

# Cultural Attitudes and Caregiver Service Use: Lessons from Focus Groups with Racially and Ethnically Diverse Family Caregivers

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**ABSTRACT.** Focus groups were conducted with caregivers from eight racial-specific or ethnic-specific populations (African Americans, Chinese, Filipinos, Hispanics, Koreans, Native Americans, Russians, and Vietnamese), to examine cultural variations in caregiving experiences,

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care-related values and beliefs, care practices, and factors contributing to decisions about the use of caregiver support services. Analysis of focus group transcripts revealed three cross-cutting constructs: familism, group identity, and attitudinal and structural barriers to service use. We discuss these findings in terms of their implications for existing knowledge regarding family responsibility, resource utilization, and program development for racially and ethnically diverse family caregivers. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2006 by The Haworth Press, Inc. All rights reserved.]

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Despite demanding care situations (Aranda & Knight, 1997; NAC/AARP, 2004; Navaie-Waliser et al., 2001) and related caregiver strain (Adams et al., 2002; Aranda et al., 2003; Cox & Monk, 1990; Harwood, Baker, Cantillon, Lowenstein, Ownby & Duara, 1998; Markides et al., 1997; Connell & Gibson, 1997; NAC/AARP, 2004; Adams et al., 2002; Lee & Sung, 1998), minority caregivers tend to use formal support services substantially less than their non-Hispanic White counterparts (Dilworth-Anderson et al., 2002; Dunlop et al., 2002; Mausbach et al., 2004; Tennstedt & Chang, 1998; White-Means & Thornton, 1996).

Low service use among minority ethnic caregivers is of particular concern because it has been associated with unmet needs for assistance and support. Caregivers from African American, Latino, Asian, and Pacific Island populations consistently express a greater need for formal support services and higher levels of unmet social and mental health needs than do non-Hispanic White caregivers (Cox, 1999; Hinrichsen & Ramirez, 1992; NAC/AARP, 2004; Wallace & Lew-Ting, 1992; Ho et al., 2000).

The reasons for the apparent underutilization of caregiver services among non-White and Hispanic populations are not well understood. Efforts to explain restricted service use among caregivers from racial and ethnic minority groups have typically relied on correlational data, most often from African American caregivers (Ajrouch, Antonucci & Janevic, 2001; Connell & Gibson, 1997; Dilworth-Anderson et al.,

2002), who apparently are substantially more likely to use support services than are other racial and ethnic groups.

Culturally-defined values, norms, and roles have been identified as major determinants of the caregiving experience, and are likely to affect service utilization. *Familism*, a primary value of Latino cultures, is often cited as a motivating factor for providing care (Becker, Beyene, Newsom & Mayen, 2003), including the expectation that extended family will assist with the care of older relatives (Cox & Monk, 1993; Clark & Huttlinger, 1998). Closely linked to familism are the concepts of mutual support; reciprocity (giving back love and support to family members who have given the same); filial obligation, and, respect shown for an older relative's worthiness and authority (Nkongo & Archbold, 1995; Giunta et al., in press; Ishii-Kuntz, 1997; Connell & Gibson, 1997).

Several studies have linked the availability of informal support to reduced use of formal services (Strain & Blandford, 2002; Kosloski, Montgomery, & Youngbauer, 2001; Horowitz, 1998). The majority of existing research suggests that ethnic minority caregivers have wider and stronger informal support networks than White caregivers (Aranda & Knight, 1997; Connell & Gibson, 1997; Dilworth-Anderson et al., 2002; Mui, Choi, & Monk, 1998; Smerglia, Deimling & Barresi, 1998; Giunta et al., in press). Other evidence suggests that informal support may not always be so available for Hispanic and non-White caregivers. Phillips and colleagues (2000) found that Mexican American caregivers had smaller social support networks and received significantly less support than did non-Hispanic White caregivers. Youn and colleagues (1999) found that Korean American caregivers, primarily daughters, reported having less social support than White caregivers.

Caregivers from racial and ethnic minority groups also may be especially likely to experience structural barriers to service utilization, including inadequate transportation, insufficient knowledge about services, cost of services, language barriers, negative prior experiences with services, and lack of culturally-sensitive services (Damskey, 2000; Mui et al., 1998; Toseland, McCallion, Gerber, and Banks, 2002; Gill, Hinrichsen, & DiGiuseppe, 1998; Williams and Dilworth-Anderson, 2002; Dilworth-Anderson et al., 2002; Levkoff, Levy, & Weitzman, 1999; Giunta et al., in press).

