


# Interventions for Hispanic Caregivers of Patients with Dementia: A Review of the Literature

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## Abstract

**Background:** The number of Hispanics/Latinos living with dementia in the United States is expected to rise from 200,000 to 1.3 million by 2050, which will result in large numbers of Hispanics/Latinos assuming the role of caregiver. The demands of caregiving can negatively impact caregivers' health. The purpose of this review was to identify intervention strategies that can help Hispanics/Latinos deal with the burden associated with providing care for older adults with dementia. **Methods:** The authors critically reviewed and analyzed the literature for interventions and their relevance to these caregivers. The search engines and electronics databases of Google Scholar; Social Gerontology; Health Source: Nursing/Academic Edition; MEDLINE; PsycARTICLES; CINAHL; and PubMed, were used to locate articles published between 1999 and 2011. **Results:** Ten intervention studies published between 2000 and 2011 were identified that targeted Hispanic/Latino caregivers: most were from one clinical trial (REACH). **Discussion:** Future studies should consider culturally tailoring interventions for Hispanic/Latino caregivers from differing sub-cultures, utilizing relevant technology in studies, and evaluating the functional level of the care receiver and assess where he/she is in the disease process continuum. A better understanding of within-group differences among Hispanic/Latino caregivers, especially with respect to acculturation, could lead to better tailoring of interventions. Future research should consider the possibility of discovery-based participatory approaches. Few studies have addressed these areas of concern in this population.

## Keywords

Alzheimer's disease, dementia, caregiving, Hispanics, interventions

## Introduction

Hispanics/Latinos and older in the United States is predicted to increase to 17.5 million by the year 2050, a growth of 258%.<sup>1-4</sup> Access to health care, increased education, and better quality of working conditions over the last century have increased the life expectancy of this population.<sup>5</sup> However, as the Hispanic/Latino population ages, the risk of chronic health problems such as diabetes and hypertension also increases.<sup>1</sup> The vascular changes often associated with these chronic diseases, which are prevalent in the Hispanic/Latino population, put Hispanic/Latino older adults at higher risk of Alzheimer's and other related dementias (ADRD).<sup>6</sup> In fact, Hispanic/Latino older adults are approximately 1.5 times more likely to have ADRD than elderly White adults.<sup>7</sup> By the year 2050, the number of Hispanic/Latino older adults diagnosed with ADRD could increase more than 6-fold, from fewer than 200 000 to as many as 1.3 million.<sup>8</sup> This predicted rise in Hispanic/Latino older adults with dementia will lead to large numbers of Hispanic/Latinos who will assume the role of caregiver for an older adult family member with dementia.<sup>2,9</sup>

Past studies suggest that the majority of Hispanic/Latino caregivers believe that taking on the role of caregiver for older adult relatives is an expectation of their culture.<sup>10,11</sup> In fact,

most feel that not accepting the role of caregiver would bring shame on their family.<sup>10</sup> The emphasis in Hispanic/Latino culture on the family, or "familismo," most likely accounts for this strong sense of caregiver role responsibility.<sup>10,12</sup> Past research also suggests that Hispanic/Latinos endorse family-centered care,<sup>13</sup> meaning that caregivers may prefer the person with dementia receive care from family members rather than professional caregivers.<sup>14</sup>

Hispanic/Latino caregivers are typically unpaid females in their 40s who are caring for a parent, in-law, or other elderly relative in the caregiver's home.<sup>2,9,15,16</sup> Hispanics/Latinos in the caregiver role typically spend more hours per week, 37 versus 31 hours, performing caregiver activities and are less likely to utilize formal care services (ie, personal care, case management, homemaking, etc) than their non-Hispanic/

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Latino counterparts.<sup>2,10</sup> Further, Hispanic/Latino caregivers tend to be more intensive in caregiving situations, with 63% in high-burden<sup>16</sup> situations compared to 51% of non-Hispanic/Latino caregivers.<sup>2</sup> In addition, Hispanic/Latino caregivers perform a greater number of personal care tasks (ie, activities of daily living [ADLs]) for their loved one—43% versus 32%—than non-Hispanic/Latino caregivers.<sup>2</sup>

