

Racial, Ethnic, and Cultural Differences in the Dementia Caregiving Experience: Recent Findings

Mary R. Janevic, MPH,¹ and Cathleen M Connell, PhD¹

Purpose: This research reviewed studies that compare two or more racial, ethnic, national, or cultural groups on aspects of the dementia caregiving experience. **Design and Methods:** Electronic databases were searched to find studies published between 1996 and 2000 in peer-reviewed journals that met the above criteria. **Results:** Twenty-one studies based on 18 samples were identified. These articles included comparisons involving the following groups of caregivers: African Americans, Chinese, Chinese Americans, Koreans, Korean Americans, Latinos, Whites, and residents of 14 European Union countries. Consistent with previous research, White caregivers were more likely to be spouses when compared to other groups. White caregivers tended to report greater depression and appraised caregiving as more stressful than African American caregivers. Findings were mixed regarding differences in coping and social support, but suggested that minority groups may not have more available support than Whites. Common methodological limitations were a lack of noncaregiving control groups and failure to test specific pathways by which the grouping variable (e.g., race) exerts its impact on outcome variables. **Implications:** Future studies in this area should use both quantitative and qualitative research methods to specify the pathways by which race, ethnicity, and culture affect the caregiving experience, and should expand their focus beyond the primary caregiver to include the effects of caregiving on families and networks.

Key Words: African Americans, Asian Americans, Hispanic Americans, Alzheimer's disease

Racial, ethnic, and cultural variations in the nature and effects of the dementia caregiving experience have received increasing attention over the last decade. The older adult population in the United States is rapidly becoming more diverse. By the middle of the next century, African Americans, Latinos, Asian Americans, and Pacific Islanders are expected to compose more than 30% of the nation's population age 65 and over, compared to about 15% in 1990 (Hobbs, 1999). Assumptions about the nature of the dementia caregiving experience based on research using samples of White American caregivers may not hold true for other groups, and service delivery based on such assumptions may be inappropriate (Yeo, 1996). By being aware of possible racial, ethnic, and cultural variations in the caregiving experience, health care professionals and policy makers can better meet the needs of the diverse groups of caregivers whom they serve. In addition to these practical benefits, contrasting the caregiving experience of different groups can also enhance the theoretical understanding of this experience by distinguishing its universal elements from those that are mediated by the norms, expectations, or experiences of a given cultural group (Patterson et al., 1998).

The increased interest in cultural differences in dementia caregiving is illustrated by the accelerated rate at which articles on this topic are being published. Connell and Gibson (1997) reviewed 12 articles published between 1985 and 1996 that examined the impact of race, ethnicity, and culture on the caregiving experience. In the short time since the time period covered by that review, an additional 21 articles on this topic have been published. Connell and Gibson concluded that although the small body of literature they reviewed suggested several consistent variations in the caregiving experience when Whites were compared to African Americans or Latinos, many of the articles had significant methodological limitations. Among these limitations were the failure of many studies to use large or representative samples, include control groups, or test a clearly specified theoretical framework. The racial/ethnic groups examined by this earlier group of studies

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Address correspondence to Mary Janevic, MPH, Department of Health Behavior and Health Education, School of Public Health, University of Michigan, 1420 Washington Heights, Ann Arbor, MI 48109-2029. E-mail: mjanevic@umich.edu

¹Department of Health Behavior and Health Education, School of Public Health, University of Michigan, Ann Arbor.

were limited: The majority of the studies (10 of 12) compared African Americans and Whites; of the remaining two, one compared Latinos and Whites and the other African Americans and Latinos.

The purpose of the current study was to review recently published research on dementia caregiving that compares groups as defined by race, ethnicity, culture, national origin, or country of residence. This article will serve as an update to the Connell and Gibson (1997) review and will answer the following questions: (a) Are the substantive conclusions drawn from the 1997 review regarding between-group differences supported by the more recent body of literature? What new information does this current group of studies offer? (b) What important methodological issues are brought to light by recent cross-cultural dementia caregiving research? and (c) What are fruitful directions for future research in this area?

Methods

In order to facilitate comparisons with the body of literature identified by Connell and Gibson (1997), similar search strategies and terms were used to identify appropriate studies for the current review. Articles were sought that compared two or more racial, ethnic, cultural, or national groups on variables related to the dementia caregiving experience. The search was conducted using the following electronic databases: Medline, PsycInfo, Sociofile, and CINAHL. Search terms used were: African Americans, Alzheimer disease, Asian Americans, Blacks, caregivers, caregiving, dementia, ethnicity, ethnic minorities, Hispanic Americans, Hispanics, Latinos, minorities, race, racial differences, Whites.

The current review includes articles published between 1996 and 2000 that were not included in the 1997 review. As with the earlier review, articles that focused on just one racial, ethnic, or cultural group were excluded (e.g., Sterritt & Pokorny, 1998), as were book chapters, unpublished dissertations, and empirical studies on dementia caregiving that include race/ethnicity as a variable but do not have ethnic differences as a main research question (e.g., Miller & Mukherjee, 1999).

Also omitted were articles that examine racial/ethnic differences in the nondementia caregiving experience (e.g., Tennstedt, Chang, & Delgado, 1998). Compared with general caregiving, dementia caregiving requires more hours per week and is also more likely to result in employment complications, strain, mental and physical health problems, reduced leisure time, and family conflict (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Dementia caregiving is thus sufficiently unique in the "extreme challenges" it poses (Schulz, O'Brien, Bookwala, & Fleissner, 1995) that it merits a separate analysis. Moreover, cultural factors may play a larger role in the context of dementia caregiving than in caregiving for other illnesses. Cultural norms vary regarding the meaning and degree of stigma associated with cognitive impairment in old age; these norms may determine pat-

terns of interaction with the health and social services system and health care decision making, and may also have implications for the psychosocial experience of family members (Yeo, 1996).

After articles were identified, they were assessed according to four guidelines in order to answer the three research questions. Specifically, we assessed: (1) the groups examined in each article, (2) study sample composition and source, (3) the data collection methods used, and (4) the between-group differences, if any, that were observed in the outcomes of interest.

Results

To simplify cross-study comparisons, Table 1 provides, where possible, detailed information about the samples (i.e., size, source, relation to care recipient, gender) used in each of the articles included in this review. In addition, the data collection methods and primary outcomes of interest—that is, the main variables or models on which the study groups were compared—are also described. Studies are presented in chronological order.

