Developing Culturally Sensitive Dementia Caregiver Interventions: Are We There Yet?

Anna M. Nápoles, PhD, MPH[1], **Letha Chadiha, PhD**[2], **Rani Eversley, PhD**[3], and **Gina Moreno-John, MD**[1]

Letha Chadiha: lethac@umich.edu; Rani Eversley: Rani.Eversley@ucsf.edu; Gina Moreno-John: ginam@medicine.ucsf.edu

[1]Center for Aging in Diverse Communities, Division of General Internal Medicine, Department of Medicine, University of California San Francisco (UCSF), San Francisco, CA

[2]School of Social Work, University of Michigan, Ann Arbor, MI

[3]Department of Social and Behavioral Sciences, UCSF, San Francisco, CA

Abstract

Despite evidence of ethnic differences in family caregivers' experiences, the extent to which caregiver interventions are culturally tailored to address these differences is unknown. A systematic review of literature published from 1980–2009 identified: differences in caregiving experiences of African American, Latino and Chinese American caregivers; psychosocial support interventions in these groups; and cultural tailoring of interventions. Ethnic differences in caregiving occurred at multiple levels (intrapersonal, interpersonal, environmental) and in multiple domains (psychosocial health, life satisfaction, caregiving appraisals, spirituality, coping, self-efficacy, physical functioning, social support, filial responsibility, familism, views toward elders, use of formal services and health care). Only 18 of 47 intervention articles reported outcomes by caregiver ethnicity. Only 11 reported cultural tailoring; 8 were from the REACH initiative. Cultural tailoring addressed: familism, language, literacy, protecting elders, and logistical barriers. Results suggest that more caregiver intervention studies evaluating systematically the benefits of cultural tailoring are needed.

Keywords

cultural sensitivity; cultural competence; dementia caregivers; Latinos; African Americans; Chinese Americans; support interventions

INTRODUCTION

Older segments of the U.S. population are not only growing in size, they are also becoming more ethnically diverse. In 2006, 81 percent of the U.S. older population (aged 65+) was non-Latino White, 9 percent was African American, 3 percent was Asian American, and 6 percent was Latino. By 2050, projections indicate that the composition of the older population will be 61% non-Latino White, 18 percent Latino, 12 percent African American,

CORRESPONDING AUTHOR: Anna M. Nápoles, PhD, MPH, University of California San Francisco, 3333 California Street, Suite 335, San Francisco, CA 94118-1944, USA, Phone: 415 476-6290, Fax: 415 502-8291, anapoles@ucsf.edu.

and 8 percent Asian American, highlighting the increasing numbers of older ethnic minorities. [1]

Consistent with these demographic changes, we are also observing a growing number of older persons with Alzheimer's disease (AD) and related dementias. [2] Some ethnic minority groups bear a disproportionately greater burden associated with AD and related dementias. Studies have found higher prevalence and incidence rates of dementias and AD among African Americans and Latinos, while Asian Americans had comparable rates to Whites. [3]

Compared to Whites, rates of institutionalization of minority elders with dementia tend to be lower and reliance on family caregivers seems to be greater. [4, 5] In general, family caregivers who report high stress and strain are at high risk of psychological and physical morbidity due to the challenges of caring for older persons who may have both poor cognitive and physical functioning. [6–9] Maintaining the health of family caregivers will become more important as gaps in the availability of formal supportive services become more acute and widespread. Psychosocial support services, especially those that focus on caregiver coping skills training, are promising interventions for reducing caregiver burden and depression. [10–13] Reducing caregiver stress delays and reduces nursing home admissions as well. [14, 15]

Substantial evidence exists that the caregiving experiences of ethnic minority caregivers in the U.S. differ significantly from those of White caregivers. [16] Appraisals of caregiving burden and depression tend to vary by ethnicity. [7] African American caregivers tend to report lower levels of caregiver burden and depression than White caregivers, while Latino and Asian American caregivers report higher levels of depression. [7, 17] Cultural explanations for these ethnic differences in caregiving experiences have pinpointed differences in familism, ethnic group identity, levels of acculturation, and related cultural values and beliefs, such as reciprocity, sense of duty, and God's will. [18–23]

Conceptually, an ethnic group is one having a shared heritage, ancestry, religion, language or common culture. [16] A consensual definition of culture found in the literature consists of shared group behaviors and norms, such as traditions, values, beliefs, attitudes, symbols, language, religion, and social roles of an ethnic group. [16, 20, 46, 100] Cultural tailoring has been defined as "the development of interventions, strategies, messages and materials to conform with specific cultural characteristics." [24] Cultural tailoring can include incorporation of themes, messages and graphics found to be consistent with the values and beliefs shared by subgroups, e.g., African Americans. [24]

Despite substantial evidence of ethnic, racial and cultural variations in caregiving, little research has addressed the extent to which psychosocial interventions for family caregivers are effective and culturally appropriate for specific ethnic groups. [6] Because of variability in the needs of ethnically diverse caregivers, some degree of tailoring to individuals that considers their cultural context is warranted. [25–27] Yet optimal methods for culturally tailoring psychosocial interventions for ethnic minority caregivers are not well understood. In this study we addressed the following research question: to what extent does current psychosocial support intervention research involving African American, Latino, and Chinese American family caregivers of persons with dementia incorporate what we know about ethnic differences in caregiving? We sought to examine the degree to which caregiver psychosocial interventions targeting these ethnic groups, culturally tailor the interventions. Operationally, for the purposes of this review, we defined cultural tailoring as the development or adaptation of a caregiver intervention with attention to ethnicity-specific factors identified in the literature, that is, ethnic group specific evidence-based differences in caregiving.

METHODS

We conducted two systematic literature reviews. In the first systematic review we identified ethnic group differences in the caregiving experiences of ethnically diverse family caregivers of people with dementia. In the second review, we examined the extent to which psychosocial support interventions for ethnically diverse caregivers incorporate evidence of ethnicity-specific differences in dementia caregiving in designing their interventions.

We focused these reviews on African American, Latino, and Chinese American caregivers because these groups represent the largest ethnic minority groups in the United States. Because 90% of Latinos in the U.S. are represented by three national origin subgroups, most of whom are of Mexican origin (67%), and they share the same language of origin, we represent data for Latinos as a whole although we acknowledge that these data may mask subgroup differences. [28] Asian Americans are very heterogeneous in terms of language, nativity, culture, national origins, and time period of migration to the United States. [29] Since Chinese Americans represent the largest Asian American group in the U.S. (21% of Asian Americans), [30] we reviewed any studies that focused on Chinese Americans; however, we also included studies that reported data on Asian Americans as a whole since there were so few studies conducted among Chinese Americans compared to African Americans and Latinos.

Systematic review to identify ethnic differences in caregiving

First, we conducted a systematic literature review to identify ethnic differences in the dementia caregiving experiences of African American, Latino, and Chinese/Asian American family caregivers. We used a broad systematic review approach to allow us to capture findings from a breadth of studies including those that were qualitative in nature. Systematic reviews have been criticized for the use of reductionist and standardized models that fail to acknowledge individual variability and the influence of contextual variables. [31] Including qualitative data in reviews helps address these limitations, which may be especially important in a review such as this one that seeks to examine ethnic differences in caregiver experiences.

Inclusion criteria for this part of the study were: articles published from 1980 through April 2009, in English, included human data specific to African American, Latino, Chinese/Asian American family caregivers of people with dementia, and reported on physical and mental health of caregivers. As previously mentioned, since there were so few studies of Chinese Americans and many studies did not distinguish between Asian American subgroups, we included studies reporting on Chinese or Asian Americans.

All abstracts were reviewed to identify articles that indicated that one of the targeted ethnic groups differed in a statistically significant way from another ethnic group on the major outcome variables. We also included studies of single ethnic groups that demonstrated a descriptive within group finding with respect to the caregiver experience that was corroborated in a multiple ethnic group study as being unique to that group. Review articles that examined ethnic differences in caregiving were also included. The full articles were pulled to identify significant ethnic differences not reported in the abstracts. The goal was to be as inclusive as possible to generate a rich framework of cultural factors that influence family caregiving and that vary across racial/ethnic groups. Multi-ethnic group studies that found no differences by race or ethnicity were not included.

Conceptually, these ethnicity-specific factors were grouped by the level at which they operate, namely, at the intrapersonal (e.g., self-efficacy; coping strategies), interpersonal (e.g., relationship between caregiver and care recipient), and environmental (use of formal

supportive services) levels. We grouped these factors by the level at which they operate to facilitate the identification of potential interventions and their targeted scope.