Some descriptive studies have reported high levels of burden<sup>17</sup> among Hispanic/Latino caregivers. A descriptive study found that Hispanic/Latino caregivers had higher levels of personal and role strain than black caregivers.<sup>18</sup> Another study revealed that Hispanic/Latinos had higher levels of burden than non-Hispanic/Latino White caregivers.<sup>19</sup> Nevertheless, other studies have reported that Hispanic/Latino caregivers are more likely to rate their caregiving situation as nonstressful, when compared to other caregiver groups.<sup>20,21</sup> Although the degree of perceived burden and stress among Hispanic/Latino caregivers appears to vary in the literature, the demands of caregiving have been shown to negatively impact caregiver health. Caregivers are at higher risk for infectious diseases (ie, influenza) due to the weakening of the immune system and also at higher risk of chronic illnesses such as cardiovascular disease, diabetes, and cancer due to the chronic stress of caregiving.<sup>22</sup> There is a need for targeted interventions that have the potential to increase quality of life, enhance health outcomes, and decrease the risk of burnout for Hispanic/Latino caregivers of older adults with dementia.

## Purpose

The purpose of this review of the literature was (a) to analyze and critically review pertinent published intervention studies that have focused on enhancing the health of Hispanic/Latino caregivers of older adults with dementia, (b) to indicate a direction for building on the existing research noted in this literature review, and (c) to make recommendations for clinical practice.

## Methods

Initially, a search of the literature from 2000 to 2011 was undertaken using Google Scholar with keywords “Dementia,” “Caregivers,” “Hispanic,” “Latino,” and “Intervention.” The Google Scholar search yielded 1,880 results. The following electronic databases were also used to search for relevant literature using the same keywords and time period of publication with the Boolean/Phrase search mode: Abstracts in Social Gerontology; Health Source: Nursing/Academic Edition; MEDLINE; PsycARTICLES; and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The additional search yielded 19 articles and then PubMed was also utilized to search for relevant articles, separately, which resulted in 37 articles. Identified publications were reviewed and evaluated for relevance with regard to the purpose of this literature review. Articles in English that evaluated an intervention with Hispanic/Latino caregivers of persons with dementia as all or part of the target population were included. Interventions

targeting caregivers that did not include any Hispanic/Latino participants were excluded from the review. Ten articles met the criteria for inclusion in this review.

## Results

There have been a number of descriptive and exploratory studies that have included Hispanic/Latino caregivers.<sup>13,18,23-26</sup> However, intervention studies that have focused on the needs of Hispanic/Latino caregivers with dementia are scant. After reviewing the literature, only 10 published intervention articles were found that included Hispanic/Latino caregivers of older adults with dementia as the target population. Table 1 provides a description of the articles included in this review.

Of these 10 articles, 7 were publications from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) I and II studies,<sup>29,31-36</sup> 2 were pilot studies,<sup>27,28</sup> and 1 focused on describing an intervention but did not provide outcome data for the intervention.<sup>30</sup> All interventions were multisession, meaning that they were implemented over more than 1 time period. The REACH II study<sup>34</sup> was the largest caregiver intervention study and included a large number of Hispanic/Latinos ( $n = 212$ ). Past interventions implemented for Hispanic/Latino caregivers have included telephone support groups, face-to-face support groups, psychoeducational programs such as skills training, respite care, and counseling.<sup>29</sup>

## Interventions Studies Targeting Hispanic/Latino Dementia Caregivers

### REACH I and II

REACH was a 2-phase study conducted at multiple sites throughout the United States.<sup>37</sup> In the first phase, the REACH I study, 15 well-defined interventions were implemented in response to the needs of caregivers of persons with dementia. The REACH I study design consisted of 6 control group conditions and 9 active groups. In phase two, the REACH II study was conducted to examine the impact of a multicomponent intervention on caregivers of persons with dementia.<sup>34</sup> The REACH II intervention was a compilation of the most effective interventions that emerged from the REACH I study.

The REACH II study was inclusive of 3 heterogeneous cultures and ethnicities: Hispanic/Latino or Latino, white, and black dementia caregivers.<sup>34</sup> The REACH II study investigators randomly assigned caregivers to a treatment or control group. A sample of over 600 participants participated in the study: 212 Hispanic/Latinos, 219 white, and 211 black caregivers.<sup>34</sup> The intervention involved a range of strategies such as provision of information, didactic instruction, role-playing, problem solving, skills training, stress management techniques, and telephone support groups to reduce risk in the study's 5 target areas. Education and skills were provided to caregivers for social support, management of problematic behaviors exhibited by the person with ADRD, cognitive approaches, and tactics for enhancing health and managing

**Table 1.** Findings From 10 Interventions Studies Examining Hispanic/Latino Caregivers of Older Adults With Dementia, Published 2000–2011 (in order by year)