Sample Selection

The articles included in this review were heterogeneous both in the selection of target groups and in the outcomes of interest. Eight studies compared samples of White and African American caregivers; one compared samples of White, African American, and Latino caregivers; one compared White and Latino caregivers; one compared African American and Chinese American caregivers; one compared African American and Latino caregivers; one compared African American, Latino, Chinese American, and Irish American caregivers; and another focused on differences between Irish American and Latino caregivers. An additional seven studies included samples drawn from outside the United States: two articles looked at different research questions using the same sample of Chinese and American caregivers; two articles explored outcomes in the same sample of Korean and American caregivers; another compared Korean, Korean American, and White American caregivers; and two articles used data from a study comparing caregivers in 14 European Union countries. The total sample sizes ranged from 20 (Weitzman, Chee, & Levkoff, 1999) to 2,947 (Kosloski, Montgomery, & Karner, 1999). Although a few studies had criteria for caregiver age (Farran, Miller, Kaufman, & Davis, 1997) or relationship to care recipient (e.g., Gonzales, 1997; Lee & Sung, 1997), most did not. Virtually all samples were recruited from clinical settings and/or from community sources serving dementia patients and their families, with the sole exception being a sample identified in an epidemiological survey in China (Patterson et al., 1998; Shaw et al., 1997).

Where there were no selection criteria in terms of age or relationship, several consistent findings emerged regarding sample composition. White caregivers were

Table 1. Sample Descriptions, Data Collection Methods, and Major Outcome Variables From Dementia Caregiving Studies Examining Racial/Ethnic Differences, Published 1996–2000

Studies	Sample Characteristics	Data Collection Methods	Major Outcome Variables
Cox, 1996	African American ($n = 99$; 92% women, 27% spouses) and White ($n = 80$; 68% women, 28% spouses) caregivers of dementia patients hospitalized (not necessarily for dementia) in five Washington, DC, area hospitals.	Telephone interviews.	Predictors of and satisfaction with discharge outcome (home vs nursing home) and satisfaction with discharge planning process.
Cox & Monk, 1996	African American ($n = 76$; 77% women) and Latino ($n = 86$; 76% women) caregivers of relatives with AD recruited through hospital clinics, senior centers, community organizations, support groups, local churches. About 25% of each group were spouses; majority of remaining caregivers were daughters.	In-person interviews in English and Spanish.	Personal strain and role subscales of Burden Index (Zarit & Zarit, 1987); informal support.
Haley et al., 1996	White ($n = 123$; 62.4% women, 56.9% spouses) and African American ($n = 74$; 71.6% women, 29.7% spouses) family caregivers of patients with AD and other progressive dementing illnesses recruited as part of a larger study at the Memory Disorders Clinic at the University of Alabama at Birmingham.	In-home interviews and questionnaires.	Various stress process variables; mediators of well-being as measured by CES-D (Radloff, 1977) and the Life Satisfaction Index (LSI-Z; Wood et al., 1969); and a multivariate stress process model.
Farran et al., 1997	African American ($n = 77$; 71% women) and White ($n = 138$; 59% women) spouse caregivers (aged >60 years) of persons with dementia recruited from health service facilities.	In-home interviews.	Depression (CES-D; Radloff, 1977), role strain (Global Role Strain Scale; Archbold et al., 1990), task distress, and day-to-day and spiritual meaning in caregiving.
Gonzales, 1997	African American ($n = 25$; average age 59; 48% daughters, 36% spouses) and White ($n = 25$; average age 61; 32% daughters, 48% spouses) female primary caregivers of relatives diagnosed with probable AD recruited through a network of social and medical organizations.	In-person oral interview and written survey completion.	Appraisal of memory and behavior problems (Revised Memory and Behavior Problems Checklist; Teri et al., 1992); coping efforts (The Ways of Coping Checklist, rev.; Vitaliano et al., 1985); and resourcefulness.
Lee & Sung, 1997	Korean ($n = 60$; 55% daughters-in-law) and Caucasian American ($n = 47$; 79% daughters) adult children caregivers of family members with dementia, recruited from community programs serving elders and their families.	Mailed surveys.	Beliefs about filial responsibility (Filial Expectancy Scale; Seelbach & Sauer, 1977); affection in caregiver/recipient relationship.
Shaw et al., 1997	Caregivers of AD patients. Chinese sample: ($n = 110$; 57% women, 31% spouses) and controls ($n = 110$; 53% women, 30% spouses) identified from epidemiologic survey. U.S. sample: ($n = 139$; 65% women, 100% spouses) and controls ($n = 51$; 49% women, 100% spouses) recruited through university research center, community groups, and clinics.	In-home interviews (Chinese sample), written surveys and in-home interviews (U.S. sample).	Factor structure of the Ways of Coping-Revised questionnaire (Folkman & Lazarus, 1988), anxiety and depression (HSCCL: brief symptom inventory; Derogatis et al., 1974), Hamilton Rating Scale for Depression (Hamilton, 1960), physical symptoms.
Harwood et al., 1998	White ($n = 469$; 58% women, 65% spouses, 35% children) and Latino (85% Cuban American; $n = 184$; 70% women, 45% spouses, 55% children) primary caregivers of family members with AD who presented at an outpatient memory disorders clinic in Miami, Florida.	In-clinic screening of caregivers for depression as part of initial patient assessment.	Depression (CES-D).
Knight & McCallum, 1998	White ($n = 110$; 71% women, 61% spouses) and African American ($n = 44$; 82% women, 41% spouses) caregivers of demented family members drawn from a research center and service settings.	At-home or in-laboratory interviews and cardiovascular reactivity stress sessions.	Cardiovascular reactivity (heart rate), depression (CES-D), positive reappraisal (Ways of Coping-Revised questionnaire; Folkman & Lazarus, 1988), and giving socially desirable responses.