As the ethnic and cultural diversity of the United States' population increases, so does the need to understand the reasons for the underutilization of formal services by ethnic minority caregivers. Hypotheses to explain observed patterns of low formal service use have included fam-

ily-centered cultural norms, greater informal support, and structural barriers to service use. However, studies to date have been based primarily on information from individuals already receiving services, and have provided only limited guidance regarding the perspectives of caregivers from a wide range of racial and ethnic minority groups. Little is known about caregivers' own experiences and attitudes about service use, from their own cultural perspectives and in their own languages. Especially lacking is information from Asian and Pacific Island caregivers, the groups least likely to use formal support services.

This study examines reasons for restricted service use among caregivers from eight racial and ethnic minority groups. Particular attention is given to commonalities in the experiences of caregivers from diverse groups regarding their family care responsibilities, the role of current informal and formal supports, and the potential utility of desired supports.

### **METHODS**

Racial-specific and ethnic-specific caregiver focus groups were held to examine cultural variations in the family caregiving experience and to identify factors contributing to decisions about the use of caregiver support services, among each of the eight non-White populations with the greatest representation in California (U.S. Census, 2000): African-Americans, Chinese, Filipinos, Korean, Native Americans, Hispanics, Russian, and Vietnamese. Focus groups are in-depth, open-ended, facilitator-moderated group discussions of one to two hours duration that explore a specific set of issues on a predefined and limited topic (Robinson, 1999). Focus groups have been found to be an effective way to "obtain data about feelings and opinions from a small group of participants about a given problem, experience, service or other phenomenon" (Leung, Wu, Lue, & Tang, 2004), especially in order to provide insight from socially marginalized groups regarding specific phenomena that have emerged in existing data (Hudson & McMurray, 2002; Kidd & Parshall, 2000).

#### ***Focus Group Recruitment***

Focus group participants were recruited through community organizations serving each of the eight racial or ethnic populations (African American, Chinese, Filipino, Korean, Native American, Hispanic, Rus-

sian, and Vietnamese): three in the San Francisco Bay Area, one in Sacramento, one in Los Angeles, and three in outlying areas of Southern California. These organizations included community centers (e.g., the Asian Community Center, the Filipino American Council, First Nations Tribal Family Center), churches, health clinics, senior services agencies, and local Area Agencies on Aging (AAA). Most of the organizations chosen did not already have programs explicitly targeted to caregivers, and efforts were made to recruit individuals who were not necessarily already utilizing caregiver support programs. Focus group participants were recruited through posted fliers and personal contact with organization members or consumers, and received \$50.00 for their participation.

### *Participant Characteristics*

A total of 76 individuals participated in the eight focus groups, from six participants in the Hispanic group to 12 in the African-American and Vietnamese groups (see Table 1). Participants ranged in age from their early 20s to their early 70s; approximately two-thirds were women. The majority of participants were providing care to an elderly parent, with smaller numbers caring for spouses, other family members, neighbors, or friends.

### *Procedure*

Focus groups lasted approximately two hours, and were conducted in the preferred language of the participants. The focus groups were facilitated by graduate students, staff and faculty members from the University of California at Berkeley and California State University San Bernardino. The facilitators were matched to the language, ethnicity, and cultural backgrounds of each group, and received training in conducting focus groups from experienced practitioners. Focus group moderators followed a semi-structured discussion guide, translated as necessary, which included the following primary prompts:

- For whom do participants provide care?
- How do participants view their role as a care provider?
- What has the experience of providing care been like for them, and (how) is that affected by their race or ethnicity?
- Where do participants turn for support and assistance?
- What would they ideally like from a caregiver support agency?

TABLE 1. Focus Group Participants

Focus Group	# of participants	Age range	Gender	Care recipient
African-Americans	12	20-70	10 female 2 male	Parent-8 Aunt-2 Grandmother-1 Daughter-1
Chinese	8	30-70	4 female 4 male	Spouse-1 Parent-4 Aunt-1 Multiple persons-1 Unknown-1
Filipino	9	30-60	7 female 2 male	Spouse-3 Parent-1 Aunt -1 Friend-3 Overlaps-1
Korean	9	25-65	4 female 5 male	Parent-8 Brother-1
Native American	11	30-60	6 female 5 male	Parent-4 Grandmother-2 Unknown-5
Hispanic	6	20-25	3 female 3 male	Parent-1 Grandparent-3 Neighbor-2
Russian	9	40-60	7 female 2 male	Spouse-1 Parent-7 Son-1
Vietnamese	12	28-61	9 female 3 male	Parent-11 Friend-1

These questions were used to promote open discussion among the participants regarding their experiences as care providers, and were accompanied by specific follow-up prompts as needed. The focus groups were audiotaped, and at least one note taker was present at each session.