Author (year of publication)	Sample characteristics	Type of intervention	Findings
1. Gallagher-Thompson et al (2001) <sup>27</sup>	Hispanic/Latino caregivers (n = 70)	Coping with frustration	Participants in the experimental group (n = 43) were shown to have significantly fewer depressive symptoms and demonstrated increased control of anger and frustration compared to those in the control group (n = 27). Results supported the feasibility of this intervention for distressed Hispanic/Latino caregivers for future studies.
2. Morano and Bravo (2002) <sup>28</sup>	Hispanic/Latino caregivers (n = 20)	Psychoeducation	Participants scored significantly higher on the posttest Alzheimer's knowledge survey as compared with the pretest survey. Participants showed significant improvement on questions regarding their understanding of the progression of Alzheimer's, its etiology, treatment of the disease, knowledge of home- and community-based services, and the function of their local Alzheimer's Association.
3. Czaja and Rubert (2002) <sup>*29</sup>	Cuban American (n = 21) and white caregivers (n = 23)	Computer-generated telephone system	The intervention was easy to implement. Caregivers reported that the ability to communicate with other caregivers, particularly those who did not live nearby, was important to them. The caregivers, especially those who were Cuban American, reported that the system facilitated their ability to communicate with family members and their therapist. Online discussion groups were valuable, an online resource guide was useful.
4. Aranda et al (2003) <sup>30</sup>	Hispanic/Latino caregivers (n = 273)	An interorganizational, community-based collaborative program	An evaluation of services used by caregivers showed a reduction in barriers to care and an increase in services utilization among Hispanic/Latino caregivers. Two primary sources of learning about services were service providers and word of mouth via friend or family member. Approximately 70% of the project's families requested some form of respite care. Results suggested that awareness of services should target nontraditional recruitment sources (i.e. Laundromats, beauty parlors, and storefront botanical shops), as they are points of information sharing for many families in Hispanic/Latino communities. Findings also revealed that this population of caregivers rated themselves as poorer in health and higher in symptoms of depression than the control group.
5. Eisdorfer et al (2003) <sup>*31</sup>	Cuban American (n = 114) and White (n = 111) caregivers	Family therapy and technology-based intervention	Caregivers in the combined family therapy and technology intervention experienced a significant reduction in depressive symptoms at 6 months' follow-up. The 18-month follow-up data suggested that the intervention was particularly beneficial for Cuban American husband and daughter caregivers.
6. Gallagher-Thompson et al (2003) <sup>*10</sup>	Hispanic/Latino (n = 91) and white (n = 110) female caregivers	Coping with caregiving	A psychoeducational group intervention was used to teach caregivers to relax, communicate more assertively, develop strategies to do more small, everyday pleasant activities, and set self-change goals and reward themselves for accomplishments along the way. Results revealed that Hispanic/Latino and white female caregivers in the intervention group reported a significant reduction in symptoms of depression, increased use of adaptive coping strategies, and a decrease in the use of negative coping strategies when compared with those in the comparison group.

(continued)

**Table 1.** (continued)

Author (year of publication)	Sample characteristics	Type of intervention	Findings
7. Bank et al (2006) <sup>33</sup>	White (n = 19) and Cuban American caregivers (n = 22)	Telephone support group	Findings revealed that 81% of the participants found the group “valuable,” largely because of the social and emotional support and useful information obtained from other group members. The majority of caregivers also reported that their participation had increased their knowledge and skills as caregivers.
8. Belle et al (2006) <sup>34</sup>	Hispanic/Latino (n = 212), white (n = 219), and black (n = 211) caregivers and their care recipients with Alzheimer’s disease or related disorders	Multicomponent	A multicomponent intervention that included didactic instruction, role-playing, problem solving, skills training, stress management techniques, and telephone support groups. Hispanic/Latino and white caregivers in the intervention group experienced a significant improvement in their quality of life compared with the control group. Prevalence of clinical depression was lower among caregivers in the intervention group across all races and ethnicities. There were no statistically significant differences in the rate of institutionalization at 6 months’ follow-up.
9. Mitrani et al (2006) <sup>35</sup>	Cuban American and (n = 97) white (n = 84) caregivers	Multicomponent	This multicomponent intervention included didactic instruction, role-playing, problem solving, skills training, stress management techniques, and telephone support groups. Findings revealed that level of family functioning significantly contributed to level distress in both Cuban and white caregivers and partially mediated the relationship between objective burden and distress.
10. Gallagher-Thompson et al (2008) <sup>36</sup>	Middle-aged older women that included white (n = 95) and Hispanic/Latino (n = 89) caregivers	Coping with caregiving	Results revealed that participants in the intervention group, for both Hispanic/Latino and white caregivers, showed improvement from baseline to postintervention on measures of depressive symptoms, overall life stress, and caregiving-specific stress. Caregivers in the experimental group reported increased skills learned from the intervention and greater perceived helpfulness of newly acquired skills than caregivers in the comparison group.