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Table 1. Sample Descriptions, Data Collection Methods, and Major Outcome Variables From Dementia Caregiving Studies Examining Racial/Ethnic Differences, Published 1996–2000 (Continued)

Studies	Sample Characteristics	Data Collection Methods	Major Outcome Variables
Lee & Sung, 1998	See Lee & Sung (1997).	See Lee & Sung (1997).	Burden (Burden Interview; Zarit & Zarit, 1987, and Caregiver Burden Inventory; Novak & Guest, 1989), extended family support, formal support, filial responsibility, gratification from caregiving.
Patterson et al., 1998	See Shaw et al. (1997) for sample source. This study used a subsample of Chinese caregivers ($n = 100$; 57% female, 34% spouse) and controls ($n = 99$; 51% female, 33% spouse) and U.S. caregivers ($n = 74$; 66% female, 100% spouse) and controls ($n = 41$; 46% female, 100% spouse).	See Shaw et al. (1997).	Multivariate relationships between caregiver characteristics and their health and a stress process model; emotional support; role overload (Pearlin et al., 1990); see Shaw et al. (1997) for additional measures.
Cox, 1999a	African American ($n = 150$; 22% spouses, 53% children, 22% other) and White ($n = 150$; 38% spouses, 49% children, 12% other) caregivers of individuals with AD who contacted Washington, DC, or Maryland Alzheimer's associations for the first time.	Telephone interview.	In addition to variables described in Cox (1999b), support group membership and use of information/referral services.
Cox, 1999b	See Cox (1999a).	See Cox (1999a).	Caregiver burden; depression (CES-D; Radloff, 1977); personal gain from caregiving; informal help; competence; reasons for calling Alzheimer's Association.
Hinton & Levkoff, 1999	African American, Chinese American, Irish American, and Latino (Puerto Rican and Dominican) family caregivers ($n = 10$ each group) of older adults with dementing illness, recruited from health care and social service settings. Across groups, most caregivers were daughters or daughters-in-law.	In-home, unstructured interviews (protocol specified general domains) in caregivers' preferred language.	Narratives, or stories, about the nature and cause of illness and patterns of care-seeking.
Kosloski et al., 1999	White ($n = 1,486$), African American ($n = 703$), and Latino ($n = 758$) primary caregivers (86% or other family members (14%) of patients with AD enrolling for support services as part of the Demonstration Grants to States Program.	In-person or telephone intake interviews.	Use of discretionary (adult day care, in-home respite, meal services) and nondiscretionary (home health care) services.
Murray et al., 1999	20 coresident spouses of AD patients in each of 14 European Union countries ($N = 280$), recruited through service agencies.	Four open-ended questions as part of semistructured interview.	Main difficulties in coping with dementia, caregiving-related rewards, perceived social reactions to person with dementia, and perceived support.
Ortiz et al., 1999	The Latino ($n = 10$) and Irish American ($n = 10$) subsample as described in Hinton & Levkoff (1999).	See Hinton & Levkoff (1999).	Ways in which ties to homelands and neighborhood institutions mediate and shape anticipatory grief, caregiver burdens, and caregiver resources.
Schneider et al., 1999	See Murray et al. (1999).	Semistructured interview.	Self-reported primary stressors, psychological distress (GHQ-12; Goldberg & Hiller, 1979), informal and formal support; burden (Carer Burden Inventory; Zarit et al., 1980).
Weitzman et al., 1999	The African American ($n = 10$) and Chinese American ($n = 10$) subsample as described in Hinton & Levkoff (1999).	See Hinton & Levkoff (1999).	Conflict strategies, caregivers' levels of "social perspective coordination," and satisfaction with family sharing of caregiving responsibilities.

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Table 1. Sample Descriptions, Data Collection Methods, and Major Outcome Variables From Dementia Caregiving Studies Examining Racial/Ethnic Differences, Published 1996–2000 (Continued)

Studies	Sample Characteristics	Data Collection Methods	Major Outcome Variables
Youn et al., 1999	White ($n = 54$; 70% spouses), Korean ($n = 44$; 80% daughters-in-law) and Korean American ($n = 32$; 40% spouses, 37% daughters-in-law) caregivers of relatives with dementia. Sources for U.S. samples included a research center and community agencies; Korean sample was from a research society, hotline, and community senior centers.	At-home interviews in English and Korean.	Instrumental and emotional support; burden (Burden Interview; Zarit & Zarit, 1987); familism; depression (CES-D; Radloff, 1977); anxiety (State-Trait Anxiety Inventory; Spielberger et al., 1985).
Knight et al., 2000	See Knight & McCallum (1998).	See Knight & McCallum (1998).	Sociocultural stress and coping model predicting emotional distress (as measured by Spielberger State-Trait Anxiety Inventory; Spielberger et al., 1985); depression (CES-D; Radloff, 1977), HACL; brief symptom inventory; Derogatis et al., 1974).

Note: AD = Alzheimer's disease; CES-D = Center for Epidemiologic Studies–Depression scale.

more likely to be spouses compared to African Americans (Cox, 1996; Cox, 1999b; Gonzales, 1997; Haley, Roth, Coletton, Ford, & West, 1996; Kosloski et al., 1999), to Latinos (Harwood et al., 1998; Kosloski et al., 1999), and to Korean Americans (Youn, Knight, Jeong, & Benton, 1999). In one study comparing African Americans to Latinos, Latino caregivers were more likely to be adult children and African American caregivers were more likely to be extended relatives (Cox & Monk, 1996).

Data Collection Methods

The overwhelming majority of studies in this review reported data that were collected via in-person interviews or written surveys, often using standardized psychosocial instruments common in caregiving research. These data were analyzed statistically to determine the significance of between-group differences in mean levels of variables or in models of psychosocial processes. Four articles, however, described findings obtained through qualitative research methods. One used a semistructured interview protocol with open-ended questions to explore caregiving-related difficulties, rewards, and support (Murray, Schneider, Banerjee, & Mann, 1999). The other three articles were based on a set of unstructured, in-home interviews that enabled the interviewer to explore caregiving-related themes that arose during the course of the interview (Hinton & Levkoff, 1999; Ortiz, Simmons, & Hinton, 1999; Weitzman et al., 1999). One study (Knight & McCallum, 1998) used laboratory data (measurements of physiological stress).

Observed Between-Group Differences

Table 2 shows the findings of all studies, in chronological order, regarding differences observed in the primary outcome variables between the study groups as defined by the authors. Where standard instruments were used, references are provided. Primary outcomes, as well as other variables measured in the studies, fell into the following categories: burden and psychological distress, coping strategies and stressfulness appraisal, social support, outcomes relating to use of health or social services, and illness meanings and representations.

