontological Society of America, Washington, DC.

Fruhauf, C. A., Gomez, C. R. D., & Barber, C. E. (2005, November). The contribution of religiosity to the well-being of filial caregiving in Hispanic families. Poster presentation at the Gerontological Society of America’s Annual Conference, New Orleans, LA.

Gelman, C. R. (2010). “La Lucha”: The experiences of Latino family caregivers of patients with Alzheimer’s disease. Clinical Gerontologist, 33, 181-193.

Griffith, J. L., & Griffith, M. E. (2002). Encountering the sacred in psychotherapy: How to talk with people about their spiritual lives. New York, NY: Guilford.

Haug, M. R., Ford, A. B., Stange, K. C., Noeker, L. S., & Gaines, A. D. (1999). Effects of giving care on caregivers’ health. Research on Aging, 21, 515-538.

Hughes, T., Tyler, K., Danner, D., & Carter, A. (2009). African American caregivers: An exploration of pathways and barriers to a diagnosis of Alzheimer’s disease for a family member with dementia. Dementia, 8, 95-116.

Irwin, R. R. (2002). Human development and the spiritual life: How consciousness grows toward transformation. New York, NY: Plenum.

Karlin, N. J. (2004). An analysis of religiosity and exercise as predictors of support group attendance and caregiver burden while caring for a family member with Alzheimer’s disease. Journal of Mental Health and Aging, 10, 99-106.

Karlin, N. J., Bell, P. A., & Noah, J. L. (2001). Long-term consequences of the Alzheimer’s caregiver role: A qualitative analysis. American Journal of Alzheimer’s Disease & Other Dementias, 16, 177-182.

Karlin, N. J., Eguiquere, A., & Torres, A. (2009). Hispanic family members and caring for those with Alzheimer’s disease. Alzheimer’s Care Today, 10, 191-203.

Krause, N., & Bastida, E. (2011). Religion, suffering, and self-rated health among older Mexican Americans. Journals of Gerontology: Social Sciences, 66B, 207-216.

Leggett, A. N., Zait, S., Taylor, A., & Galvin, J. E. (2011). Stress and burden among caregivers of patients with Lewy body dementia. The Gerontologist, 51, 76-85.

Lieberman, M. A., & Mullan, J. (1978). Does help help? The adaptive consequences of obtaining help from professionals and social networks. American Journal of Community Psychology, 6, 499-517.

Losada, A., Robinson, S. G., Knight, B. G., Marquez, M., Montorio, I., Izal, M., & Ruiz, M. A. (2006). Cross-cultural study comparing the association of familialism with burden and depressive symptoms in two samples of Hispanic dementia caregivers. Aging & Mental Health, 10, 69-76.

Mace, N. L., & Rabins, P. W. (1999). The 36-hour day: A family guide to caring for persons with Alzheimer’s disease, related dementing illnesses, and memory loss in later life. Baltimore, MD: Johns Hopkins University Press.

Mahoney, D. F., Clutterbuck, J., Neary, S., & Zhan, L. (2005). African American, Chinese, and Latino family caregivers’ impressions of the onset and diagnosis of dementia: Cross-cultural similarities and differences. The Gerontologist, 45, 783-792.

Mier, N. (2007). The caregiving experience among Hispanic caregivers of dementia patients. Journal of Cultural Diversity, 14(1), 12-18.

Montoro-Rodriguez, J., & Gallagher-Thompson, D. (2009). The role of resources and appraisals in predicting burden among Latina and non-Hispanic White female caregivers: A test of an expanded socio-cultural model of stress and coping. Aging & Mental Health, 13, 648-658.

Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kueppers, A. N., & Donelan, K. (2001). The experiences and challenges of informal caregivers: Common themes among Whites, Blacks, and Hispanics. The Gerontologist, 41, 733-741.

Nicolau, P. L., Egan, S. J., Gasson, N., & Kane, R. T. (2010). Identifying needs, burden, and distress of careers of people with frontotemporal dementia compared to Alzheimer’s disease. Dementia, 9, 215-235.

Ory, M., Hoffman, R., Yee, J., Tennstedt, S., & Shulz, R. (1999). Prevalence and impact on caregiving. The Gerontologist, 39, 177-185.

Pearlin, L. I., Lieberman, M. A., Menaghan, E. G., & Mullan, J. T. (1981). The Stress process. Journal of Health and Social Behavior, 22, 337-356.

Pearlin, L. I., Mullan, J. T., Seple, S., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30, 583-594.

Pinquart, M., & Sorensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 62, P126-P137.

Powell, L. S., & Courticc, K. (1983). Alzheimer’s disease: A guide for families. Reading, MA: Addison-Wesley.

Radina, M. E., & Barber, C. E. (2004). Utilization of formal support services among Hispanic Americans caring for aging parents. Journal of Gerontological Social Work, 43(2/3), 5-23.

Radina, M. E., Gibbons, H. M., & Lim, J. (2009). Explicit versus implicit family decision-making strategies among Mexican American caregiving adult children. Marriage & Family Review, 45, 392-411.

Raschick, M., & Ingersoll-Dayton, B. (2004). The costs and rewards of caregiving among aging spouses and adult children. Family Relations, 53, 317-325.