Systematic review to assess nature and extent of cultural tailoring

For the second systematic review, using the total search results obtained in the first review, we separated out those studies that consisted of caregiver support interventions conducted in one or more of the targeted ethnic groups. The systematic review of interventions assessed the extent to which the evidence-based ethnicity-specific factors identified in the first review (ethnic group specific differences in the experiences of caregivers) were incorporated into intervention studies targeting African American, Latino, and Chinese American family caregivers of persons with dementia. The extent to which these empirically derived cultural factors were incorporated in the design and delivery of those interventions was viewed as a global indicator of their cultural competence.

Inclusion criteria for the second systematic review were: psychosocial support intervention for family caregivers of people with dementia, conducted in the U.S., and reported stratified caregiver health outcomes for African Americans, Latinos, or Chinese Americans, or overall results if they tested for and found no ethnic differences. We did not restrict these studies to controlled trials as we wanted to include preliminary tests of interventions (pilot or feasibility studies).

Search method

We searched the following electronic data bases: CINAHL (Cumulative Index to Nursing and Allied Health Literature), PsychINFO, PubMed, and Sociological Abstracts. Searches were performed using the following keywords: African American OR Black OR Hispanic American OR Hispanic OR Latino OR Asian Americans OR Chinese American OR Chinese OR ethnic group OR minority group AND caregiver AND dementia AND quality of life OR health status OR physiological OR mental health OR depression OR anxiety OR stress OR personal satisfaction OR self-efficacy AND 1980:2009. Searches were not restricted by study design to ensure the inclusion of qualitative and quantitative studies. Additionally, the reference lists of all relevant studies and review articles were reviewed for other potentially relevant articles.

Selection and data extraction methods

Selection of the relevant abstracts and articles was performed by two independent reviewers. Disagreements on the eligibility of articles occurred in only a few cases and were discussed until consensus was reached. Two reviewers independently abstracted the published articles.

For the review of ethnicity-specific cultural factors, a data abstraction form was used to collect the following study characteristics: 1) the citation; 2) the ethnic groups included in the study; 3) the sample sizes by ethnicity; and 4) a narrative description of any differences across ethnic groups or within a cultural group. For the review of the cultural tailoring of behavioral interventions, a data abstraction form was used to obtain the following: 1) the citation; 2) study design; 3) sample and setting; 4) description of the intervention and control conditions; 5) outcome measures; 6) cultural adaptations that were made for the group(s); and 7) the main findings.

RESULTS

The combined searches yielded a total of 1,438 unique citations. Of these, from the abstracts we identified 78 studies (some had multiple ethnic groups) that reported significant differences in the caregiving experiences of African Americans, Latinos, or Chinese/Asian

Americans and 47 studies of psychosocial support interventions for family caregivers of people with dementia that included African Americans, Latinos or Chinese Americans.

Systematic review of ethnic differences in caregiving

Table 1 describes the domains and subdomains of ethnicity-specific factors for which ethnic differences were found and the number of studies by domain and ethnic group. The majority of these studies were conducted in African Americans (55 studies), followed by Latinos (33), and Chinese or Asian Americans (20).

Ethnic differences in caregiving were observed at multiple levels (intrapersonal, interpersonal, and environmental) and across multiple domains (psychosocial health, life satisfaction, appraisals of caregiving, spirituality, coping strategies, self-efficacy, physical functioning, social support, filial responsibility, familism, conceptualizations of care recipient's dementia and aging, use of formal support services, and use of health care). Most studies involved concepts that appear to operate at the individual or intrapersonal level, followed by studies of interpersonal concepts relating to relationships between caregivers, care recipients, and others. Fewer studies addressed environmental level factors, such as access and use of formal support and health care services. The domains that were most frequently studied were appraisals of caregiving (33 studies), spirituality (20), psychosocial health (20), filial responsibility (17), familism (14), and use of formal support services (13).

The most frequently documented cultural differences for African American caregivers were better psychosocial health, more positive appraisals of caregiving, and greater spirituality or use of prayer than a comparison group, which most often consisted of White caregivers. Although reported less frequently, African Americans also tended to report more social support, stronger beliefs about filial responsibility, a higher value placed on extended family networks, and a greater aversion to institutionalization of relatives.

For Latinos, the most frequently occurring differences were worse psychosocial health, more positive appraisals of coping, greater spirituality, stronger beliefs about filial responsibility and familism, and a greater aversion to institutionalization of relatives.

Among Asian Americans, although fewer studies were available, the most commonly found differences related to strong beliefs about filial responsibility and misconceptions or stigmatization related to dementia.

Systematic review of cultural tailoring of psychosocial support interventions

We identified 47 studies that involved psychosocial support interventions for family caregivers. Only 18 of the 47 psychosocial intervention studies met inclusion criteria for the study; the rest did not report outcomes stratified by caregiver ethnicity (Table 2). Ten studies included African Americans, 11 included Latinos, and only one included Chinese Americans. Of the 18 intervention studies meeting criteria, only 11 considered cultural factors in their design; 8 of the 11 that addressed cultural tailoring were from one multi-site research initiative, the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program. Cultural tailoring addressed: familism, language, bilingual-bicultural staff, literacy, need for advocacy, protecting elders, and logistical barriers. There were too few studies to allow for conclusive interpretations of the association of cultural tailoring of interventions and their effectiveness for specific ethnic groups.

Among African Americans, several studies using multicomponent skills training or social support interventions demonstrated improvements in terms of decreased burden, [32–34] decreased upset with memory related problems of the care recipient, [26] better affect, [26] more positive ratings of caregiving, [35] greater happiness, [36] and greater self-efficacy for providing

assistance with Instrumental Activities of Daily Living (IADLs). [37] Most of these studies described no or little ethnic tailoring of interventions.

Among Latinos, several skills training or psychoeducational interventions demonstrated decreased burden, [32] decreased depression, [38, 26, 39–42] decreased negative coping, [40] decreased stress, [41] decreased behavioral bother, [41] better anger control, [39] and better self-efficacy. [42] Most of these interventions were associated with the REACH studies, some of which involved substantial cultural tailoring.

The one randomized trial in Chinese Americans involved an in-home behavioral management intervention that demonstrated decreased depression and behavioral bother. [43] This study was sensitive to several cultural factors among Chinese Americans including the need to provide services in the home and consideration of language differences.

DISCUSSION

In the present study, we sought to describe ethnic differences in caregiving and the extent to which caregiver interventions were culturally tailored to take into account these differences. We found numerous differences among ethnic minority dementia caregivers in outcomes of caregiving and cultural factors that merit further investigation as potential mediators and moderators of those outcomes. Despite these differences, most dementia caregiver intervention studies that included ethnic minority members failed to report their findings stratified by race/ethnicity. Even fewer studies reported tailoring their interventions for a particular cultural or ethnic group. The lack of attention to cultural tailoring of dementia caregiver interventions is concerning, given the growing number of ethnically diverse older adults in this country.

Consistent with previous reviews, our review found numerous racial/ethnic differences in the experiences of family caregivers of people with dementia. [4, 5, 7, 17] Such differences can be linked to a variety of cultural, socioeconomic, and language factors. To better inform advances in the design of psychosocial support interventions for ethnically diverse caregivers, theory-based multidimensional models of caregiver experiences and outcomes that take into account the roles of culture, ethnicity, and structural inequality are needed. [44–46] A comprehensive model of caregiver outcomes must also include positive outcomes (e.g., mastery, gratification). Paradoxically, although African American and Latino caregivers may experience more financial and resource constraints in meeting their caregiver demands, they generally report less caregiver stress, burden, and depression than White caregivers. [4, 17, 20, 47, 48] Possible mechanisms include appraisal of caregiving as less stressful, greater self-efficacy for caregiving, [17, 47] and greater use of religious coping. [49] These positive coping strategies could be tested in future intervention studies that aim to preserve the well-being of minority caregivers.

