



Research Article

## Evaluating a Multi-Component Spanish Caregiver Monolingual Intervention

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### Abstract

As the number of Hispanic elderly is predicted to grow significantly in the next few decades, there will be an increase in need for elderly caregiving. Due to cultural values of familism, Hispanics are more likely to rely on family caregivers. Using a quasi-experimental, single group pre/post-test design, we sought to examine if Spanish caregivers of older adults with dementia (n=61) experienced less depression and caregiver after participating in a monolingual Spanish Caregiver Support/Training Program (CS/TP). While caregiver depression decreased significantly, there was no significant difference in caregiver burden. Future research should examine the cultural context for Hispanic caregivers. Practitioners should continue to focus on multicomponent interventions and develop more targeted interventions that take specific characteristics of Hispanic monolingual informal caregivers into consideration.

### Introduction

Approximately 15 million people are informal caregivers for older adults with Alzheimer's disease or other dementias; this number is poised to grow significantly as the older adult population expands far more quickly than other population segments [1]. The USA Hispanic elder population is expected to have one of the largest growths. The USA Census projections find that over the next five decades, the Hispanic population age 65+ is expected to increase 592% between 2000 and 2050 to 17.5 million [2]. While Hispanics have better mortality outcomes, they have worse morbidity, higher disability rates, poorer self-rated health, and more functional difficulties and chronic health conditions (e.g., diabetes, high blood pressure) compared to their non-Hispanic Whites counterparts [3,4]. Hispanic older adults are approximately 2.5 times more likely to have dementia than elderly non-Hispanic white adults [5]. According to the Alzheimer's Association, one of the reasons Hispanics has an increased risk of Alzheimer's disease and other dementia is because

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their life expectancy surpasses that of all other ethnic groups. In Gurland et al.'s study, the largest difference in prevalence rates between Hispanics and Whites/African Americans was seen in older adults 85+ [5].

Due to the cultural value of familism, family-centered informal caregiving is highly prevalent in Hispanic families [6], with one third of middle-aged USA Hispanic caring for elders [7]. Compared to their non-Hispanic counterparts, Hispanic caregivers are more likely to be in intensive caregiving situations, spend more hours per week giving care, provide help with a greater number of ADLs (Activities of Daily Living), and live with their care recipient [7,8]. In the study of Evercare and NAC (2008), which included over 1,000 USA Hispanic caregivers, approximately half (52%) felt that it was important to be given caregiving information in Spanish and a little less than half (48%) were somewhat/not satisfied with the availability of Spanish language information for caregivers. In 2011, of the 60.6 million people who spoke a non-English language at home, 37 million (almost two-thirds) spoke Spanish [9]. Using Census data, Ortman and Shin [10], project that this number will increase to 43 million in 2020. Thus, consideration of the language needs of the USA monolingual Spanish caregivers is important.

### Literature review

**Caregiver depression and burden:** Caregiving for a family member with dementia is stressful and exhausting. It is associated with depression, anxiety, hostility and poor self-reported physical health [11-14]. In fact, caregiving has been likened to being exposed to a severe, long-term stressor [15]. Another common psychosocial response is perceived burden. Caregiver burden refers to the physical, emotional, psychological and financial problems that may arise with respect to caregiving [16,17]. The more functional limitations (ADLs and IADLs) the care recipient has, the greater the caregivers stress [18]. Functional limitations are defined as needing help performing ADLs (Activities of Daily Living) and IADLs (Instrumental Activities of Daily Living). ADLs are required to live independently and include bathing, using the toilet, walking, and eating; IADLs are related to executive functioning and include grocery shopping, doing light/heavy housework, and lifting 10-15 lbs [19]. Poorer caregiver physical health also predicts greater caregiver burden [20,21].

**Sociocultural stress and coping model:** The sociocultural stress and coping model builds upon the common core model of caregiving [22]. The common core model, which is consistently applied across racial and ethnic groups, argues that the more behavioral problems the person with dementia has, the more distress the caregiver feels [23]. The caregiver's appraisal of caregiver burden is a key mediator in caregiver distress and greater distress is related to poorer mental and physical health outcomes. Basing their model on Hispanics, Aranda and Knight [22] introduced "ethnicity as culture" into the caregiving model to consider how cultural values may influence the caregiving process. Cultural values were described using the individualism/familism continuum. They argue that the majority of Western cultural identifies with individualism and perceive caregiving as a burden.