Burden and Psychological Distress.—When Whites were compared to African Americans, findings were mixed regarding caregiving-related burden and psychological distress. Two studies using the Center for Epidemiologic Studies–Depression scale (CES-D; Radloff, 1977) found that Whites had more depressive symptomatology than African Americans (Farran et al., 1997; Haley et al., 1996), but two others did not (Cox, 1999b; Knight & McCallum, 1998). In two studies that compared caregiving burden between African Americans and Whites (using different measures), one found that African American caregivers had lower levels of burden (Knight, Silverstein, McCallum, & Fox, 2000), while no between-group dif-

Table 2. Between-Group Differences in Major Outcome Variables From Dementia Caregiving Studies Examining Racial/Ethnic Differences, Published 1996–2000

Studies	Between-Group Differences
Cox, 1996	African Americans were less satisfied with the discharge planning process than Whites; both groups were equally satisfied with the outcome. Availability of another caregiver was the strongest predictor of discharge home for African Americans; for Whites, availability of another caregiver and more hours of agency assistance were predictive of discharge home.
Cox & Monk, 1996	Latino and African American caregivers had comparable informal support. Latino caregivers reported more personal and role strain, controlling for contextual characteristics and stressors.
Haley et al., 1996	No African American–White differences in use of formal and informal services, social support variables, church-related variables, and LSI-Z scores. Whites used more approach and avoidance coping, and had higher CES–D scores. African Americans appraised self-care, memory, and behavioral problems as less stressful, and had greater self-efficacy for handling problems. Structural equation modeling showed that the stress process model was comparable between groups, and that African Americans’ lower stressfulness appraisals contribute to their lower depression.
Farran et al., 1997	Whites had better physical health, higher levels of distress with behavioral problems, lower levels of provisional and ultimate meaning, and higher levels of depression and role strain than African Americans. Higher levels of provisional (but not ultimate) meaning were associated with lower levels of depression and role strain among both groups.
Gonzales, 1997	African Americans had higher resourcefulness scores than Whites and appraised disruptive behaviors in care recipient as less stressful. No differences in use of coping strategies, or in stressfulness appraisal of memory-related behaviors or depression symptoms in care recipients.
Lee & Sung, 1997	Koreans scored higher on filial obligation and lower on filial affection than Americans. In a daughters-only subsample, Korean caregivers reported higher filial responsibility scores but similar levels of filial affection.
Shaw et al., 1997	No effects of culture or caregiving status found on behavioral confronting and cognitive distancing. Caregiving led to more cognitive confronting in both cultures, and the Chinese sample used this strategy more often. Caregiving led to increased behavioral distancing/social support coping in the U.S. sample only. Only U.S. caregivers had elevated levels of distress compared to controls. Both groups of caregivers had more physical symptoms than controls. All four coping factors were related to depression and anxiety among U.S., but not Chinese, caregivers.
Harwood et al., 1998	Higher prevalence of depression in Latino than White caregivers. Significant predictors of depression were being female and presence of patient psychosis for White spouse caregivers; being female and lower patient cognitive status for Latino spouse caregivers; being female for White children caregivers; and patient cognitive impairment for Latino children caregivers.
Knight & McCallum, 1998	No differences between African Americans and Whites in positive reporting bias, though positive reappraisal was more common in African Americans than in Whites. Higher cardiovascular reactivity among Whites was associated with higher levels of depression and higher levels of positive reappraisal. For African Americans, higher depression and positive reappraisal were associated with lower CVR.
Lee & Sung, 1998	Koreans reported higher levels of developmental burden and emotional burden than Americans. Americans reported higher gratification from caregiving and used coping strategies more actively than Koreans. Koreans had more extended family support but used formal services less frequently than Americans. Lower levels of burden among Koreans appeared to be associated with higher levels of filial responsibility and family support.
Patterson et al., 1998	U.S. sample (caregivers and controls) reported more emotional support than the Chinese sample, but there were no within-country differences between caregivers and controls. Both groups of caregivers reported more depression and role overload than controls. U.S. caregivers reported more depression, anxiety, and global psychological distress than Chinese caregivers and both control groups. Chinese caregivers reported more physical symptoms than Chinese controls. Path analysis revealed that in the U.S. sample, unlike in the Chinese sample, emotional support and the interaction of role overload and emotional support (i.e., a buffering effect) were not significantly related to depression. Avoidant coping and depression were positively associated among U.S. caregivers but negatively associated in the Chinese sample. The Chinese sample used more problem and emotional confronting than the U.S. sample, but no within-country differences between caregivers and controls.
Cox, 1999a	Race not a significant predictor of support group membership or information and referral use at 1 year after first contact with Alzheimer’s Association.
Cox, 1999b	No differences between African Americans and Whites in informal help received, CES–D, burden, feelings of competence or personal gain from caregiving. The most frequent reason among both groups for calling the Alzheimer’s Association was to obtain information about the illness. More White caregivers called for information on support groups, and more African Americans called for home health care or day care.
Hinton & Levkoff, 1999	African American, Chinese American, and Irish American caregivers told stories about AD as a disease that robs loved ones of their identities; some Chinese caregivers emphasized how families managed the disease and the normative nature of confusion in old age; some Puerto Rican and Dominican families put AD in the context of tragic family histories.
Kosloski et al., 1999	The impact of need variables (ADL/IADL status of the patient and a diagnosis of AD) on day care use was similar across all three groups. For respite use, however, the impact of need differed by ethnic group. Need variables were the most important predictor of respite use among Latinos, and least important among African Americans. For meal services, need factors were also the most important among Latinos.

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Table 2. Between-Group Differences in Major Outcome Variables From Dementia Caregiving Studies Examining Racial/Ethnic Differences, Published 1996–2000 (*Continued*)

Studies	Between-Group Differences
Ortiz et al., 1999	Irish American caregivers discussed role of community members and institutions in the diagnosis and care of demented elders. Caregivers had idealized representations of Ireland and drew on these for strength and comfort. Latino caregivers integrated story of demented family members into ongoing, often tragic, familial history and current struggles, including migration-related difficulties.
Weitzman et al., 1999	Conflict with family members was mentioned by almost all caregivers in both groups. About half of caregivers in both groups used “higher-level” conflict resolution strategies that involved cooperation or collaboration with family members. The remainder used a lower strategy level, with African Americans using predominantly avoidance strategies (e.g., “giving in”) and Chinese Americans using predominantly directive strategies (e.g., directing the other person to act in a certain way). About half of each group used higher levels of “social perspective coordination” (i.e., demonstrating understanding of another’s perspective), and about half used lower levels.
Youn et al., 1999	Korean caregivers showed the highest levels of familism, Korean Americans the next highest, and White Americans the lowest. Levels of burden were similar across all three groups. When the subsample of children and children-in-law was examined separately, burden scores were higher in Korean Americans and Koreans than in Whites, due to higher levels on the Embarrassment/Anger subscale. Koreans reported the least instrumental and emotional support. White Americans reported more emotional support than Korean Americans. There were no significant group differences on CES–D scores when demographics were controlled.
Murray et al., 1999 Schneider et al., 1999	Across countries, the same range of difficulties was described with similar frequency. Between-country differences were found in all outcomes of interest, although burden and distress were consistently high across countries.
Knight et al., 2000	Structural equation model showed that the effects of being African American on emotional distress are mediated by stressfulness appraisal (reducing distress) and by emotion-focused coping (increasing distress), so that there are no differences in overall emotional distress between African Americans and Whites.