Abbreviation: REACH, Resources for Enhancing Alzheimer’s Caregiver Health.

<sup>a</sup> Part of the REACH I or REACH II study.

stress. The intervention materials were available in Spanish and English. Trained professionals with a minimum educational level of a bachelor's degree delivered the intervention. It was conducted over a 6-month period and included a total of 12 sessions, of which 9 were conducted at the home of the caregiver, lasting 1.5 hours each, and three 30-minute telephone sessions. In addition, 5 structured telephone support group sessions were implemented.<sup>34</sup> Findings from the REACH II study showed significant improvement in the quality of life of Hispanic/Latino caregivers in the intervention group when compared to the control group.<sup>34</sup>

### *Interventions that involved Hispanic/Latino participants in REACH I and II*

**Family therapy and technology-based intervention.** The Miami site of the REACH I study examined the efficacy of a family therapy and technology-based intervention in reducing depressive symptoms among family caregivers of patients with Alzheimer's disease (AD) with 6 and 18 months of follow-up.<sup>31</sup> The study included white ( $n = 111$ ) and Cuban American ( $n = 114$ ) caregivers that were randomized into 3 groups. These groups included a minimal-support control condition, structural ecosystems therapy (SET) plus computer–telephone integrated system, and SET.<sup>31</sup> The intervention included family therapy sessions. Therapists helped caregivers with a specific problem that the caregiver was experiencing, helped them to find various resources available to both the caregiver and the person with AD, and helped caregivers and their families to collaborate in caregiving efforts. Those caregivers who were not able to attend therapy sessions were provided with a computer–telephone integrated system; this was a custom-built application, placed in the participant users' home, which allowed both text and audio to be sent and received during an interactive session. The computer–telephone integrated system allowed participant users to make phone calls, send and receive messages, leave reminders, access databases, and conference simultaneously with several other caregivers of persons with AD.<sup>31</sup>

Results revealed that both Hispanic/Latino and white caregivers in the combined family therapy and technology treatment group (SET plus computer–telephone integrated system) experienced a significant reduction in depressive symptoms at the 6 months interval.<sup>31</sup> After 18 months, follow-up data were collected which indicated that the intervention was particularly beneficial for Cuban American male-spousal and daughter caregivers. The results indicated that information technology has a promising role in alleviating distress and depression among groups of AD caregivers. The data also demonstrated that interventions have differential impacts according to type of ethnic group and the caregiver–patient relationship.<sup>31</sup>

### *Structural Ecosystems Therapy: A Structural Family*

**Intervention.** Mitrani et al<sup>35</sup> evaluated the role of family functioning, within the stress process model of caregiving,<sup>38</sup> in a group of white and Cuban American dementia caregivers by

using a structural family framework. This study was conducted at the Miami site of the REACH I study.<sup>35</sup> The aim of structural family therapy intervention was to identify and correct problematic structures by observing and reshaping them as they occur in family therapy sessions. The focus of the intervention was on process (ie, how family members interact), rather than content (ie, the issues they are dealing with). Results showed that that interventions aimed at changing problematic family interaction patterns and supporting protective family patterns can help to prevent or alleviate the distress in caregivers.<sup>35</sup> Furthermore, the results supported the adoption of family interventions that promote family cohesion, involvement of the care recipient in family activities, resolution of disagreements, and expressions of affection and levity.<sup>35</sup>

**Telephone support group intervention.** In 2006, Bank, Argüelles, Rubert, Eisdorfer, and Czaja<sup>33</sup> implemented a telephone support group intervention with Cuban Americans and white caregivers. A total of 41 Cuban American and white caregivers who were participating at the Miami site of the REACH I program were part of the study.<sup>33</sup> All participants were in the SET intervention augmented by a computer–telephone integrated system intervention.<sup>31</sup> The intervention included telephone support group sessions facilitated by study-certified therapists. Each session lasted approximately 1 hour and was held 2 times per month during the beginning of the intervention period, and monthly after this period. The caregivers were able to select the areas discussed during each group session. Examples of topics they chose included medication management, behavioral interventions, instrumental support, and emotional support. Participants and the group leader provided emotional support. It was reported that 81% of both Cuban American and Caucasian caregivers found telephone support groups valuable due to the social and emotional support along with useful information obtained from other group members. However, there was no statistically significant difference between white and Cuban American caregivers with regard to whether they found the group to be of value to them. The technology was generally well accepted by this diverse sample of caregivers, with relatively few problems reported.<sup>33</sup>