Hispanics are more likely to identify with the other end of the continuum, familism. Familism emphasizes the salient role of the family in an individual's life and the high reliance upon the family to provide physical and emotional support to the elderly [22,24]. Hispanic caregivers' ethnic and cultural factors can also influence their beliefs, attitudes, and experiences towards illness and treatment [22]. For example, there is a belief that Alzheimer's disease is a mental (not physical) illness; this stigma leads to increased shame and isolation for the caregivers and an underutilization of services [25].

While some researchers found Hispanics reported greater psychological distress and caregiver burden compared to other ethnic/racial groups with the same caregiving responsibilities [22-26], other researchers found that Hispanic caregivers are actually less likely to report caregiver burden [27-29].

### Caregiver interventions

Caregiver interventions seek to lessen caregiver burden and improve their psychosocial health. These programs vary and typically include a variety of educational and psychotherapeutic interventions, such as problem solving, coping skills training, support groups, and cognitive behavioral therapy [30,31]. Once the caregivers' informational needs (e.g., knowledge about disease, available resources) have been met, they also benefit from training in managing the care recipient's behavior, as well as their own emotional response to caregiving [30]. Multicomponent interventions are generally more effective than those with a single component [31-33]. Meta-analysis of over 127 interventions found that only multicomponent interventions were effective in delaying institutionalization as they are more intense and provide a broader array of services to caregivers.

Seminal research by Gallagher-Thompson et al., [32] found that caregiver programs that include a psycho-educational component are more effective than traditional caregiver support programs. Specifically, participants in the psycho-educational group reported a significant reduction in depression, increased use of adaptive coping strategies, and decreased use of negative coping skills compared to those in the traditional caregiver support group. Similarly, Hepburn et al., [34] found that caregivers in the psycho-educational program reported improvement in burden and well being, and increased skill, knowledge and confidence. The results of the original Caregiver Support and Training Program (CS/TP) study, which was a multicomponent intervention developed from the Gallagher-Thompson's "Coping with Caregiving" (CWC) Program, found significant improvement in depression [35].

### Purpose and Background of Intervention

Despite the growing number of Hispanic caregivers, a limited amount of research has been done on this population [29]. The current study adds to the sparse literature on Hispanic caregivers by evaluating a multicomponent Spanish Caregiver Support/Training Program (CS/TP) for monolingual Spanish caregivers. This builds off of the multicomponent CS/TP done for all racial groups [35]. The findings from the initial project, which was performed in Los Angeles, showed a demonstrated need for a monolingual CS/TP. There was an overwhelming representation of Hispanics and of those, almost half (46%) said that their primary language at home was Spanish [35].

The multicomponent CS/TP was adapted from Gallagher-Thompson's CWC model [36], which is designed to teach participants various cognitive-behavioral strategies for managing the common stressors

associated with caregiving, and therefore, improve health outcomes. CWC is based on Beck's [37] and Lewinsohn et al., [38] work which focuses on the role that cognition and behavior play in the development and maintenance of affective states. The greater the sense of mastery or the more available resources caregivers have, the more likely they will maintain a positive affective state and adopt positive coping behaviors.

In addition to Gallagher-Thompson et al.'s [32] model, in order to make this program more relevant to an ethnically and economically diverse population, this multicomponent program included skill-training modules that present information and strategies to increase caregivers' knowledge of chronic disease management. This includes characteristics, symptoms, progression and stages of various diseases and conditions as well as their caregiving requirements. Strategies and techniques for facilitating day-to-day care of personal hygiene, eating, transferring, and problem behaviors common among care recipients were provided. In addition, caregiver and family members' roles in caring were discussed. The legal and financial planning session provided strategies for developing financial plans for long-term care needs. The main purpose of the sessions was to present participants with practical information to help caregivers with daily tasks and future planning.

The support component was weaved throughout and participants were encouraged to share their experiences with one another during each session. Oftentimes, the larger group would break up into smaller groups for discussion and role-playing. Not only does group discussion help normalize the experiences of caregivers, it allows for opportunities for modeling adaptive coping behaviors and strategies. The concept of empowerment is also omnipresent in a support group as individuals learn to gain perceptions of personal control over issues of concern; they are taking a proactive approach to life and a critical understanding of their intrapersonal and social environment [39]. As mentioned earlier, many caregivers often feel isolated from their friends and family due to the amount of time given to the care recipient and because they may feel reluctant to leave the care recipient at home alone or go out with them. There was emotional support, which includes having someone to talk to and confide in and informational support, which includes formal advice from health professionals, such as physicians and counselors, as well as informal advice from others who have experienced similar situations. While most caregiver interventions focus on either support or a psychoeducational component, this multicomponent program incorporated training, psychoeducational, and support.