Note: ADL = activity of daily living; IADL = instrumental activity of daily living; CES–D = Center for Epidemiologic Studies–Depression scale.

ferences were found in the other (Cox, 1999a, 1999b). Cox (1996) found that White caregivers felt more restricted in their activities than African Americans and had more financial difficulties as a result of caregiving. Of the studies involving Latino caregivers, one found that Latino caregivers had more depressive symptomatology than Whites, and that the predictors of depression varied by ethnicity and relationship to patient (Harwood et al., 1998). Another study found that Latino caregivers had higher levels of personal and role strain than African American caregivers (Cox & Monk, 1996).

The studies involving Asian and Asian American samples also presented mixed findings regarding burden and psychological distress. Lee and Sung (1998) found that Korean caregivers had more developmental and social burden than American caregivers, and another study (Youn et al., 1999) found that Korean and Korean American caregivers who were children or children-in-law of the patient had higher levels of burden related to anger/embarrassment than their White counterparts. No differences in depression among White American, Korean American, and Korean caregivers were discovered in this study when demographics and health were controlled (Youn et al., 1999). Shaw and colleagues (1997) found that U.S. caregivers had elevated rates of depression and anxiety compared to controls, but Chinese caregivers did not. Schneider and colleagues (1999) noted that there were between-country differences in burden and distress among caregivers in 14 European Union countries but that caregivers in all countries had high levels of these two constructs.

Stressfulness Appraisal and Coping Strategies.— Compared to White caregivers, Haley and colleagues (1996) and Farran and coworkers (1997) found that African American caregivers appraised patient-related problems as less stressful; Gonzales (1997) found that African American and White female caregivers appraised memory-related behaviors or depression symptoms in care recipients equally but that Whites found disruptive behaviors more stressful. Results from the Gonzales study also showed that African Americans exhibited higher levels of “resourcefulness,” or skills used to self-regulate internal or external stressful events, but that there were no differences in frequency of use of coping strategies. Compared to Whites, African American caregivers were found to report greater use of positive reappraisal (Knight & McCallum, 1998) and to derive higher levels of day-to-day and spiritual meaning from caregiving (Farran et al., 1997); one study, however, found no African American–White differences in personal gain from the caregiving experience (Cox, 1999b). The only study in the current review that included a measure of religious practices (i.e., prayer and church attendance) found no differences between African Americans and Whites (Haley et al., 1996), but another study reported that African Americans found more spiritual meaning in caregiving than did Whites (Farran et al., 1997).

Two studies employed structural equation modeling techniques to determine differences in the processes by which race affected emotional distress, and both examined coping as an important mediator in this process. Haley and colleagues (1996) found that

African American caregivers used less approach and avoidance coping than White caregivers; they found that less use of avoidant coping, as well as lower stress appraisal, may contribute to the lower levels of depression observed in this group. Knight and associates (2000) found that the African American caregivers in their sample used more emotion-focused coping (conceptually similar to avoidance coping), and that while this led to greater emotional distress, the lower burden scores among this group served as a “counterbalance” so that overall distress scores were similar to those of the White sample.

Regarding coping in other groups, Lee and Sung (1998) found that U.S. caregivers used more coping strategies than Koreans. Shaw and coworkers (1997) took an in-depth look at coping in samples of Chinese and U.S. caregivers and controls. Based on a factor analysis of the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) in both samples, they constructed a scale made up of four factors that were consistent across groups. They found that there were no between-country differences in the use of behavioral confronting (e.g., “Stood my ground and fought”) or cognitive distancing (e.g., “Refused to think about it”). Both cognitive confronting (e.g., “Just accepted it”) and behavioral distancing/social support (e.g., “Asked someone for advice”) were more prevalent in the Chinese sample. Greater use of coping strategies was associated with greater distress in the U.S. sample only.

Several studies employed qualitative data-gathering and analytic techniques to learn more about the subjective experience of diverse groups of caregivers regarding caregiving-related difficulties and coping strategies. Ortiz and colleagues (1999) collected data on these phenomena from narratives elicited from interviews with Latino and Irish American caregivers of demented elders. They found that both groups invoked the notion of homelands when relating stories of coping or burden. Many of the Irish American caregivers drew comfort from an idealized version of Ireland and Irish culture, and also discussed resources available to them within their current community. Some of the Latino caregivers, in contrast, spoke about their homeland in the context of often tragic life histories, of which dementia was sometimes seen as a result, and also discussed the difficulties they had with accessing services in their community. In another qualitative study, no major differences were found between Chinese American and African American caregivers in the types of strategies they used to deal with caregiving-related interpersonal conflict, and most in each group used advanced social cognitive skills (i.e., they acknowledged the needs and viewpoints of the other person). However, in those cases where less adaptive strategies were used, Chinese American caregivers used more “directive” strategies and African Americans more “avoidant” (Weitzman et al., 1999).

In response to general questions about the challenges and rewards of caregiving, as well as perceived social reactions and support, Murray and coworkers

(1999) found that caregivers in 14 different European Union countries described their experiences in similar ways. The authors concluded that in spite of between-country differences in levels of government support for caregivers and laws regarding family caregiving duty, there were no obvious qualitative differences in the caregiving experience.

Social Support.—In the current review, a number of studies addressed between-group differences in social or informal support. One study (Cox, 1996) found that African Americans were less satisfied with their informal support than were Whites. Cox (1999a) found that African Americans were more satisfied with overall support. A third study (Haley et al., 1996) found no African American–White differences in social support. No differences in informal support were found between African American and Latino caregivers by Cox and Monk (1996). One study found that Korean caregivers had more extended family support than White U.S. caregivers (Lee & Sung, 1998), whereas in another, White American caregivers reported more emotional support than Korean and Korean American caregivers, and both U.S. groups reported more instrumental support than their Korean counterparts (Youn et al., 1999). The latter study found, however, that Korean caregivers reported the highest levels of familism, followed by Korean American and White American caregivers. U.S. caregivers and controls were also found to have more emotional support than Chinese caregivers and controls (Patterson et al., 1998).