**Telecommunications technology intervention.** Researchers Czaja and Rubert<sup>29</sup> tested an intervention at the Miami site of the REACH I study, which involved a telecommunications system designed to augment a family therapy intervention by enhancing access to formal and informal support services. The goal of the intervention was to facilitate linkages between caregivers and other family members, friends, and other caregivers as well as to facilitate access to information on available resources. A total of 76 Cuban American and white caregivers of patients with ADRD were included in the study. Results showed that the telecommunications system was easy to use and the caregivers found it valuable. The most common reason that the caregivers used the system was to communicate with other caregivers, especially those who did not live nearby. The caregivers, especially the Cuban American

caregivers, reported that the system facilitated their ability to communicate with family members and their therapist. The caregivers also indicated that they found participation in the “online discussion” groups to be very valuable and also found the “online resource guide” useful.

*Coping with caregiving psychoeducational intervention.* Gallagher-Thompson et al<sup>32</sup> published a site-specific analysis of the outcome data from the Palo Alto site of the REACH II study. This intervention examined whether the coping with caregiving psychoeducation program improved certain cognitive and behavioral skills in participants.<sup>32</sup> The target population included white (n = 122) and Hispanic/Latino (n = 91) caregiver participants. These participants were divided into either a treatment or comparison group. Those in the coping with caregiving treatment group were taught a limited number of cognitive-behavioral mood management skills through 2 key approaches. First, education was implemented on how to reduce negative affects of caregiving through relaxation during stressful situations. Caregivers learned how to appraise the care receiver's behavior more realistically and communicate more assertively. A second approach focused on increasing positive mood through skill building. More specifically, caregivers were taught how to identify correlations between mood and caregiving activities, develop strategies to partake in small everyday pleasant activities, and establish self-change goals as well as reward themselves for accomplishments along the way.

The comparison group used an enhanced support group, patterned after typical caregiver support groups in the community. It was designed by using principles outlined in a manual on support groups published by the Alzheimer's Association. Peer support was used for this group, rather than teaching participants how to care for their own needs. The enhanced support group was considered “enhanced” because initially it met weekly rather than monthly, as is typical in the community.<sup>32</sup>

The coping with caregiving treatment condition reported a significant reduction in depressive symptoms. Participants also increased their use of adaptive coping strategies, while at the same time decreasing their use of negative coping skills, results that were not observed in those in the enhanced support group comparison condition. In addition, this study provided empirical support that female caregivers benefited more from a skill-building approach to manage their distress than they did from support group membership alone. The Hispanic/Latino caregivers responded well on key outcome variables, suggesting that Hispanics/Latinos will participate in clinical research and will benefit from their involvement when services are provided that meet their specific needs.

### *Other Intervention Studies That Have Involved Hispanic/Latino Participants*

*Coping with frustration.* Gallagher-Thompson, Arean, Rivera, and Thompson<sup>27</sup> conducted a quasi-experimental study to determine the feasibility of a psychoeducational intervention in a group format for Hispanic/Latino family caregivers

(n = 70) of persons with ADRD. The experimental group included 43 people, while 27 caregivers were placed in a control group (ie, waiting list) for 3 months. Pre- and posttest data were collected. The intervention included a culturally sensitive, 8-week class. Caregivers were taught several cognitive and behavioral skills for coping with the frustrations associated with caregiving. Those in the experimental group reported significantly fewer depressive symptoms. They also exhibited an increased control of feelings of anger and frustration, compared to those in the control group. Results of the study supported the feasibility of providing “coping classes” (in Spanish) to distressed caregivers. Limitations of the study include lack of generalizability, absence of systematic follow-up, and the use of measures not specifically designed for Hispanic/Latino caregivers.<sup>27</sup>

*Psychoeducation.* Researchers Morano and Bravo<sup>28</sup> conducted a pilot intervention study that tested a psychoeducational model designed for Hispanic/Latino caregivers of people with AD. This intervention utilized a 5-day (20 hours total) psychoeducational program aimed at increasing adult (n = 10) and spousal (n = 10) caregiver's understanding and acceptance of AD, coping skills, knowledge of resources, and expression of concerns and emotions of caregiving. Results demonstrated a significant improvement in caregiver knowledge, an increased awareness of community-based services, increased willingness to attend support groups, and overall satisfaction with the program.