Pinquart and Sörensen offer a promising conceptual model that explains ethnic differences in caregiving in terms of differences in personal resources, stressors, background characteristics (including individual level income), and baseline differences in physical and mental health. [7] Investigators from the REACH program also offer a promising model of the sociocultural context of caregiving that includes care recipient characteristics, caregiver strengths and vulnerabilities, the physical environment, familial and social support networks, and their effects on physical and mental health and functioning. [50] The variables in our framework of ethnic differences in caregiving experiences can be grouped according to these models to suggest potential mediators and moderators that may help explain ethnic differences in health outcomes. For example, evidence suggests that African American dementia caregivers experience better mental health and more positive appraisals of

caregiving compared to other ethnic minority groups. The use of religious coping strategies and informal support partially explain this ethnic advantage. [49]

The complexity of models that will be needed for both within and across ethnic group studies is becoming increasingly obvious. For example, Dilworth-Anderson and colleagues found that among African Americans, high caregiving mastery was associated with poorer psychosocial health, possibly reflecting a cultural script referred to as "John Henryism" or prolonged high-effort in stressful situations. [23] They also found a curvilinear relationship between scores on a cultural justification for caregiving scale and health such that a very weak and very strong culturally-based rationale for caregiving was associated with poorer psychosocial health. They speculated that those with very high cultural rationale for caregiving were doing so primarily out of a sense of obligation and that those with low cultural justifications for caregiving were providing care out of necessity perhaps because no one else was available. Models also need to test for interaction effects of ethnicity and moderating or treatment variables. For example, the effects of race/ethnicity on strain may depend on the extent of resources available (e.g., social support, spirituality) such that when resources are low, all ethnic groups experience equal levels of strain. [35] A significant interaction effect of ethnicity and treatment on psychosocial health outcomes was found in the REACH studies such that there were significantly greater improvements on five domains for Latinos and Whites in the intervention group compared to controls, but for African Americans improvements depended upon the relationship between caregivers and care-recipients. [32]

Psychosocial support interventions to promote the health of ethnically diverse dementia caregivers must address cultural attitudes, such as distrust, perceived discrimination, reticence toward having strangers in the home, and preferences for taking care of elders without support from those outside the family. However, in our review, we found that these factors are seldom addressed in intervention studies. Asian American caregivers frequently report feeling too proud to accept services or not wanting outsiders in the home. [51] Among Whites and Latinos, use of supportive home care services was related to perceived need for and awareness of such services. [21] These studies along with the effectiveness of psychoeducational approaches cited in our review suggest that providing information and addressing barriers to supportive home care services is a promising strategy although as the aging population increases the availability of these services may become scarcer. [52]

The extent of evidence on ethnic differences in caregiving experiences, [25–27] along with evidence from the only multi-site intervention study focused on the health of ethnically diverse dementia caregivers, the REACH program, support cultural tailoring of psychosocial support interventions for family caregivers. The REACH studies demonstrated the effectiveness of in-home, telephone, and small group support on depression, quality of life, and adaptive coping strategies of ethnically diverse caregivers. [32, 40] Populations studied include African Americans, Chinese Americans and Latinos. [40, 43] The REACH program stands out among the literature because of the rigorous, comprehensive methods used to develop and empirically test caregiver support interventions among various ethnic groups. The results of our comprehensive review point to the need for rigorously testing the effectiveness of culturally tailored interventions and the specific mechanisms through which they affect health outcomes among specific ethnic subgroups.

In conclusion, although the literature on minority caregivers is growing, randomized trials of interventions to promote their physical and mental health are limited. What is clear from the evidence is that programs, such as REACH, which take into account the needs and cultural nuances of ethnically diverse groups of caregivers can effectively improve coping skills, as well as quality of life. More research is needed that addresses socioeconomic and language

barriers, and considers how to integrate religious coping for some caregiver groups. [20] Caregiving places family members at increased risk of adverse mental and physical outcomes. [53] Minority caregivers may be at particularly high risk because their care recipients have a higher prevalence of dementia-related behaviors [54] and greater physical and functional impairment, [7] and they are less likely than White caregivers to utilize formal support services. With more evidence regarding factors that are associated with improved health outcomes of minority caregivers, we can develop and better target interventions to improve their health. Our review focuses attention on the importance of this work to prepare to meet the needs of a growing U.S. population of ethnically diverse older adults and their caregivers.

Acknowledgments

References

1. Federal Interagency Forum on Aging-Related Statistics, Older Americans. 2008: Key Indicators of Well-Being. Washington, D.C: U.S. Government Printing Office; 2008. p. 1-160.

2. Alzheimer's Disease International. World Alzheimer's Report 2009 Executive Summary. London, UK: Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc; 2009. p. 1-21.

3. Manly, JJ.; Mayeux, R. Ethnic Differences in Dementia and Alzheimer's Disease. In: Anderson, NB.; Bulatao, RA.; Cohen, B., editors. Critical Perspectives on Racial and Ethnic Differences in Health in Late Life. Washington, D.C: National Research Council, The National Academies Press; 2004.

4. Connell CM, Gibson GD. Racial, ethnic, and cultural differences in dementia caregiving: review and analysis. Gerontologist. 1997; 37:355–64. [PubMed: 9203759]

5. Dilworth-Anderson P, Williams IC, Gibson BE. Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980–2000). Gerontologist. 2002; 42:237–72. [PubMed: 11914467]

6. Connell CM, Janevic MR, Gallant MP. The costs of caring: impact of dementia on family caregivers. J Geriatr Psychiatry Neurol. 2001; 14:179–87. [PubMed: 11794446]

7. Pinquart M, Sorensen S. Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. Gerontologist. 2005; 45:90–106. [PubMed: 15695420]

8. Roth DL, Perkins M, Wadley VG, Temple EM, Haley WE. Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults. Qual Life Res. 2009; 18:679–88. [PubMed: 19421895]

9. Schulz R, Martire LM. Family caregiving of persons with dementia: Prevalence, Health Effects, and Support Strategies. American Journal of Geriatric Psychiatry. 2004; 12:240–249. [PubMed: 15126224]

10. Cooke DD, McNally L, Mulligan KT, Harrison MJ, Newman SP. Psychosocial interventions for caregivers of people with dementia: a systematic review. Aging Ment Health. 2001; 5:120–35. [PubMed: 11511059]

11. Schulz R, O'Brien A, Czaja S, et al. Dementia caregiver intervention research: In search of clinical significance. The Gerontologist. 2002; 42:589–602. [PubMed: 12351794]

12. Selwood A, Johnston K, Katona C, Lyketsos C, Livingston G. Systematic review of the effect of psychological interventions on family caregivers of people with dementia. J Affect Disord. 2007; 101:75–89. [PubMed: 17173977]

13. Thompson CA, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J. Systematic review of information and support interventions for caregivers of people with dementia. BMC Geriatr. 2007 Jul 27.7:18. [PubMed: 17662119]

14. Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci. 2009; 11(2):217–28. [PubMed: 19585957]

15. Spillman BC, Long SK. Does high caregiver stress predict nursing home entry? Inquiry. 2009; 46:140–61. [PubMed: 19694388]

16. Aranda MP, Knight BG. The influence of ethnicity and culture on the caregiver stress and coping process: a sociocultural review and analysis. Gerontologist. 1997; 37:342–54. [PubMed: 9203758]

17. Janevic MR, Connell CM. Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. Gerontologist. 2001; 41:334–47. [PubMed: 11405431]

18. Scharlach AE, Kellam R, Ong N, Baskin A, Goldstein C, Fox PJ. Cultural attitudes and caregiver service use: lessons from focus groups with racially and ethnically diverse family caregivers. J Gerontol Soc Work. 2006; 47:133–56. [PubMed: 16901881]

19. Angel RJ, Angel JL, Lee GY, Markides KS. Age at migration and family dependency among older Mexican immigrants: recent evidence from the Mexican American EPESE. Gerontologist. 1999; 39:59–65. [PubMed: 10028771]

20. Coon DW, Rubert M, Solano N, et al. Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: findings from the REACH study. Aging Ment Health. 2004; 8:330–45. [PubMed: 15370049]

21. Crist JD, Woo SH, Choi M. A comparison of the use of home care services by Anglo-American and Mexican American elders. J Transcult Nurs. 2007; 18:339–48. [PubMed: 17911574]

22. Kosloski K, Schaefer JP, Allwardt D, Montgomery RJ, Karner TX. The role of cultural factors on clients' attitudes toward caregiving, perceptions of service delivery, and service utilization. Home Health Care Serv Q. 2002; 21:65–88. [PubMed: 12665072]

23. Dilworth-Anderson P, Goodwin PY, Williams SW. Can Culture Help Explain the Physical Health Effects of Caregiving Over Time Among African American Caregivers? Journals of Gerontology: Series B: Psychological Sciences and Social Sciences. 2004; 59B:S138–S145.