Service Utilization.—Four articles described outcomes related to service utilization. One study found that “need” variables (primarily the functional status of the patient) were more predictive of respite use and meal services (considered “discretionary” services) among Latinos than among African Americans and Whites, although need variables predicted home health care use (considered a “nondiscretionary” service) equally in all three groups (Kosloski et al., 1999). Another study found few differences between African Americans and Whites in perceived need for Alzheimer’s Association services, and no differences in actual service use (Cox, 1999b). Further analyses on this sample showed that “need” factors (patient status and caregiver burden), but not race, predicted support group membership and service use one year after contact with the Alzheimer’s Association (Cox, 1999a). Results from a fourth study (Cox, 1996) indicated that although there were no African American–White differences in satisfaction with hospital discharge outcomes or predictors of these outcomes, African Americans were less satisfied with the discharge planning process (Cox, 1996). Two studies measured use of formal services: One indicated that African Americans used more formal home care than Whites (Cox, 1996), and the other found no African American–White differences in use of formal services (Haley et al., 1996).

Illness Meaning and Representations.—One qualitative study explored differences across cultures in ideas about the nature and meaning of dementing illness among caregivers. Hinton and Levkoff (1999) found both consistencies and differences among family caregivers from four ethnic groups in the Boston area. African American, Chinese American, and Irish American caregivers all talked about Alzheimer's disease as a "loss of identity" or "loss of self." Chinese American caregivers tended to view the disease with less trepidation than other groups, perhaps because of cultural beliefs that normalize confusion in old age, and focused on filial duties when relating their stories. Puerto Rican caregivers tended to view the disease as a result of past personal or family tragedies.

Discussion

The current review of racial, ethnic, cultural, or national differences in the dementia caregiving experience expands considerably on the findings from an earlier review on this topic (Connell & Gibson, 1997), in terms of both groups examined and range of outcomes assessed.

Sample Demographics

As in Connell and Gibson's (1997) review on this topic, the current review reveals that African American and Latino caregivers are less likely than Whites to be spouses and more likely to be another family member. In one study from the current review, this was also true of Korean and Korean American caregivers (Youn et al., 1999). These findings are consistent with literature on general caregiving among these groups. For example, Burton and colleagues (1995) found that older, disabled Whites were more likely than Blacks to have a spouse caregiver, and they point out that this is a reflection of differences in these groups in marital status. In cultures with Confucian values, the norm of the eldest son and daughter-in-law providing care to aging parents is well recognized (Braun & Browne, 1998). The greater likelihood of caregivers in non-White groups being younger relatives—who may be employed with families of their own—should thus be considered in the design of service programs to address the needs of dementia caregivers.

Burden and Psychological Distress

Connell and Gibson (1997) found in the earlier group of studies that, with several exceptions, White caregivers reported higher levels of burden and depression than African American caregivers. Regarding depression, these findings were only partially corroborated by the more recent research reviewed here, even when the same measure, the CES-D, was used across studies. One reason for this inconsistency may be noncomparability of samples, in terms of geographic residence, socioeconomic status (SES), or other characteristics. Also, because spouse caregivers tend to have higher levels of depression than other

caregivers (Schulz et al., 1995), relationship to patient may be a confounding factor when samples are mixed and caregiver relationship is not controlled for statistically (e.g., Cox, 1999b; Haley et al., 1996).

The studies involving Korean, Chinese, and Korean American samples also presented mixed findings regarding burden and depression. Researchers have speculated that the more normative nature of caregiving in Eastern cultures may be protective against distress (Shaw et al., 1997) just as it may be in African American cultures (Haley et al., 1996). The qualitative research reviewed here on Chinese American caregivers supports, to some extent, this hypothesis (Hinton & Levkoff, 1999), as does Shaw and colleagues' (1997) finding that U.S. caregivers had more depression compared to controls, whereas Chinese caregivers did not. Other scholars have suggested, however, that dementia symptoms may sometimes be a source of shame in Asian or Asian American cultures (Braun & Browne, 1998), which may help to explain why Korean American adult-child caregivers scored high on an Anger/Embarrassment scale (Youn et al., 1999). Clearly, existing research on Asian American caregivers is minimal, and it is premature to draw conclusions about the impact of cultural factors on the caregiving experience among Asian American groups.

It is also important to note that baseline depression level may vary among ethnic groups, although comparable mental health data on U.S. minority groups are limited (Jackson, Antonucci, & Gibson, 1995), and there are few psychiatric epidemiological studies of Asian Americans (Kang & Kang, 1995). The National Comorbidity Survey revealed that African Americans have a lower prevalence of affective disorders than Whites, and that Hispanics have a higher prevalence (Kessler et al., 1994). Thus, differences in psychological distress found in the current review may not be due to a more negative impact of caregiving on these groups, but may instead be a reflection of baseline differences in these groups.

Coping and Stressfulness Appraisal

As in the Connell and Gibson (1997) review, several studies in the current review suggested that African Americans appraise aspects of caregiving as less stressful than Whites, and that they derive more benefit and meaning from the experience (Farran et al., 1997; Gonzales, 1997; Haley et al., 1996; Knight & McCallum, 1998). No clear-cut patterns involving the use of coping strategies among different groups were discernible, however. In their review, Connell and Gibson (1997) noted that African American caregivers were more likely than White caregivers to use religious coping. Although religious coping was not examined specifically in the current review of articles, one study found no differences in religious practices between African Americans and Whites (Haley et al., 1996).

Some of the more methodologically innovative studies in this review examined coping strategies. Three studies tested models of the caregiving stress

process in samples of African American and White caregivers (Haley et al., 1996; Knight et al., 2000; Patterson et al., 1998). Another compared the factor structure of a commonly used coping instrument (Ways of Coping-Revised; Folkman & Lazarus, 1988) in Chinese and U.S. caregivers, after first attempting to construct a conceptually comparable version of the instrument in Chinese. Such studies are important in that they provide information about culturally based reasons for differential psychosocial outcomes between groups, as coping is likely to be influenced to a large extent by cultural factors (Aranda & Knight, 1997). The qualitative studies in the current review offer some additional insight into how specific strategies for coping with the demands of caregiving vary across groups, although the strategies described may be sample-specific and results should be generalized with caution. Unfortunately, cross-cultural research on coping in general, which might serve as useful context for caregiving-specific findings, remains sparse.

Social Support

Cultural norms and structural conditions are likely to influence the extent to which support is available to caregivers (Aranda & Knight, 1997; Dilworth-Anderson & Burton, 1999; Miller, Randolph, Kaufman, Dargan, & Banks, 2000). The mixed findings in the current review regarding perceived support suggest that non-White caregivers may not have more informal support available to them than White caregivers, contrary to assumptions often made about the extensive social networks of ethnic minorities. Researchers elsewhere have questioned this assumption: Roschelle (1997) has found evidence that African Americans may be disadvantaged in terms of social relations compared to Whites, and attributes this phenomenon to the continuing structural, economic, and social discrimination that has eroded traditional networks in African American and other minority communities. Miller and colleagues (2000) have also noted that policies such as the welfare reform act of 1996 may have a negative impact on traditional family supports among African Americans.