*El Portal.* Aranda et al<sup>30</sup> described the El Portal Latino Alzheimer's project based in Los Angeles. This project provided an example of an interorganizational community-based collaboration. Coordinated and culturally sensitive services were provided to Latino older adults with ADRD and their caregivers.<sup>30</sup> Case management and community services were provided by a consortium of nonprofit human services providers and government entities. Two full-time social worker advocates or “servidoras” coordinated case management services, facilitated support groups, and carried out education programs with families and the community. Both care advocates received ongoing consultation and mentoring assistance on issues related to social work practice with Hispanic/Latino families and culturally sensitive service delivery.<sup>30</sup> Although this study does not provide information about the effectiveness of the program, descriptive data were presented as well as information about culturally specific outreach strategies for service delivery. This study also offered ideas for more sophisticated analytical efforts, and modeling or hypothesis testing in the future.

### *Participant Characteristics*

In general, caregivers were included in the studies reviewed if they were over 18 or 21 years of age and were caring for a person with ADRD. Some studies had additional stipulations for inclusion/exclusion in the research for the care receiver as well as the caregiver. Gallagher-Thompson and colleagues<sup>36</sup> excluded caregivers with a diagnosis of cognitive impairments,

Cushing or Addison disease, or terminal illness. Additionally, the care receiver had to have a documented dementia diagnosis of a score of 23 or less on the Mini-Mental State Examination (MMSE), plus not be able to perform 1 or more ADLs or not be able to perform 2 or more instrumental ADLs (IADLs). Other studies, such as Morano and Bravo's<sup>28</sup> psychoeducational model for Alzheimer's caregivers, were less stringent with exclusion and inclusion criteria. In all of the studies reviewed, Hispanic/Latino caregivers were recruited from large urban areas such as Miami, Florida, and Palo Alto, California (C. L. Morano, personal communication, September 27, 2010). Hispanic/Latino caregivers living in the Los Angeles county area in California were also included in the study of Aranda et al.<sup>30</sup>

### *Instruments Used to Evaluate Interventions*

Most of the studies<sup>28,34,36,37</sup> utilized pre- and posttest Likert scale instruments to evaluate the intervention impact. The State-Trait Anger Expression Inventory,<sup>35,27</sup> Structural Family Systems Ratings–Dementia Caregiver, Revised Memory and Behavior Problems Checklist,<sup>31</sup> Katz Activities of Daily Living scale,<sup>31</sup> Lawton Instrumental Activities of Daily Living scale,<sup>31</sup> Perceived Stress scale,<sup>36</sup> Skill Utilization Questionnaire,<sup>36</sup> Center for Epidemiologic Studies–Depression scale,<sup>34,35</sup> Perceived Physical Health,<sup>35</sup> and the Zarit Caregiver Burden Inventory<sup>34</sup> were administered from baseline to posttest in the REACH II study.<sup>34</sup> The Alzheimer's Knowledge Survey was used to evaluate Hispanic/Latino caregivers' knowledge of the origin, treatment, prognosis, and management of AD in the pilot study by Morano and Bravo.<sup>28</sup> Caregivers were also questioned about their knowledge and use of community resources and caregiver support groups.<sup>28</sup> Other instruments used in the studies included the self-reported health, psychological well-being, older adult health and mood index, caregivers' need for support group, adult day care, in-home respite, transportation, legal services, and case management.<sup>30</sup>

### **Discussion**

This review of the literature critically analyzed published interventions that have focused on enhancing the health of Hispanic/Latino caregivers of older adults with dementia. Only 10 articles, most from the same clinical trial, were identified that were published from 2000 to 2011 and met the inclusion criteria for this review. Thus, it seems that more intervention research focusing on Hispanic/Latino caregivers of persons with dementia is warranted. However, the research to date provides valuable information that can be utilized by researchers and clinicians. In order to meet the health needs of this population, it is necessary that interventions be culturally appropriate. Values that the Hispanic/Latino culture endorses should be considered, such as religiosity, familism, and folk remedies.<sup>10,14,39</sup> Bilingual, bicultural health care workers, and/or culturally compassionate health care workers who serve as liaisons to caregivers can enhance communication between caregivers and health care providers.<sup>10,39</sup> Researchers suggested that a lack of

culturally compatible staff necessitates sensitivity training.<sup>40</sup> For example, the fact that Hispanic/Latino caregivers consider caregiving "a hard job done with love," rather than a burden.<sup>41</sup> Thus, language and communication should be considered when presenting information and developing interventions to these caregivers. Additionally, interventions should not only be culturally appropriate but also easy to understand so that caregivers and health care professionals can utilize the intervention on an ongoing basis to support caregivers.