### Methodology

Prior to collecting data, approval was obtained from the California State University, Los Angeles Institutional Review Board. A pre-experimental, single group pre-test/post-test design was implemented. It was hypothesized that caregivers who completed the monolingual Spanish Caregiver CS/TP would exhibit a marked improvement in their level of depression and caregiver burden. Monolingual Spanish-speaking adult caregivers for a family or friend who was 60+ years with dementia were recruited through Spanish newspaper announcements and a mass mailing was sent to local adult day care centers, churches, hospitals and medical clinics in the East Los Angeles area. All materials were in Spanish. Eligibility requirements for the study were that participants were monolingual Spanish-speaking adult caregivers for a family or friend who was 60+ years with dementia. At the first session, participants received

information about the 8-week CS/TP; they were given the informed consent forms and told about the legal requirement to report elder abuse. They were told that participation in the study was completely voluntary and that they could quit anytime. Participants were given \$100 for attending all eight sessions, with each session lasting an hour and a half. There were a total of 61 participants in the study. Trained interventionists included Licensed Clinical Social Workers (LCSWs), psychologists, nurses, physical therapists, and attorneys.

To measure the effectiveness of the intervention, a pre-test and post-test of depression and caregiver burden were given. The two scales that have been widely used to measure the impact of caregiving across a diverse population are the Center for Epidemiological Studies Depression scale (CESD) and the Zarit Burden Index (ZBI). The CESD is a highly popular and frequently used 20-item scale originally designed to measure depression in the general population for epidemiological research [40,41]. The possible score ranges from 0-60, with a higher score representing greater depression. The cutoff score for clinical depression is 16. With high internal consistency with Cronbach's alpha scores ranging from .85-.92 and high validity with Pearson correlations ranging from .74-.75 [40-42], the CESD has proven to be an accurate and valid measure of depression. One of the most commonly used measures at the international level, the ZBI is a 22-item scale designed to measure feelings of burden experienced by caregivers of older adults with dementia [43]. The possible range is from 0-88, with a higher score meaning greater caregiver burden [44]. Argue that the longer version is better for longitudinal studies in detecting change compared to the shorter 4 or 12 questions ZBI. Like the CESD, the ZBI has also shown strong psychometric properties; the Cronbach's alpha score shows a high internal consistency at .93 and test-retest reliability is .89 [45]. Both of these scales have been translated into Spanish and have demonstrated adequate internal consistency and test-retest reliability within the Latino population [46,47]. The Spanish version of the CESD and ZBI has an internal consistency of .93 and .92, respectively [48]. A questionnaire that included socio-demographic information relating to age, gender, ethnicity, marital status, years in the US, education and income was taken at the first session. In order to measure for functional limitations of the caregiver and care recipient, ADLs and IADLs for each were measured at the first session as well.

Descriptive statistics were used to provide a demographic profile of the sample. Using SPSS v. 22, a paired samples t-test was used to examine if the monolingual Spanish CS/TP produced an effect by lowering participant's level of depression and their degree of caregiver burden from pre-test to post-test. The P-value used to consider significance was .05.

## Results

As shown in table 1, there were a total of 61 participants, with the majority being female (82%), Hispanic ethnicity (49.2%), and married (50.8%). The average age of the caregiver was 54.1 years old. With respect to ethnicity, Mexican Americans made up the next largest group (37.7%), followed by Latinos (11.5%). The average number of years in the U.S. was 32.5, with a range from 6 to 77 years. With respect to education, one-third had a high school diploma and one-third had a college degree or more. The majority made between \$10,000-\$24,999 (49.2%) and the least amount making over \$55,000 (3.3%). The majority were the primary caregivers (59 %).