Research on nondementia caregiving provides additional evidence that the informal caregiving networks of elderly disabled Blacks are not larger than those of Whites (Burton et al., 1995), although Tennstedt and coworkers (1998) found that African American and Puerto Rican elders received more informal care than Whites. Nonetheless, policymakers should not assume that lack of use of formal care among minority groups is due to a greater likelihood of these groups receiving informal care (Burton et al., 1995); nor should program planners assume that members of minority groups receive sufficient support from existing networks.

Service Utilization

Outcomes related to use of health or social services in the articles included in this review were lim-

ited, as were the groups examined on these variables. Cox (1996) found that African American caregivers were less satisfied with hospital discharge planning than Whites, and that African American caregivers used more formal home care than Whites. Cox also suggests that there may be issues related to underutilization of Alzheimer Association services that transcend African American/White differences in the dementia caregiving experience (Cox, 1999a, 1999b). Kosloski and associates (1999) found that a patient's functional status was more important among Latinos than among African Americans or Whites in predicting the use of community health services; they suggest that this could reflect decreased access to services among Latinos. Finally, the qualitative study by Ortiz and colleagues (1999) provides insight into the types of barriers Latinos may experience to accessing services, such as difficulties navigating bureaucracies.

Differences in access to services may be a result of cultural preferences, language limitations, institutional exclusions, or financial barriers (Aranda & Knight, 1997; Wallace, Campbell, & Lew-Ting, 1994), and differential use by elderly people of health and social services across racial/ethnic groups has received considerable attention elsewhere. Although minorities make less use of institutional long-term care, there is mixed evidence regarding use of community long-term care services (Wallace, Levy-Storms, Kington, & Andersen, 1998). For example, one study found that elderly Latinos obtained less paid assistance than similar non-Latino Whites (Wallace, Levy-Storms, & Ferguson, 1995); yet, Miller and associates (1996) found no differences among African American, Hispanic, or White frail older persons in use of community-based long-term services.

Although dementia-specific studies are lacking, it has been found that African Americans with Alzheimer's disease spend a longer time in the community prior to nursing home admission, suggesting that there may be substantial unmet need on the part of their caregivers (Miller & Mukherjee, 1999). A similar phenomenon may be present among Latinos: Harwood and coworkers (1998) found that the Latino patients presenting to a university memory clinic were more cognitively impaired and had a longer duration of illness than their White counterparts. A more systematic and in-depth look at use of dementia services by diverse groups of caregivers is thus warranted.

Methodological Issues

The current studies highlight the importance of a number of methodological issues related to cross-cultural research on dementia caregiving. The first of these is the extent to which the nonequivalence of measures in different cultural and linguistic contexts is addressed by researchers. This concern is notoriously difficult to address, because mere translation (or back-translation) of instruments does not ensure equivalence of meaning (Padgett, 1995; Patterson et al., 1998). However, the current group of articles of-

fers one excellent example of how researchers can strive for cross-cultural measurement equivalence: the factor analysis of a coping scale by Shaw and colleagues (1997) in Chinese and U.S. samples. Other researchers in the studies reviewed have noted the problem of cross-cultural measurement and conceptual equivalence and addressed the issue in the discussion of their results. Youn and coworkers (1999), for example, noted that the construct of familism has different meanings in different cultures, suggesting that in Korean culture “familism does not seem to reflect a strong tradition of mutual support, as is hypothesized to be true of African American and of Latino caregivers in the U.S.” (p. 362). Rather, Korean daughters-in-law provide care out of a sense of duty, and this role often brings conflict. The high level of familism among Korean caregivers may not, therefore, protect them from burden, as seen in their empirical work reviewed here (Youn et al., 1999).

A related concern is the extent to which measures that examine caregiving-related outcomes capture the true impact of caregiving across different cultures. For example, the finding in many studies that African American caregivers tend to have less caregiving-related stress and burden than White American caregivers may not mean that the negative impact of caregiving is less in this group, but rather that this impact is manifested in a different way; for example, in greater physical health problems. It has been suggested, for example, that African Americans of low SES who tend to use active coping strategies in response to stressors in their environment may be at elevated risk for hypertension compared to Whites at the same level of active coping (James, Strogatz, Wing, & Ramsey, 1987). The tendency of Asian Americans to somatize emotional distress has also been noted (Braun & Browne, 1998), and this tendency has been found among African American and Puerto Rican women as well (Calderon & Tennstedt, 1998).

The absence of control groups from virtually all studies in the current review suggests another important methodological issue. Only two studies (based on the same sample) included a noncaregiving control sample (Patterson et al., 1998; Shaw et al., 1997). As noted earlier, because baseline levels of conditions such as depression may vary by ethnic group, it is difficult to know whether such differences can be attributed to the caregiving experience in the absence of a noncaregiving comparison group. Although differences not due to caregiving may also have implications for service provision to diverse groups, the question about a differential impact of the caregiving experience on certain variables remains unanswered. In other words, cross-cultural studies without noncaregiving control groups ultimately measure levels of the variables of interest (e.g., distress) among different groups of caregivers, as opposed to the differential impact of caregiving on these variables. The findings of Shaw and colleagues (1997) and Patterson and colleagues (1998) highlight the utility of employing a control group, as several between-group dif-

ferences were identified between Chinese and U.S. samples (including when controls were compared) that may have otherwise been erroneously attributed to differential effects of caregiving.

An additional important methodological issue concerns the appropriateness of attributing differences between groups of dementia caregivers to the “grouping variable”—race, ethnicity, culture, national origin, or country of residence. When grouping caregivers by any of these categories, researchers should have a clear idea about the hypothesized mechanism by which membership in this category can affect the caregiving experience. In general, effects of the grouping variable may be due to cultural factors (the symbolic and normative aspects of social life, such as language, values, beliefs, or norms; Angel & Angel, 1995) or minority status (Aranda & Knight, 1997), with the latter implying the effects of inequality and discrimination, factors that continue to play a major role in the lives of minority group members in the United States and affect psychosocial outcomes in these groups (Jackson et al., 1995).