24. Pasick RJ. Response to Kreuter and Skinner: consensus regarding use of the terms targeting and tailoring. Health Educ Res. 2001; 16:503–8. [PubMed: 11525396]

25. Gallagher-Thompson D, Haley W, Guy D, et al. Tailoring psychological interventions for ethnically diverse dementia caregivers. Clinical Psychology: Science and Practice. 2003; 10:423–438.

26. Gitlin LN, Belle SH, Burgio LD, et al. Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. Psychol Aging. 2003; 18:361–74. [PubMed: 14518800]

27. Schulz R, Burgio L, Burns R, et al. Resources for Enhancing Alzheimer's Caregiver Health (REACH): overview, site-specific outcomes, and future directions. Gerontologist. 2003; 43:514–20. [PubMed: 12937330]

28. U.S. Census Bureau. The Hispanic Population in the United States: March 2002. Vol. 2009. U.S. Department of Commerce; 2003.

29. Chen MS Jr, Shinagawa SM, Bal DG, et al. Asian American Network for Cancer Awareness, Research, and Training's legacy. The first 5 years Cancer. 2006; 107:2006–14.

30. Bureau USC. The Asian Population: 2000. Vol. 2009. U.S. Department of Commerce; 2002.

31. Dixon-Woods M, Sutton A, Shaw R, et al. Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. J Health Serv Res Policy. 2007; 12:42–7. [PubMed: 17244397]

32. Belle SH, Burgio L, Burns R, et al. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial. Ann Intern Med. 2006; 145:727–38. [PubMed: 17116917]

33. Burgio L, Stevens A, Guy D, Roth DL, Haley WE. Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. Gerontologist. 2003; 43:568–79. [PubMed: 12937335]

34. Dang S, Remon N, Harris J, et al. Care coordination assisted by technology for multiethnic caregivers of persons with dementia: a pilot clinical demonstration project on caregiver burden and depression. J Telemed Telecare. 2008; 14:443–7. [PubMed: 19047456]

35. Hilgeman MM, Durkin DW, Sun F, et al. Testing a theoretical model of the stress process in Alzheimer's caregivers with race as a moderator. Gerontologist. 2009; 49:248–61. [PubMed: 19363019]

36. Sistler A, Washington KS. Serenity for African American caregivers. Social Work with Groups. 1999; 22:49–62.

37. Gitlin LN, Corcoran M, Winter L, Boyce A, Hauck WW. A randomized, controlled trial of a home environmental intervention: effect on efficacy and upset in caregivers and on daily function of persons with dementia. Gerontologist. 2001; 41:4–14. [PubMed: 11220813]

38. Eisdorfer C, Czaja SJ, Loewenstein DA, et al. The effect of a family therapy and technology-based intervention on caregiver depression. Gerontologist. 2003; 43:521–31. [PubMed: 12937331]

39. Gallagher-Thompson D, Arean P, Rivera P, Thompson LW. A psychoeducational intervention to reduce distress in Hispanic family caregivers: Results of a pilot study. Clinical Gerontologist. 2001; 23:17–32.

40. Gallagher-Thompson D, Coon DW, Solano N, Ambler C, Rabinowitz Y, Thompson LW. Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: site-specific results from the REACH national collaborative study. Gerontologist. 2003; 43:580–91. [PubMed: 12937336]

41. Gallagher-Thompson D, Gray HL, Dupart T, Jimenez D, Thompson LW. Effectiveness of cognitive/behavioral small group intervention for reduction of depression and stress in non-Hispanic White and Hispanic/Latino women dementia family caregivers: Outcomes and mediators of change. Journal of Rational-Emotive & Cognitive Behavior Therapy. 2008; 26(4):286–303.

42. Waelde LC, Thompson L, Gallagher-Thompson D. A pilot study of a yoga and meditation intervention for dementia caregiver stress. Journal of Clinical Psychology. 2004; 60:677–687. [PubMed: 15141399]

43. Gallagher-Thompson D, Gray HL, Tang PC, et al. Impact of in-home behavioral management versus telephone support to reduce depressive symptoms and perceived stress in Chinese caregivers: results of a pilot study. Am J Geriatr Psychiatry. 2007; 15:425–34. [PubMed: 17463192]

44. Dilworth-Anderson P, Gibson BE. The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. Alzheimer Dis Assoc Disord. 2002; 16 (Suppl 2):S56–63. [PubMed: 12351916]

45. Hinton L. Improving care for ethnic minority elderly and their family caregivers across the spectrum of dementia severity. Alzheimer Dis Assoc Disord. 2002; 16 (Suppl 2):S50–5. [PubMed: 12351915]

46. Milne A, Chryssanathopoulou C. Dementia care-giving in Black and Asian populations: reviewing and refining the research agenda. Journal of Community & Applied Social Psychology. 2005; 15:319–337.

47. Haley WE, Roth DL, Coleton MI, et al. Appraisal, coping, and social support as mediators of well-being in black and white family caregivers of patients with Alzheimer's disease. J Consult Clin Psychol. 1996; 64:121–9. [PubMed: 8907091]

48. Lawton MP, Rajagopal D, Brody E, Kleban MH. The dynamics of caregiving for a demented elder among black and white families. J Gerontol. 1992; 47:S156–64. [PubMed: 1624710]

49. Richardson RC, Sistler AB. The well-being of elderly Black caregivers and noncaregivers: a preliminary study. Journal of Gerontological Social Work. 1999; 31:109–117.

50. Gallagher-Thompson, D.; Arean, PA.; Coon, D., et al. Development and implementation of intervention strategies for culturally diverse caregiving populations. In: Schulz, R., editor. Handbook on Dementia Caregiving: Evidence-based Interventions in Family Caregiving. New York, NY: Springer Publishing Company, Inc; 2000. p. 151-185.

51. Li H. Barriers to and unmet needs for supportive services: experiences of Asian-American caregivers. J Cross Cult Gerontol. 2004; 19:241–60. [PubMed: 15243200]

52. Kaye HS, Chapman S, Newcomer RJ, Harrington C. The personal assistance workforce: trends in supply and demand. Health Aff (Millwood). 2006; 25:1113–20. [PubMed: 16835193]

53. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. Gerontologist. 1995; 35:771–91. [PubMed: 8557205]

54. Sink KM, Covinsky KE, Newcomer R, Yaffe K. Ethnic differences in the prevalence and pattern of dementia-related behaviors. J Am Geriatr Soc. 2004; 52:1277–83. [PubMed: 15271114]

55. Clay OJ, Roth DL, Wadley VG, Haley WE. Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. Int J Geriatr Psychiatry. 2008

56. Farran CJ, Miller BH, Kaufman JE, Davis L. Race, finding meaning and caregiver distress. Journal of Aging and Health. 1997; 9:316–333. [PubMed: 10182396]

57. Haley WE, West CA, Wadley VG, et al. Psychological, social, and health impact of caregiving: a comparison of black and white dementia family caregivers and noncaregivers. Psychol Aging. 1995; 10:540–52. [PubMed: 8749581]

58. Haley WE, Perkins EA. Current status and future directions in family caregiving and aging people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities. 2004; 1:24–30.

59. Kaye J. Spirituality and the emotional and physical health of Black and White Southern caregivers of persons with Alzheimer's disease and other dementias. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2001; 61:4651.

60. Miller B, Campbell RT, Farran CJ, Kaufman JE, Davis L. Race, control, mastery, and caregiver distress. J Gerontol B Psychol Sci Soc Sci. 1995; 50:S374–82. [PubMed: 7583816]

61. Roff LL, Burgio LD, Gitlin L, Nichols L, Chaplin W, Hardin JM. Positive aspects of Alzheimer's caregiving: the role of race. Journals of Gerontology: Series B: Psychological Sciences and Social Sciences. 2004; 59B:P185–P190.

62. Roth DL, Haley WE, Owen JE, Clay OJ, Goode KT. Latent growth models of the longitudinal effects of dementia caregiving: a comparison of African American and White family caregivers. Psychol Aging. 2001; 16:427–36. [PubMed: 11554521]

63. Morano CL, Sanders S. Exploring differences in depression, role captivity, and self-acceptance in Hispanic and non-Hispanic adult children caregivers. Journal of Ethnic & Cultural Diversity in Social Work. 2005; 14:27–46.

64. Fox K, Hinton WL, Levkoff S. Take up the caregiver's burden: Stories of care for urban African-American elders with dementia. Culture, Medicine and Psychiatry Special Issue: Aging, ethnicity, and dementia: Family caregiving. 1999; 23:501–529.