All studies that were reviewed utilized caregiver samples from large urban settings where Hispanic/Latino communities have been established for many decades or centuries, such as large urban and suburban areas in California and Florida.<sup>28,32-34</sup> This review yielded no Hispanic/Latino intervention studies conducted in Texas, Arizona, or New Mexico, which was surprising, given that those states have large populations of Hispanic/Latino elders.<sup>42</sup> Hence, future research intervention research should also include other parts of the country, for example Hispanic/Latinos living in rural areas. In addition, there are many areas in the United States, where new Hispanic/Latino immigrants have recently settled, who are less acculturated.<sup>43</sup> In regions such as the Midwest, Hispanic/Latino communities are forming neighborhoods within large cities.<sup>44</sup> Hispanics/Latinos living in these new small communities may have difficulty accessing health and social services due to isolation and geographic from surrounding cities; barriers include lack of access to transportation, lack of knowledge, financial constraints, mistrust of the health care system, immigration status, and/or language differences.<sup>14</sup> These barriers can make seeking help outside the community very difficult. As a result, most Hispanic/Latino caregivers living in these areas rarely seek help or use resources that might be available to them.

### *Heterogeneity of Hispanics/Latinos*

Given the heterogeneity of the Hispanic/Latino population, caregivers may be of any race and come from any 1 of the more than 20 countries in Latin America.<sup>45</sup> For example, many farm workers who originally came from various countries in Central America and have settled in California and the Midwest are indigenous people. Many are from Mexico, which has over 6 million indigenous inhabitants who speak many distinct languages and who represent 30% of the population.<sup>45,46</sup> Caregivers from these indigenous subcultures may be more comfortable with certain caregiving interventions delivered in their native languages rather than in Spanish or English. Their mores, cultural traditions, and attitudes may differ from other persons of Hispanic/Latino descent.

A large proportion Hispanics/Latinos, particularly older adults, were born outside of the United States. These caregivers may be more comfortable participating when bicultural and/or bilingual professionals implement the interventions. The diversity of Hispanics/Latinos, with their extensive variation in origins, generational experience, languages, and acculturation, must be taken into account in designing research studies, health care services, and creating policy to address the issue of

dementia and the needs of those individuals and families affected by it.<sup>7</sup> Future studies with Hispanic/Latino caregiver interventions should consider culturally tailoring interventions for Hispanic/Latino caregivers from differing subcultures.

### *A Participatory Approach*

Most interventions reviewed used a pre-designed intervention approach, where a hypothesis was proposed as to what would be the impact of a previously developed intervention. Few studies have taken into account caregivers' perceptions of dementia or specific caregiving needs that the Hispanic/Latino population may have. Future research should consider the possibility of discovery-based participatory approaches, where the needs, and/or problems among Hispanic/Latino caregivers are identified first and then used to design intervention tools for a particular community. For example, focus groups could be utilized to assess the help needed and the perspective of Hispanic/Latino caregivers. One such approach is utilizing a participatory action research (PAR) methodology. Kelly states that PAR provides a way for researchers and community members to work together to define a problem, take action, and evaluate an intervention program.<sup>45</sup> The model for PAR has been implemented heavily in community health interventions. This model can be used by health care professionals to conduct community assessments, initiate community collaborations, involve the target population, and include reflection.<sup>47</sup> Utilizing this methodology in developing intervention for Hispanic/Latino caregivers of persons with dementia could provide a novel approach for assessing outcomes and maintaining the intervention after the study is completed.

### *Technology and Caregiving*

As technology changes, caregivers of the future may utilize new technologies for their caregiving needs. Hispanic/Latino caregivers of tomorrow may have a different perception of dementia and, consequently, different needs and/or difficulties than those of today. Technologies such as apps (ie, applications), podcasts, and face-to-face chats in real time could provide endless possibilities for caregivers. For example, Eisdorfer and colleagues' study utilized a computer–telephone integrated system to augment the therapy with Hispanic/Latino caregivers of persons with dementia.<sup>31</sup> Future research including other means of technology may provide additional progress with this method of intervention delivery. Programs such as Skype, Facebook, Twitter, and YouTube can have an impact on caregivers who use these programs for communication and information. For example, future caregiving interventions may integrate technology such as apps regarding how to transfer a person with dementia from the bed to a chair. Caregivers can download apps to an ipod, iphone, or ipad and review them anywhere and anytime they wish. Another form of technology is video chat via Skype, which is free anywhere in the world. Caregivers could video chat with their relative or health care workers living in another country and time zone about their concerns for the person with dementia.