| Gender              |                        | n  | %       |
|---------------------|------------------------|----|---------|
|                     | Female                 | 50 | 82      |
|                     | Male                   | 11 | 18      |
| Age                 |                        |    |         |
|                     | Range                  |    | 31-87   |
|                     | Mean                   |    | 54.1    |
|                     | Standard Deviation     |    | (+12.3) |
| Primary Caregiver   |                        | 36 | 59      |
| Ethnicity           |                        |    |         |
|                     | Hispanic               | 30 | 49.2    |
|                     | Mexican                | 23 | 37.7    |
|                     | Latino                 | 7  | 11.5    |
|                     | Refused to answer      | 1  | 1.6     |
| Marital Status      |                        |    |         |
|                     | Married                | 31 | 50.8    |
|                     | Single                 | 17 | 27.9    |
|                     | Widowed                | 4  | 6.6     |
|                     | Divorced               | 8  | 13.1    |
|                     | Refused to answer      | 1  | 1.6     |
| Years in US         |                        |    |         |
|                     | Range                  |    | 28277   |
|                     | Mean                   |    | 32.5    |
|                     | Standard Deviation     |    | (+16.4) |
| Amount of Education |                        |    |         |
|                     | 0-6 Years              | 11 | 18      |
|                     | 7-8 Years              | 10 | 16.4    |
|                     | 9-11 Years             | 14 | 23      |
|                     | High School Diploma    | 19 | 31.1    |
|                     | Some University        | 5  | 8.2     |
|                     | College Degree or more | 63 | 31.66   |
| Income              |                        |    |         |
|                     | \$0-\$9,999            | 14 | 23      |
|                     | \$10,000-\$24,999      | 30 | 49.2    |
|                     | \$25,000-\$39,999      | 8  | 13.1    |
|                     | \$40,000-\$54,999      | 3  | 4.9     |
|                     | \$55,000+              | 2  | 3.3     |
|                     | Refused to answer      |    | 6.5     |

**Table 1:** Socio-demographic Characteristics of Caregivers (N=61).

In order to get a sense of overall health of caregiver and care recipient, ADLs and IADLs were measured, as shown in table 2. The majority of caregivers did not report any difficulties performing ADLs (85.2%) or IADLs (50.8%). However, the vast majority of care recipients reported difficulties performing ADLs and IADLs, with only 13.1% and 1.6% reporting no difficulties respectively.

As shown in table 3, with respect to the psychosocial measures, there was clear improvement in depression as seen by a significant decrease in the CESD from the pre-test (M=19.5, sd=13.1) and the post-test (M=17.6, sd= 2.6); t (60)=1.93, p<0.05. Notably, the mean scores for both the pre-test (M=19.5) and post-test (M=17.6) for the CESD met the cut off score of 16 or higher, which classifies individuals as having elevated levels of depression. For the ZBI, there

| ADLs (difficulty performing)   | Caregiver (%) | Care recipient (%) |
|--------------------------------|---------------|--------------------|
| Bathing                        | 0             | 60.7               |
| Dressing                       | 1.6           | 57.4               |
| Using the toilet               | 0             | 47.5               |
| Eating                         | 3.3           | 34.4               |
| Walking                        | 11.5          | 78.7               |
| Transferring from bed to chair | 0             | 45.9               |
| No difficulties                | 85.2          | 13.1               |
| IADLs (difficulty performing)  |               |                    |
| Using the telephone            | 1.6           | 52.4               |
| Grocery shopping               | 4.9           | 72.1               |
| Managing money                 | 9.8           | 52.5               |
| Lifting 10-15 pounds           | 11.5          | 68.9               |
| Lifting 25 pounds              | 24.6          | 75.4               |
| Doing light housework          | 8.2           | 57.4               |
| Doing heavy housework          | 29.5          | 86.9               |
| No difficulties                | 50.8          | 1.6                |

**Table 2:** Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs).

was no significant difference in caregiver burden from the pre-test (M=37.1, sd=19.4) and the post-test (M=34, sd=15.5);  $t(60) = .85$ ,  $p > 0.05$ . The mean caregiver burden scores for pre-test (M=37.0) and post-test were moderate (M=34.0).

| CESD (Possible Range:0-60) | Pre-test | Post-test | t(60)=1.93, p=.039 |
|----------------------------|----------|-----------|--------------------|
| Range                      | 1-54     | 1-55      |                    |
| Mean                       | 19.5     | 17.6      |                    |
| Standard Deviation         | +13.1    | +12.6     |                    |
| ZBI (Possible Range: 0-88) |          |           | t(60)=.85, p=.058  |
| Range                      | 3-78     | 8-71      |                    |
| Mean                       | 37.0     | 34.0      |                    |
| Standard Deviation         | +19.4    | 15.5      |                    |

**Table 3:** Depression (CESD) and Caregiver Burden (ZBI).

## Discussion

Overall, the multicomponent Spanish Caregiver Support/Training Program (CS/TP) showed mixed results. Depression levels decreased as predicted. The program's psychoeducational skills taught problem-solving skills through a cognitive behavioral framework. Participants were taught to identify the event that is causing them distress (e.g., behavior of the care recipient), brainstorm options and weigh the advantages and disadvantages of each. Additionally, participants were taught how to discriminate between the event and the emotions that they are feeling due to the event. This is an important distinction because participants were taught that while they may not be able to change the event, they can change how they feel toward the event. Another skill that was taught was to reward oneself for caregiving tasks; therefore, individuals focused on small pleasant activities throughout the week.