65. Adams B, Aranda MaP, Kemp B, Takagi K. Ethnic and gender differences in distress among Anglo American, African American, Japanese American, and Mexican American spousal caregivers of persons with dementia. Journal of Clinical Geropsychology. 2002; 8:279–301.

66. Cox C, Monk A. Minority caregivers of dementia victims: A comparison of Black and Hispanic families. Journal of Applied Gerontology. 1990; 9:340–354.

67. Cox C, Monk A. Hispanic culture and family care of Alzheimer's patients. Health Soc Work. 1993; 18:92–100. [PubMed: 8288146]

68. Harwood DG, Barker WW, Cantillon M, Loewenstein DA, Ownby R, Duara R. Depressive symptomatology in first-degree family caregivers of Alzheimer disease patients: a cross-ethnic comparison. Alzheimer Dis Assoc Disord. 1998; 12:340–6. [PubMed: 9876963]

69. Shurgot GSR, Knight BG. Preliminary study investigating acculturation, cultural values, and psychological distress in Latino caregivers of dementia patients. Journal of Mental Health and Aging. 2004; 10:183–194.

70. Gonzalez EW. Resourcefulness, appraisals, and coping efforts of family caregivers. Issues Ment Health Nurs. 1997; 18:209–27. [PubMed: 9362714]

71. Hinrichsen GA, Ramirez M. Black and white dementia caregivers: a comparison of their adaptation, adjustment, and service utilization. Gerontologist. 1992; 32:375–81. [PubMed: 1500003]

72. Knight BG, McCallum TJ. Heart rate reactivity and depression in African-American and white dementia caregivers: Reporting bias or positive coping? Aging & Mental Health. 1998; 2:212–221.

73. Knight BG, Silverstein M, McCallum TJ, Fox LS. A sociocultural stress and coping model for mental health outcomes among African American caregivers in Southern California. J Gerontol B Psychol Sci Soc Sci. 2000; 55:P142–50. [PubMed: 11833976]

74. Kosberg JI, Kaufman AV, Burgio LD, Leeper JD, Sun F. Family caregiving to those with dementia in rural Alabama: racial similarities and differences. J Aging Health. 2007; 19:3–21. [PubMed: 17215199]

75. Macera C, Eaker E, Goslar P, et al. Ethnic differences in the burden of caregiving. American Journal of Alzheimer's Disease. 1992 Sep-Oct;

76. McCallum TJ. Dementia caregiving and ethnicity: African American caregivers and the sociocultural stress and coping model. Dissertation Abstracts International Section A: Humanities and Social Sciences. 2003; 64:2211.

77. Morycz RK, Malloy J, Bozich M, Martz P. Racial differences in family burden: Clinical implications for social work. Gerontological Social Work with Families. 1987; 10:133–154.

78. Mui AC. Caregiver strain among black and white daughter caregivers: a role theory perspective. Gerontologist. 1992; 32:203–12. [PubMed: 1577316]

79. Picot SJ, Debanne SM, Namazi KH, Wykle ML. Religiosity and perceived rewards of black and white caregivers. Gerontologist. 1997; 37:89–101. [PubMed: 9046710]

80. Toth-Cohen S. Factors influencing appraisal of upset in black caregivers of persons with Alzheimer disease and related dementias. Alzheimer Dis Assoc Disord. 2004; 18:247–55. [PubMed: 15592139]

81. White TM, Townsend AL, Stephens MA. Comparisons of African American and White women in the parent care role. Gerontologist. 2000; 40:718–28. [PubMed: 11131088]

82. Williams IC. Emotional health of black and white dementia caregivers: a contextual examination. J Gerontol B Psychol Sci Soc Sci. 2005; 60:P287–P295. [PubMed: 16260702]

83. Wood JB, Parham IA. Coping with perceived burden: Ethnic and cultural issues in Alzheimer's family caregiving. Journal of Applied Gerontology. 1990; 9:325–339.

84. Young RF, Kahana E. The context of caregiving and well-being outcomes among African and Caucasian Americans. Gerontologist. 1995; 35:225–32. [PubMed: 7750779]

85. John R, Resendiz R, De Vargas LW. Beyond familism?: Familism as explicit motive for eldercare among Mexican American caregivers. J Cross Cult Gerontol. 1997; 12:145–62. [PubMed: 14617933]

86. Phillips LR, de Ardon ET, Komnenich P, Killeen M, Rusinak R. The Mexican-American caregiving experience. Hispanic Journal of Behavioral Sciences. 2000; 22:296–305.

87. Cox C, Monk A. Strain among caregivers: comparing the experiences of African American and Hispanic caregivers of Alzheimer's relatives. Int J Aging Hum Dev. 1996; 43:93–105. [PubMed: 8945642]

88. Levkoff S, Levy B, Weitzman PF. The role of religion and ethnicity in the help seeking of family caregivers of elders with Alzheimer's disease and related disorders. J Cross Cult Gerontol. 1999; 14:335–56. [PubMed: 14618013]

89. Navaie-Waliser M, Feldman PH, Gould DA, Levine C, Kuerbis AN, Donelan K. The experiences and challenges of informal caregivers: common themes and differences among whites, blacks, and hispanics. Gerontologist. 2001; 41:733–41. [PubMed: 11723341]

90. Nkongo NO, Archbold PG. Reasons for caregiving in African American families. Journal of Cultural Diversity. 1995; 2:116–123. [PubMed: 8788848]

91. Picot SJ. Rewards, costs, and coping of African American caregivers. Nurs Res. 1995; 44:147–52. [PubMed: 7761290]

92. Segall MH, Wykle ML. The Black family's experience with dementia. Journal of Applied Social Sciences. 1989; 13:170–188.

93. Wykle M, Segal M. A comparison of black and white family caregivers with dementia. Journal of the National Black Nurses Association. 1991; 5:28–41.

94. Mausbach BT, Coon DW, Cardenas V, Thompson LW. Religious coping among Caucasian and Latina dementia caregivers. Journal of Mental Health and Aging. 2003; 9:97–110.

95. Thompson LW, Solano N, Kinoshita L, Coon DW, Mausbach B, Gallagher-Thompson D. Pleasurable activities and mood: Differences between Latina and Caucasian dementia family caregivers. Journal of Mental Health and Aging. 2002; 8:211–224.

96. Weitzman PF, Chee YK, Levkoff SE. A social cognitive examination of responses to family conflicts by African-American and Chinese-American caregivers. American Journal of Alzheimer's Disease. 1999:14.

97. Depp C, Sorocco K, Kasl-Godley J, Thompson L, Rabinowitz Y, Gallagher-Thompson D. Caregiver self-efficacy, ethnicity, and kinship differences in dementia caregivers. Am J Geriatr Psychiatry. 2005; 13:787–94. [PubMed: 16166408]

98. Valle R, Yamada AM, Barrio C. Ethnic differences in social network help-seeking strategies among Latino and Euro-American dementia caregivers. Aging Ment Health. 2004; 8:535–43. [PubMed: 15724836]

99. Coleman M, Ganong LH, Rothrauff TC. Racial and ethnic similarities and differences in beliefs about intergenerational assistance to older adults after divorce and remarriage. Family Relations Special Issue: Family Gerontology. 2006; 55:576–587.

100. Cox CB, Monk A. Caregivers to Dementia Victims: The Experience of Black and Hispanic Families. Cox, Carole B. 1990

101. Dilworth-Anderson P, Brummett BH, Goodwin P, Williams SW, Williams RB, Siegler IC. Effect of race on cultural justifications for caregiving. J Gerontol B Psychol Sci Soc Sci. 2005; 60:S257–62. [PubMed: 16131626]

102. Clark M, Huttlinger K. Elder care among Mexican American families. Clin Nurs Res. 1998; 7:64–81. [PubMed: 9526315]

103. Henderson JN, Gutierrez-Mayka M. Ethnocultural themes in caregiving to Alzheimer's disease patients in Hispanic families. Clinical Gerontologist. 1992; 11:59–74.

104. Mahoney DF, Cloutterbuck J, Neary S, Zhan L. African American, Chinese, and Latino family caregivers' impressions of the onset and diagnosis of dementia: cross-cultural similarities and differences. Gerontologist. 2005; 45:783–92. [PubMed: 16326660]

105. Neary SR, Mahoney DF. Dementia caregiving: the experiences of Hispanic/Latino caregivers. J Transcult Nurs. 2005; 16:163–70. [PubMed: 15764640]

106. Ishii-Kuntz M. Intergenerational relationships among Chinese, Japanese, and Korean Americans. Family Relations. 1997; 46:23–32.