Reisberg, B., Ferris, S. H., Anand, R., de Leon, M. J., Schneck, M., Buttinger, C., & Borenstien, J. (1984). Functional staging of dementia of the Alzheimer’s type. Annals of the New York Academy of Sciences, 435, 481-483.

Schulte, D. L., Skinner, T. A., & Claiborn, C. D. (2002). Religious and spiritual issues in counseling psychology training. Counseling Psychologist, 30, 118-134.
Schulz, R., & Salthouse, T. (1999). Adult development and aging: Myths and emerging realities. Upper Saddle River, NJ: Prentice Hall.

Schulz, R., & Williamson, G. M. (1994). Health effects of caregiving: Prevalence of mental and physical illness in Alzheimer’s caregivers. In E. Light, G. Niederehe, & B. D. Lebowitz (Eds.), Stress effects on family caregivers of Alzheimer’s patients: Research and interventions (pp. 38-63). New York, NY: Springer.

Sclan, S. G., & Reisberg, B. (1992). Functional Assessment Staging (FAST) in Alzheimer’s disease: Reliability, validity, and ordinality. International Psychogeriatrics, 4(Suppl. 1), 55-69.

Simpson, C. (2010). Case studies of Hispanic caregivers of persons with dementia: Reconciliation of self. Journal of Transcultural Nursing, 21, 164-174.

Sparks, M. B., Farran, C. J., Donner, E., & Keane-Hagerty, E. (1998). Wives, husbands, and daughters of dementia patients: Predictors of caregivers’ mental and physical health. Scholarly Inquiry for Nursing Practice, 12, 221-234.

Stolley, J. M., Buckwalter, K. C., & Koenig, H. G. (1999). Prayer and religious coping for caregivers of persons with Alzheimer’s disease and related disorders. American Journal of Alzheimer’s Disease, 14, 181-191.

Stuckey, J. C. (2001). Blessed assurance: The role of religion and spirituality in Alzheimer’s disease caregiving and other significant life events. Journal of Aging Studies, 15, 69-84.

Sweeney, C., Edwards, S. L., Baumgartner, K. B., Herrick, J. S., Palmer, L. E., Murtaugh, M. A., & . . . Slattery, M. L. (2007). Recruiting Hispanic women for a population-based study: Validity of surname search and characteristics of nonparticipants. American Journal of Epidemiology, 166, 1210-1219.

U.S. Census. (2010). 2006-2008 American community survey 3-year estimates. Retrieved from http://factfinder.census.gov/home/saff/main.html?_lang=en

Valle, R., Yamada, A. M., & Barrio, C. (2004). Ethnic differences in social network help-seeking strategies among Latino and Euro-American dementia caregivers. Aging & Mental Health, 8, 535-543.

Villa, V. M., Wallace, S. P., Bagdasaryan, S., & Aranda, M. P. (2012). Hispanic baby boomers: Health inequities likely to persist in old age. The Gerontologist, 52, 166-176.

Vitaliano, P. P., Schulz, R., Kiecolt-Glaser, J. K., & Grant, I. (1997). Research on psychological and physical concomitants of caregiving: Where do we go from here? Annals of Behavioral Medicine, 19, 117-123.

Weitzman, P., Neal, L., Chen, H., & Levkoff, S. (2008). Designing a culturally attuned bilingual educational website for US Latino dementia caregivers. Ageing International, 32, 15-24.

Whitehead, B. R., & Bergeman, C. S. (2012). Coping with daily stress: Differential role of spiritual experience on daily positive and negative affect. Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 67, 456-459.

Whilatch, A. M., Meddaugh, D. I., & Langhout, K. J. (1992). Religiosity among Alzheimer’s disease caregivers. American Journal of Alzheimer’s Care and Related Disorders and Research, 7(6), 11-20.

Wilcox, S., O’Sullivan, P., & King, A. C. (2001). Caregiver coping strategies: Wives versus daughters. Clinical Gerontologist, 23(1-2), 81-97.

Wright, S. D., Pratt, C. C., & Schmall, V. L. (1985). Spiritual support of caregivers of dementia patients. Journal of Religion & Health, 24, 31-38.

Zarit, S. H. (2008). Diagnosis and management of caregiver burden in dementia. In C. Duycklaerts, & J. Litvan (Eds.), Alzheimer’s disease, treatment, and family stress: Directions for research (pp. 458-486). Washington, DC: U.S. Government Printing Office.

Zarit, S. H., Anthony, C. R., & Boutselas, M. (1987). Interventions with caregivers of dementia patients: Comparison of two approaches. Psychology and Aging, 2, 225-232.

**Bios**

Nancy J. Karlin is a professor of psychology at the University of Northern Colorado. She has specific research interests in familial caregiving of Alzheimer’s disease patients, etic and emic constructs for cross-cultural aging, and resiliency after natural disasters.

Joyce Weil is an assistant professor of gerontology at the University of Northern Colorado. Her research interests are in aging in place, social support, resiliency, and quality of life for older persons.

James Gould is an associate professor in recreation, tourism, and hospitality. His research interests center on development of the serious leisure inventory, model confirmation, and method bias.