There was no significant change with respect to caregiver burden. This is similar to the original Caregiver Support/Training program in which only depression was significantly lowered [35]. While the original intervention included all racial and ethnic groups, approximately two-thirds were Hispanics. Therefore, it is not

surprising that these findings would be similar. These findings also mirror the literature; Pinquart & Sorenson's [33] meta-analysis of interventions found that the intervention effect sizes for caregiver burden were smaller when compared to those for depression. Specifically, the effect size for caregiver burden was 0.12 (small), while the effect size for depression was 0.24 (medium). Another explanation may be that a large number of participants were adult children, who were married with their own families. The ZBI refers specifically to the elder care recipient, but in this study, participants may also be caregiving for their children. Multigenerational caregivers often experience a different form of burden that may not be captured by the ZBI [33]. Also, poorer caregiver physical health is correlated with greater caregiver burden [20,21]; and the majority of caregivers did not have functional limitations. Thus, it is possible that as their difficulty in performing ADLs and IADLs increased, caregiver burden would increase. Finally, ethnicity and culture also play a key role in the caregiver relationship and caregiver burden [22]. The cultural expectations of taking care of one's parents lead to more acceptance of the caregiving role, and hence, less perceived caregiving burden [24,29,49]. Findings regarding Hispanics and caregiving burden were similar to the findings of this study. Both studies found Hispanic familism values to be associated with less perceived burden, but familism was not significantly related to depressive symptoms. The view of caregiving impacts the level of perceived burden; thus because Hispanics may have a greater sense of responsibility and commitment to caregiving, they have less reported caregiver burden [29]. While this study did not measure cultural values, the fact that burden did not change may speak to the fact that burden was initially at a moderate level may be related to cultural values of caregiving.

There are several limitations to the study that must be addressed. One of the limitations was the lack of a control group and randomization. The original plan was to have one track serve as the control group; however, given the limited availability of the trainers, training room, and participants, two separate 8-week sessions was not possible. Therefore, the second track started before the first track was complete. Another limitation is that while the study used a longitudinal study design to look at the effect of the intervention, data was not collected after the program in order to measure sustained effects. Additionally, the small sample size (n=61) limited the ability to generalize the findings. Another impact of the small sample size is that it would limit the power to find potentially significant associations [33]. Meta-analysis of interventions for caregivers found that the median number of study participants was 45. Therefore, this sample size may be typical to, if not slightly greater than, similar caregiver intervention studies. Given the limitations, the results of this study should be interpreted cautiously. However, the study does underscore the importance of looking at the monolingual Hispanic caregiving population and consider their unique needs, especially given the number of growing Hispanic older adults with dementia. Future studies should specifically look at cultural values and how they influence caregiver burden.

## Conclusion

The physical, emotional, and financial costs to caregivers are immense. Caregiver health has a direct impact on the level of care that caregivers offer. Hence, interventions that reduce caregiver stress and facilitate caregivers' quality of life are needed. This study tested a multicomponent program that incorporated knowledge about caregiving, psycho-education, and mutual support with the goal of decreasing participants' level of depression and caregiver burden.

Moreover, this study adds to the limited literature on Hispanic caregivers for older adults, specifically monolingual Spanish speaking.

As the number of Hispanic older adults proliferates, the demand for programs that support, educate, and assist informal Hispanic caregivers will only increase. It is imperative that long term care programs and services target the needs of in-home caregivers with multicomponent programs that provide education, support, as well as respite. The Evercare and NAC study underscored the importance of availability of Spanish language caregiving information [7]. By designing programs that meet the needs of caregivers we can begin to forestall and perhaps reverse the health and mental health vulnerabilities associated with providing care over time. Furthermore, taking into consideration the unique cultural needs of the Hispanic population is needed and this includes providing more intervention programs targeted at monolingual caregivers. Future research should also consider the caregivers' and care recipients' level of acculturation, which impacts their language, belief systems, and comfort with the U.S. health care system, and include culturally specific indicators to measure these factors.

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