107. Pang FC, Chow TW, Cummings JL, et al. Effect of neuropsychiatric symptoms of Alzheimer's disease on Chinese and American caregivers. Int J Geriatr Psychiatry. 2002; 17:29–34. [PubMed: 11802227]

108. Zhan HJ. Joy and sorrow: Explaining Chinese caregivers' reward and stress. Journal of Aging Studies. 2006; 20:27–38.

109. Losada A, Shurgot GR, Knight BG, et al. Cross-cultural study comparing the association of familism with burden and depressive symptoms in two samples of Hispanic dementia caregivers. Aging & Mental Health. 2006; 10:69–76. [PubMed: 16338817]

110. Hicks MH, Lam MS. Decision-making within the social course of dementia: accounts by Chinese-American caregivers. Cult Med Psychiatry. 1999; 23:415–52. [PubMed: 10647943]

111. Cloutterbuck J, Mahoney DF. African American dementia caregivers: The duality of respect. Dementia: The International Journal of Social Research and Practice. 2003; 2:221–243.

112. Burns R, Nichols LO, Graney MJ, Martindale-Adams J, Lummus A. Cognitive abilities of Alzheimer's patients: Perceptions of black and white caregivers. International Journal of Aging & Human Development. 2006; 62:209–219. [PubMed: 16625937]

113. Hinton WL, Levkoff S. Constructing Alzheimer's: narratives of lost identities, confusion and loneliness in old age. Cult Med Psychiatry. 1999; 23:453–75. [PubMed: 10647944]

114. Hinton L, Guo Z, Hillygus J, Levkoff S. Working with culture: a qualitative analysis of barriers to the recruitment of Chinese-American family caregivers for dementia research. J Cross Cult Gerontol. 2000; 15:119–37. [PubMed: 14618006]

115. Zhan L. Caring for family members with Alzheimer's disease: perspectives from Chinese American caregivers. J Gerontol Nurs. 2004; 30:19–29. [PubMed: 15359526]

116. Liu D, Hinton L, Tran C, Hinton D, Barker JC. Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. Journal of Cross-Cultural Gerontology. 2008; 23:283–299. [PubMed: 18665444]

117. Giunta N, Chow J, Scharlach AE, Dal Santo TS. Racial and ethnic differences in family caregiving in California. Journal of Human Behavior in the Social Environment. 2004; 9:85–109.

118. Williams SW, Anderson-Dilworth P. Systems of social support in families who care for dependent African American elders. The Gerontologist. 2002; 42:224–236. [PubMed: 11914466]

119. Mausbach BT, Coon DW, Depp C, et al. Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers. J Am Geriatr Soc. 2004; 52:1077–84. [PubMed: 15209644]

120. Valadez AA, Lumadue C, Gutierrez B, de Vries-Kell S. Family caregivers of impoverished Mexican American elderly women: the perceived impact of adult day care centers. Families in Society. 2005; 86:384–392.

121. Hinton L, Franz C, Friend J. Pathways to dementia diagnosis: evidence for cross-ethnic differences. Alzheimer Dis Assoc Disord. 2004; 18:134–44. [PubMed: 15494619]

122. Lampley-Dallas VT, Mold JW, Flori DE. Perceived needs of African-American caregivers of elders with dementia. J Natl Med Assoc. 2001; 93:47–57. [PubMed: 12653382]

123. Chow TW, Liu CK, Fuh JL, et al. Neuropsychiatric symptoms of Alzheimer's disease differ in Chinese and American patients. Int J Geriatr Psychiatry. 2002; 17:22–8. [PubMed: 11802226]

124. Cox C. Race and caregiving: Patterns of service use by African American and White caregivers of persons with Alzheimer's disease. Journal of Gerontological Social Work. 1999; 32:5–19.

125. Chan SM, O'Connor DL. Finding a voice: The experiences of Chinese family members participating in family support groups. Social Work with Groups. 2008; 31:117–135.

126. Czaja SJ, Rubert MP. Telecommunications technology as an aid to family caregivers of persons with dementia. Psychosom Med. 2002; 64:469–76. [PubMed: 12021420]

127. Gitlin LN, Winter L, Corcoran M, Dennis MP, Schinfeld S, Hauck WW. Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH Initiative. Gerontologist. 2003; 43:532–46. [PubMed: 12937332]

128. Hilgeman MM, Allen RS, DeCoster J, Burgio LD. Positive aspects of caregiving as a moderator of treatment outcome over 12 months. Psychol Aging. 2007; 22:361–71. [PubMed: 17563191]

129. Holland JM, Currier JM, Gallagher-Thompson D. Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program for bereaved caregivers. Psychol Aging. 2009; 24:190–202. [PubMed: 19290751]

130. Lichtenberg PA. Assisting Urban Caregivers After Nursing Home Placement: Results from Two Preliminary Programs. Clinical Gerontologist. 2006; 30:65–77.

131. McGinnis KA, Schulz R, Stone RA, Klinger J, Mercurio R. Concordance of race or ethnicity of interventionists and caregivers of dementia patients: relationship to attrition and treatment outcomes in the REACH study. Gerontologist. 2006; 46:449–55. [PubMed: 16920998]

Table 1

Ethnic Differences in Family Caregiving of Persons with Dementia by Level, Domain, and Ethnic Group, 1980–2009.

LEVEL DOMAIN Subdomain	Mean sample size (range)	African Americans Number of studies (reference #)	Latinos Number of studies (reference #)	Chinese or Asian Americans Number of studies (reference #)
INTRAPERSONAL LEVEL				
PSYCHOSOCIAL HEALTH				
Better psychosocial health (less depression, anxiety)	341 (113–720)	11 (17, 47, 48, 55–62)	1 (63)	0
Worse psychosocial health	188 (10–653)	1 (64)	7 (7, 16, 65–69)	1 (7)
LIFE SATISFACTION				
More life satisfaction	272 (194–415)	4 (55, 56, 59, 62)	0	0
APPRAISALS OF CAREGIVING				
More positive appraisal of caregiving	326 (15–810)	25 (7, 17, 18, 47, 48, 56, 58, 60, 61, 65, 70–84)	8 (7, 18, 20, 63, 65, 69, 85, 86)	1 (18)
Less positive appraisal of caregiving	125 (10–202)	1 (64)	3 (16, 65, 87)	0
SPIRITUALITY				
Spirituality or use of prayer	241 (40–720)	17 (22, 58, 59, 61, 65, 74, 76, 79, 80, 82, 83, 88–93)	6 (20, 65, 88, 89, 94, 95)	0
COPING STRATEGIES				
Resourcefulness	109 (50–168)	2 (70, 73)	0	0
Escape, avoidance coping	111 (20–202)	1 (96)	1 (65)	0
Emotion-focused coping	168 (168)	1 (73)	0	0
Directive coping (directing others)	20 (20)	0	0	1 (96)
SELF-EFFICACY				
Self-efficacy for caregiving	355 (197–629)	2 (47, 48)	1 (97)	0
PHYSICAL FUNCTIONING				
Better physical health	194 (194)	1 (59)	0	0
Worse physical health	415 (415)	1 (62)	0	0
INTERPERSONAL OR GROUP LEVEL				
SOCIAL SUPPORT				
More social support	264 (59–720)	7 (4, 55, 59, 65, 67, 71, 82)	3 (65, 86, 98)	0
Less social support	581 (581)	1 (78)	0	0
FILIAL RESPONSIBILITY				

LEVEL DOMAIN Subdomain	Mean sample size (range)	African Americans Number of studies (reference #)	Latinos Number of studies (reference #)	Chinese or Asian Americans Number of studies (reference #)
Strong beliefs about filial responsibility	367 (11–3097)	9 (4, 23, 48, 67, 88, 90, 99–101)	8 (4, 67, 88, 100, 102–105)	5 (88, 99, 106–108)
FAMILISM				
Importance of extended family structures (relatives and non-relatives)	125 (7–315)	4 (18, 22, 25, 76)	4 (18, 22, 63, 109)	2 (18, 110)
Respect for elders	21 (5–40)	3 (88, 90, 111)	0	1 (88)
CONCEPTUALIZATIONS ABOUT DEMENTIA AND AGING				
Overestimate care recipient's cognitive ability	240 (240)	1 (112)	0	0
Cognitive problems viewed as normal aging	32 (23–40)	0	1 (113)	3 (113–115)
Stigmatization of elders or persons with Alzheimer's Disease	26 (22–32)	0	25	3 (104, 114, 116)
ENVIRONMENTAL LEVEL				
USE OF FORMAL SUPPORT SERVICES				
Less use of formal care or support services	594 (86–1781)	2 (117, 118)	1 (67)	2 (7, 117)
Too proud to accept supportive services	157 (157)	0	0	1 (51)
Aversion to institutionalization of relative	184 (11–810)	4 (4, 71, 77, 104)	6 (4, 85, 104, 105, 119, 120)	0
Distrust of outsiders	157 (157)	0	0	1 (51)
USE OF HEALTH CARE				
Culturally and linguistically inappropriate health care	40 (40)	0	1 (88)	1 (121)
Racism/disrespect from health care providers	77 (10–262)	4 (64, 104, 111, 122)	0	2 (121, 123)
Need for information and referrals	300 (300)	1 (124)	0	0
Assertiveness on behalf of care recipient viewed as culturally inappropriate	6 (6)	0	0	1 (125)
Average no. of studies per domain		3.5	1.8	0.7
Total number of studies (78 unique studies)		55	33	20

Table 2

Family Caregiver Psychosocial Intervention Studies among African Americans, Latinos, and Chinese Americans: Study Characteristics, Cultural Tailoring, and Main Findings, 1980–2009.