Today's interventions could be updated and applied to future generations of caregivers.

### *Consideration of Acculturation*

Intervention studies' comparing birthplace (eg, Mexico, Puerto Rico, Cuba, etc) of Hispanics/Latinos versus "adopted" living place (eg, California, New York, Florida) may shed some light on acculturation and its effect on caregivers. Past research has shown mixed results regarding caregiver burden for highly acculturated versus less acculturated Mexican American caregivers. Researchers Jolicoeur and Madden found there were dramatic differences between the groups in the levels of satisfaction.<sup>48</sup> Less acculturated Mexican American caregivers experienced greater stress, burden, and significantly lower satisfaction even when they were more clearly fulfilling role obligations and had more family members available to aid in caregiving.<sup>48</sup> On the contrary, Hahn, Kim, and Chiriboga found that when controlling for background characteristics, physical health, social support, and baseline depressive symptoms, Mexican American caregivers who were highly acculturated had a greater number of depressive symptoms compared with Mexican American noncaregivers.<sup>49</sup> A better understanding of within-group differences among Hispanic/Latino caregivers, especially with respect to acculturation, could lead to better tailoring of interventions.

### *Functioning Level of the Care Receiver*

The functioning level of the care receiver and where he or she is in the disease process continuum can influence the impact of a specific intervention method. The needs of Hispanic/Latino caregivers caring for people in various stages of dementia can vary. Few studies have addressed this area of concern in this population. The REACH II study, which was inclusive of Hispanic/Latino caregivers, did not specifically report on the care receiver's stage of dementia, however, researchers did provide the care receiver's level of functioning via ADL/IADL limitations and cognition level (MMSE). Evaluating the functioning role of the care receiver as it relates to interventions targeting Hispanic/Latino caregiver interventions is needed in future research.

Interventions should examine familial collaboration in the sharing of the caregiving role, which could decrease burnout among adult female Hispanic/Latino caregivers. Future changes in the role of the Hispanic/Latino caregiver may be evolving as the role of the primary caregiver change in the future due to acculturation. Such changes can occur because of value differences between generations, occupational mobility, and higher educational attainment.<sup>32</sup> Nevertheless, community-based and family-oriented research programs, which are inclusive of all family members and relatives integrated in the role of caregiving, have the potential to make a substantial impact within the population of Hispanic/Latino caregivers of older adults.

Past studies provide a basis for future development of culturally appropriate interventions for this population. These studies<sup>10,13,14,28,30,34,34,39</sup> have also noted that an interactive and



personal approach to intervention programs with Hispanic/Latino caregivers is crucial for success of interventions with these caregivers. For example, a past study found that home-cooked treats shared with caregiving groups enhanced communication between Hispanic caregivers by bringing them together and allowing them to discuss their caregiving experiences.<sup>28</sup> Conversation via these informal discussions was noted as helpful as, or more helpful than, formal education presentations.<sup>28</sup> Gallagher-Thompson et al<sup>10</sup> suggested that interventions should be short-term, active-directive, problem-focused, and skill-enhancing forms of treatment. Cost effective, real-world, community-based interventions are necessary for caregivers to plan and implement care for their elderly loved one. It is important for health care professionals to find a viable solution to caregiver burnout and the negative health outcomes Hispanic/Latino caregivers experience from caregiving. Health care professions that work with Hispanic/Latino caregivers of persons with dementia are in a prime position to improve the quality of life and health of these caregivers. Professionals working in hospitals, adult day care centers, senior centers, community-based elder care agencies, and clinics must possess the knowledge and skills to understand, intervene, and educate Hispanic/Latino dementia caregivers.

## Conclusion

This literature review analyzed current intervention research literature regarding Hispanic/Latino caregivers of older adults. While a number of descriptive and exploratory studies have focused on Hispanic/Latino dementia, few intervention studies have been conducted with Hispanic/Latino caregivers of older adults. Evidence-based interventions are needed to facilitate and improve caregiving and health maintenance among the growing number of Hispanic/Latino caregivers and Hispanic/Latino older adults. These interventions must build on the cultural strengths that Hispanic/Latino dementia caregivers possess. Thus, culturally specific interventions may prove beneficial and help caregivers to access resources and alleviate the stress associated with caregiving.

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## Note

1. Various Spanish-speaking ethnic groups in the United States identify with either the terms Hispanic or Latino or both. For this

article, the term Hispanic/Latino will be used throughout the article to be inclusive of all ethnic groups from countries in Latin America.

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