When race is used as a grouping variable, therefore, it is not clear if African American outcomes should be attributed to their cultural distinctiveness or minority status (Manuel, 2000)—a distinction that is not always clear. For example, patterns of social support in minority groups are shaped both by culture and by economics (Dilworth-Anderson & Burton, 1999). While controlling for SES may help to determine whether cultural, and not structural/economic factors, are responsible for differential outcomes, the hypothesized cultural factors should still be measured (Mutran, 1985). This is particularly important in light of evidence that, after controlling for indicators of SES in African American and White samples, residual SES-related confounding factors (such as greater wealth among Whites even at the same income level) often remain such that apparent between-group differences may be spurious (Kaufman, Cooper, & McGee, 1997). Manuel (2000) further suggests that researchers should consider modeling multiple indicators of race, or its hypothesized effects, and to account for measurement error in race when using this “muddled and vacuous” (p. 14) concept as a predictor variable.

Many, but not all, of the studies reviewed controlled for indicators of SES; far fewer attempted to measure alternative cultural pathways by which group membership might exert its effect on the caregiving experience. A number of authors, however, did put forth explanations for observed between-group differences that invoked both cultural factors and minority group status as reasons for differences in outcome variables. For example, Haley and colleagues (1996) cite explanations that would fall under both categories (e.g., that African American caregivers may be particularly effective at using appraisal and coping due to a greater tolerance for behavioral disturbance in family members and a greater exposure to and mastery of life stress). Farran and coworkers (1997) speculate that African American culture en-

courages adaptation to difficult situations through positive appraisal, and that African Americans may not have the “luxury” of being depressed by external circumstances. Cox (1996) alluded to the potential role of discrimination in bringing about an important finding in her study; that is, that the greater dissatisfaction with discharge planning among African Americans may have been due to hospital staff involving this group less in the process.

The challenge of accurately attributing differences in caregivers to specific aspects of group membership is compounded by the substantial within-group heterogeneity found in all the groups by which dementia caregivers were classified in the current review. This heterogeneity both adds to the complexity of the causal path between the grouping variable (e.g., ethnicity) and outcome, and also limits the extent to which findings from a single study can be generalized to broadly conceived groups such as those represented by the U.S. census categories (i.e., American Indian or Alaskan Native, Asian or Pacific Islander, African American, Latino origin). Yeo (1996) suggests that the most important source of intragroup variability within these census categories is national (or tribal) origin and culture. Even within subcategories by origin, however, there is still diversity in terms of acculturation and ethnic identity, education, income, length of residence in the United States, rural or urban background, religious affiliation and participation, and family support (Yeo, 1996). This diversity, of course, also characterizes groups of caregivers who reside outside of the United States and are identified in studies only by their country of residence. Bhopal and Donaldson (1998) discuss the potential dangers of using broad categories such as race and ethnicity that have dubious scientific or anthropological validity, and suggest that it is incumbent on researchers to describe the samples used “to make clear the basis of racial or ethnic classification (e.g., ancestry, geographic origin, birthplace, language, religion, migration history)” (Bhopal & Donaldson, 1998, p. 1306).

The implications of sample composition received some limited attention in the current group of studies; for example, groups of Latino caregivers were identified by national origin (Cox & Monk, 1996; Harwood et al., 1998; Hinton & Levkoff, 1999; Ortiz et al., 1999), although only one of these studies included a measure of acculturation (Cox & Monk, 1996). Other studies acknowledged the possible implications of within-group variability among groups with the same national origin; for example, Knight and coworkers (2000) note that their findings regarding coping strategies among African Americans may have differed from those in a prior study (Haley et al., 1996), because the samples were from different regions with different histories and social contexts. Interestingly, no study made note of the race/ethnicity of care recipients, with the implied assumption being that patients were always of the same background as caregivers. With the increasing number of interethnic and interracial families in the United

States, however, researchers will not be able to make this assumption, and indeed, dementia caregiving in families of mixed cultures merits examination.

Conclusions

As a group, the studies reviewed here and previously (Connell & Gibson, 1997) suggest that there may be differences in the stress process, in psychosocial outcomes, and in variables related to service utilization among caregivers of different racial, ethnic, national, and cultural groups; however, the origin of these differences is often unclear, as is the extent to which they can be generalized beyond the samples employed in a given study. Further studies that include noncaregiving control groups and detailed models of the hypothesized pathways leading from the grouping variable (e.g., ethnicity or culture) to outcomes are clearly needed.

Future cross-cultural caregiving research should address several additional issues. First, the paradigm of the “primary caregiver” may not be equally applicable in all cultures. Future studies should expand their focus beyond the primary caregiver and include individuals from the entire family system as well as non-kin (Aranda & Knight, 1997; Dilworth-Anderson & Burton, 1999). Such inclusiveness will better capture the diversity of the caregiving experience among different racial, ethnic, or cultural groups. Aranda and Knight (1997) note, for example, that in Latino families stress may be more likely to arise from disruption to the family unit rather than from a negative impact of caregiving on individual perceived control. Strategies for measuring such family- or network-level variables, therefore, need to be conceptualized and tested.

Research that examines the impact of immigration or acculturation status on the dementia caregiving experience is needed. Aranda and Knight (1997) argue that a unique set of caregiving conflicts may arise in immigrant cultures when family members are at different levels of acculturation and have correspondingly different values or beliefs related to caregiving. Youn and coworkers (1999) noted the potential additional burden on Korean American dementia caregivers caused by the internal conflict between Korean and American values. Acculturative stress and other factors associated with immigrant status (such as cultural and economic barriers to care) may also interact with the caregiving experience, resulting in potentially greater burden and distress. The inclusion of detailed measures of acculturation in future studies of the caregiving experience may help to “tease out” some of these effects. In addition, because gender roles may be affected by immigration and acculturation, future research should address how changing norms and beliefs regarding these roles affect the dementia caregiving experience.

Finally, the limited body of qualitative or ethnographic research on the dementia caregiving experience should be expanded. Dilworth-Anderson and Burton (1999) argue that ethnographic studies on

older minorities can uncover cultural differences that survey research cannot. Such studies may be particularly useful in identifying the elusive “cultural” factors that lead to different between-group outcomes in quantitative studies. Findings in the current review also suggest how this type of research may help to inform the content of interventions. For example, variations in how caregivers from different cultural groups perceive the nature and cause of their loved one’s illness (e.g., Hinton & Levkoff, 1999) may be helpful in designing support activities that are meaningful to members of these groups. Knowledge and attitudes regarding health and social services are also critical topics to explore within a qualitative research paradigm, in order to determine the specific nature of structural and cultural factors affecting service use and to improve outreach efforts to diverse groups of caregivers.

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