First Author, Year	Design	Sample and Setting	Intervention	Outcome Measures	Cultural Tailoring	Main findings
1. Belle SH, 2006 [32]	Randomized, controlled trial	212 Latino, 219 White, and 211 African American DCGs[†] from five REACH[†] II sites	6-month multicomponent, individually tailored psychoeducational and problem skills training intervention (12 in-home and telephone sessions) to address DCG depression, burden, self-care, and social support; control group received 2 brief check-in phone calls.	6-month assessment of CES-D, Zarit Caregiver Burden Interview (ZCBI), 11-item self-care survey, 10-item social support survey, adapted Revised Memory and Behavior Problem Checklist (RMBPC).	• Translation of materials into Spanish • Bilingual – bicultural staff	Improvements in all domains were greater among Latinos (p<.001) and Whites (p=.032), but not African Americans (p=.23) in intervention vs. control group. For African Americans there was a significant interaction between care-recipient-caregiver relationship and intervention; spouses in the intervention group showed greater improvement than spouses in the control group (p=.008).
2. Burgio L, 2003 [33]	Stratified randomized controlled trial	70 White and 48 African American DCGs from Birmingham, AL REACH I study site	12-month skills training (group workshop followed by 16 in-home sessions) vs. minimal support control group.	6-month assessment of appraisals of care giving (RMBPC and Positive Aspects of Caregiving), measure of social networks, received support, satisfaction with support, and negative interactions), satisfaction with leisure activities, Center for Epidemiological Studies-Depression Scale (CES-D), Anxiety Subscale of State-Trait Personality Inventory, and 7-item Desire to Institutionalize scale.	• Culturally diverse staff • Staff training on cultural sensitivity • Home visits because African Americans reluctant to speak up in a group • Oral, written, visual, and interactive presentations in simple language • Training on assertiveness and addressing racism with medical personnel because African Americans indicated reluctance to question health care providers [25] • Training on self-empowerment through knowledge	No significant main effects for treatment condition on covariate adjusted 6-month outcomes for any variable (all p values >.10). Significant treatment x race interaction effect with African Americans in more active skills training workshop reporting less behavioral bother over time vs. Whites in the skills training intervention and African Americans in the control group (p=.01).

First Author, Year	Design	Sample and Setting	Intervention	Outcome Measures	Cultural Tailoring	Main findings
3. Czaja SJ, 2002 [126]	Usability and acceptability study	21 Cuban American and 23 White DCGs from the Miami, FL REACH I study site	18-month screen-telephone system to enhance access to informal and formal support.	6-month assessment of real-time usage and 31-item usability questionnaire assessing perceptions of system.	• Family-based (addresses *familismo*) • Addresses logistical barriers (e.g., transportation) • Available in Spanish • Respected family customs of protecting dementia patient by not sharing diagnosis and prognosis with the patient • Educational component (thought to be non-stigmatizing) • Referrals to resources [25]	80% used system to contact family. 86% found screen phone valuable and 88% liked the system. Cuban Americans were more likely than Whites to report system was easy to use (52% vs. 21%; $p<.05$) and were more satisfied (76% vs. 30%, $p<.01$). Cuban Americans were more likely than Whites to report the screen phone made it easier to contact family (85% vs. 61%, $p<.08$ and communicate with therapists (80% vs. 55%, $p=.08$). Cuban Americans were more likely than Whites (76% vs. 44%) to indicate they would like medical services and benefits added to resources.
4. Dang S, 2008 [34]	Satisfaction survey for a pilot trial of telephone-linked care program	72 White, 32 African American, and 9 Latino DCGs of Veterans Affairs medical center patients in Miami, FL	12-month screen-telephone system to enhance access to informal and formal support and DCG education modeled on REACH I intervention.	12-month Caregiver burden (ZCBI), CES-D, coping (Brief COPE), health-related quality of life (HRQOL; SF-36), knowledge about dementia and resources, and satisfaction with intervention.	• None reported.	Mean burden score at 12-months was significantly lower for African Americans than Whites (16 vs. 33, $p<.01$). There were no ethnic differences on coping, HRQOL, depression, dementia knowledge, and community resources measures.
5. Eisdorfer C, 2003 [38]	Stratified randomized controlled trial	114 Cuban American and 111 White DCGs from Miami, FL REACH I study site	18-month structural ecosystems therapy (SET), SET + screen-telephone system (SET+PH), or minimal telephone support condition (control).	6- and 18-month CES-D, RMBPC, satisfaction with support scale, Mini-Mental State Examination (MMSE), Katz Activities of Daily Living Scale (ADL).	• Family-based (addresses *familismo*) • Addresses logistical barriers (e.g., transportation) • Available in Spanish	Cuban Americans in the SET condition demonstrated decreased mean CES-D scores over time. Mean CES-D scores of Cuban Americans and Whites decreased in the SET+PH condition, especially among Cuban Americans. Decreases in CES-D score equaled or exceeded 5 points for

First Author, Year	Design	Sample and Setting	Intervention	Outcome Measures	Cultural Tailoring	Main findings
					• Respected family customs of protecting dementia patient by not sharing diagnosis and prognosis with patient	Cuban American and White daughter DCGs and Cuban American husband DCGs in the SET+PH condition at 6 months, and for Cuban American caregivers as a whole at 18 months.
					• Educational approach was non-stigmatizing)	
					• Referrals to resources [25]	
6. Gallagher-Thompson D, 2001 [39]	Feasibility study with pre-post assessments	70 Latino DCGs from Palo Alto, CA	8-week, small group psychoeducational program vs. wait-listed control group.	Post-intervention Geriatric Depression Scale (GDS), Given Caregiver Burden Scale, and State-Trait Anger Expression Inventory.	• Translation into Spanish	No difference between treatment and control group on caregiver burden. Greater improvement in the ability to control anger ($p<$.03) and in depression (p<.001) among intervention vs. control group (4- vs. 1-point drop in GDS score).
					• Increased use of visual aids	
					• Oral presentation of lessons with written materials as back-up	
					• Bilingual/bicultural outreach staff	
7. Gallagher-Thompson D, 2003 [40]	Pre-post assessments	122 White and 91 Latino female DCGs from the Palo Alto, CA REACH I study site	10-week small group psychoeducational program versus enhanced support group (guided discussion and empathic listening).	3-month Katz ADL and Lawton Instrumental ADL (IADL) scales, MMSE, CES-D, Revised Ways of Coping Checklist, 11-items from the Inventory of Socially Supportive Behaviors (ISSP), and RMBPC.	• Educational approach was non-stigmatizing	Psychoeducational group reported significant reduction in depressive symptoms (p=.00), increased use of adaptive coping (p=.00), and trend toward decreased use of negative (p=.03) vs. enhanced support group. There were no ethnic differences in treatment outcomes.
					• Interactive and personal approach consistent with *personalismo*	
					• Sessions began with social conversation	
					• Festive, celebratory atmosphere - graduation ceremony	
					• Bilingual/bicultural staff	
					• Short-term, directive approach was culturally consistent due to	

First Author, Year	Design	Sample and Setting	Intervention	Outcome Measures	Cultural Tailoring	Main findings
8. Gallagher-Thompson D, 2007 [43]	Randomized-controlled trial	45 Chinese American DCGs from San Francisco Bay Area, CA	4-month in-home behavioral management program versus telephone support condition.	Post-intervention CES-D, Perceived Stress Scale (PSS), appraisal of stress specific to caregiving (Conditional Bother subscale of the RMBPC), self-efficacy, Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA).	• Educational approach was non-stigmatizing • In-home program (preferred by Chinese American focus group members) • Translation into Chinese	Significant treatment effects for mean scores on CES-D (p=0.02) and RMBPC-CB (p=0.02) with in home program showing greatest reduction in depressive symptoms. No significant interactions between acculturation and treatment group.
9. Gallagher-Thompson D, 2008 [41]	Randomized-controlled trial to test updated and modified version of REACH II intervention	95 White and 89 Latino DCGs in Palo Alto, CA	4-month cognitive-behavioral group intervention to reduce stress and depression (updated version of that used in REACH I program); control group was minimal telephone support.	6-month CES-D, 10-item Perceived Stress Scale (PSS), Conditional Bother subscale of the RMBPC (RMBPC -CB.) new measures of use of behavioral and cognitive skills and helpfulness of these skills.	• Translation into Spanish • Oral presentation of lessons with written materials as back-up • Bilingual/bicultural outreach staff	CES-D (p=.048), PSS (p=.046), and RMBPC-CB (p=.007) post treatment scores were significantly lower in intervention vs. control group. No significant ethnicity or ethnicity x treatment interaction. More frequent use of cognitive-behavioral skills in intervention vs. control group (all p-values>.01), with no significant ethnicity x treatment interactions.
10. Gitlin LN, 2001 [37]	Randomized-controlled trial	126 White and 45 non-White (43 were African American) DCGs from Philadelphia, PA	Five 90-minute home visits by occupational therapist who provided education and modification of physical and social home environment vs. usual care control group.	3-month caregiver self-efficacy for handling disruptive behaviors, and assisting with ADLs and IADLs; Caregiver level of upset with disruptive behaviors, ADLs, and IADLs.	None reported.	Marginal improvements in experimental vs. control group, although none were significant. There was a significant ethnicity x treatment interaction for one outcome: minority caregivers in the intervention significantly improved in IADL self-efficacy vs. no benefit among Whites.
11. Gitlin LN, 2003 [26]	Meta-analysis of pooled parameter estimates	6 REACH I study sites. 511 White and 398 non-White DCGs	9 active and 6 control conditions with pooled comparisons of active vs. control conditions.	6-month caregiver burden and depressive symptoms.	• See notes above on Birmingham, Miami, and San Francisco Bay Area REACH I study sites.	For DCG burden, active interventions were superior to control conditions (p=. 02). For depressive symptoms, in Miami, SET +PH intervention (see Eisdorfer 2003 above) was superior to minimal telephone support. Active interventions were superior to control conditions for

NIH-PA Author Manuscript

First Author, Year	Design	Sample and Setting	Intervention	Outcome Measures	Cultural Tailoring	Main findings
12. Gitlin LN, 2003 [127]	Randomized controlled trial	85 White, 100 African American, and 5 other ethnicity DCG from Philadelphia, PA REACH I study site	12-month home environmental skill-building program with five home visits and 1 telephone contact (included education, problem-solving training, and adaptive equipment) vs. usual care.	6-month objective and subjective caregiver burden and well-being.	None reported.	Intervention group reported less upset with memory-related behaviors ($p=.03$), less help with ADLs from family and friends ($p=.03$), and better affect ($p=.03$) vs. control group. No significant race x treatment interactions on any outcomes.
13. Hilgeman MM, 2007 [128]	Randomized controlled trial	122 White and 121 African American DCGs from Philadelphia, PA REACH I study site	12-month home environmental skill-building program (see above) vs. usual care.	9-item Positive Aspects of Caregiving scale (PAC), CES-D, adapted RMBPC (behavioral bother), Daily care burden of providing help with ADLs across 12 months.	None reported.	PAC interacted with treatment condition and phase to predict daily care burden: caregivers who had less positive caregiving appraisals across time showed the greatest benefit. African Americans had higher PAC levels ($p=.04$) and lower levels of bother than Whites ($p<.0001$) and decreasing behavioral bother vs. Whites who reported relatively stable levels of behavioral bother across time ($p=.02$).
14. Holland JM, 2009 [129]	Meta-analysis of the randomized controlled trials of the six REACH I sites	148 White, 45 African American, and 31 Latino DCGs whose care recipient died during the study	Overall comparison of active vs. control conditions, and comparison of dosage of specific types of interventions versus control.	Long-term assessment of Inventory of Complicated Grief (ICG) and the Texas Revised Inventory of Grief as a measure of normal grief, and CES-D.	None reported.	Those with higher baseline CES-D scores ($p<.001$), African Americans ($p=.02$), who lost a spouse ($p<.01$), who were younger ($p=.02$), who were less educated ($p<.001$), and with fewer days since the loss ($p=.04$) reported higher levels of complicated grief at follow-up. African Americans had higher levels of complicated and normal grief vs. Whites.
15. Lichtenberg PA, 2006 [130]	Observational feasibility studies of two DCG interventions	For Study 1, 10 African American and 10 White DCGs in Detroit, MI. For Study 2, 15 African American and 15 White DCGs	Study 1: peer mentoring intervention for DCGs in process of placing care recipient in long term care. Study 2: caregiver training intervention	Study 1: 3-month Beck Depression Inventory II (BDI-II), satisfaction with mentor and program, contacts with mentor. Study 2: 3-month Behavioral Pathology in	None reported.	Caregiver stress declined significantly for both intervention groups ($p<.005$). African Americans and older caregivers reported less depressive symptoms than Whites and younger DCGs ($p<.001$).

First Author, Year	Design	Sample and Setting	Intervention	Outcome Measures	Cultural Tailoring	Main findings
16. McGinnis KA 2006 [131]	Secondary data analyses of randomized controlled trials from five REACH I sites	694 DCGs (378 Whites, 154 African Americans, and 162 Latinos) from the six REACH I study sites who received face-to-face interventions	Interventions varied by site, but all were based on stress-process model and were designed to change stressors, DCG's appraisal of stressors, or DCG's response to stressors. for DCGs whose care recipient had been in nursing home for 6 mos.	Alzheimer's Disease (BEHAVE-AD) Scale, Caregiver Stress and Rewards Scale, BDI-II. 12-month loss to follow-up and changes in depression (CES-D) and burden (RMBPC) by racial/ethnic concordance of interventionists and DCGs.	• Racial/ethnic matching of interventionist and DCG • Cultural sensitivity training of interviewers and interventionists	16.5% of those with concordant interventionists were lost to follow-up vs. 19.2% with discordant interventionists (p=.38); concordance was not independently associated with loss to follow-up (p>.18). Neither racial concordance nor caregiver or interventionist race/ethnicity was independently associated with CES-D (p>.35) or RMBPC (p>.25) scores.
17. Sistler A, 1999 [36]	Pre and post-tests	7 African American daughter DCGs from Baton Rouge, LA	8-week group sessions to increase dementia knowledge and improve problem-solving.	Post-intervention Memorial University of Newfoundland scale of happiness (MUNSH), self-rated confidence to handle difficult situations, and self-rated improvement in competence in caring for parent.	• Use of Serenity Prayer at each session to recognize spiritual aspects of caregiving • Problem-solving approach stressing use of faith to help work through stressful caregiving situations • Since African Americans tend to rely more on informal support, provided training on seeking information from health care professionals and other formal sources.	6 of 7 DCGs reported increased self-confidence in their ability to solve difficult situations. Scores on happiness measure also increased (specific results not provided).
18. Waelde LC, 2004 [42]	Pre- and post-tests	8 Latino and 4 White DCGs of Palo Alto, CA	6-session manualized yoga-meditation program.	Post-intervention CES-D, caregiving-specific self-efficacy (the Self-Efficacy for Controlling Upsetting Thoughts about Caregiving subscale of the Revised Scale for Caregiving Self-Efficacy), State-Trait	• Bilingual-bicultural staff • Spanish language sessions • Spanish language in-person	No ethnic differences in results. Depression (p<.01) and anxiety (p<.05) were significantly less 1 month post-intervention and perceived self-efficacy (p<.05) improved significantly.

First Author, Year	Design	Sample and Setting	Intervention	Outcome Measures	Cultural Tailoring	Main findings
				Anxiety Inventory, RMBPC, adherence to program, and self-rated improvement in 11 caregiver domains.	interviews in DCG's home	

† DCG = dementia caregiver; REACH = Resources for Enhancing Alzheimer Caregivers Health.