### *Analysis*

Following each group meeting, the moderator and note taker briefly discussed the group process, and then each separately prepared a one-page summary of their impressions. All materials from the eight groups, including tapes, transcripts, notes, and summaries, were submitted to the research team for analysis.

Based on the structure of the discussion guide and a preliminary review of focus group materials, nine general categories were identified

for organizing the data: positive aspects of the caregiving experience, negative aspects of the caregiving experience, racial/ethnic group membership, informal support, formal support, suggestions for improving formal support, characteristics of ideal agencies, policy recommendations, and other points important to participants. Two coders independently reviewed all raw data and identified key issues from each focus group corresponding to each of these nine categories. Where differences in issues were found, the coders discussed and resolved any discrepancies.

Research analysts then prepared summaries of data from each focus group, contextualizing the categorized issues with additional information regarding group location and logistics, descriptions of participants and their care recipients, caregiving experiences, sources of support, and recommendations for programs, services, and policies. The PI and three research analysts then reviewed the summaries and other available information, and independently identified major themes that appeared throughout the eight focus groups in each of three general areas: experiences providing care, attitudes and experiences with informal support networks, and attitudes and experiences with formal support services. The identified themes, and examples illustrating each of them, were discussed among the four analysts until there was agreement on a common set of nine cross-cutting themes. These nine themes, which are described in the following section, were then grouped into three overarching constructs: (1) familism; (2) group identity; (3) service barriers.

## ***FINDINGS***

### ***Familism***

Family-oriented themes emerged consistently throughout the eight focus groups, contextualizing the caregiving experience within family-centered cultural traditions and interpersonal impacts of providing care. Two primary themes related to the overarching construct of familism emerged: (1) cultural norms and traditions underlying the decision to provide care; (2) personal and interpersonal fulfillment associated with fulfilling those norms and traditions.

### ***Cultural Determinants of Caregiving Responsibilities***

In describing their motivations for providing care, focus group participants consistently identified longstanding cultural traditions that defined their family obligations. Caring for ill or disabled family members

was seen as a responsibility that fulfilled cultural norms, maintained cultural continuity, and strengthened family ties. Caregiving was described as something that just needed to be done—not merely the “correct” thing to do, but the “only” thing to do.

The cultural context of caregiving was articulated especially clearly by one African-American focus group participant: “Minority groups have more cultural emphasis on caring for their own people. It provides stronger family ties, and that’s what allows me to do it, as part of the community, part of the culture.” Many other participants in the African-American group also expressed the view that family members are expected to provide whatever care is necessary, no matter what the care recipient’s needs or circumstances. A Chinese participant said “there is a sense of tradition to take care of your parents . . . the Chinese usually take care of their own.” Vietnamese participants described caregiving as a family affair, with everyone sharing in the care responsibilities.

The benefits of maintaining continuity with one’s cultural traditions were cited by participants in a number of focus groups. One Russian caregiver commented, “We did it in Russia and we continue doing it here. I had wonderful parents and I do what they did—taking care.” Many of the Native American participants said that caregiving served as an example to other family members and allowed the caregiver to pass down their Native American traditions and values from one generation to the next.

### *Caregiving as a Source of Fulfillment*

Rather than being seen as a burden, caregiving was described most often as a source of personal satisfaction and emotional fulfillment, as a result of helping family members in their time of need, fulfilling cultural norms, and bringing family members closer together.

Many of the Russian-speaking participants, for example, shared positive emotions about providing care. They expressed feelings of happiness and joy, saying that they were very thankful for the opportunity to help family members, something that they considered a positive role in the Russian culture. Many of the Chinese caregivers also talked about how fulfilling it was to provide help. One of the Chinese caregivers commented that being able to help the care recipient provided “a happiness that money can’t buy.” Making the care recipient happy was a particular source of satisfaction and fulfillment, in spite of the work involved.

African-American focus group participants voiced similar positive views of caregiving, referring to the good feelings associated with helping someone in need, and the opportunity to become closer to relatives. One participant who had been providing care for five years summarized her feelings by saying simply, "caregiving is a blessing." Another participant described the challenges of providing care to family members who are dying, but focused on the fulfillment that comes when "you know that you were there [and] you know that you did your part."

### *Group Identity*

Cultural variations in the caregiving experience associated with membership in a particular racial or ethnic group were another major focus of discussion among focus group participants. Three primary themes related to the construct of group identity emerged: (1) group-related experiences of adversity and discrimination which affected the caregiving experience; (2) caregiving behaviors and norms which differentiated one's own group from the majority culture; (3) transitions in one's group identity and cultural context which impacted the availability of natural support networks.

### *Group Experiences with Adversity*

Many participants indicated that their experience as a caregiver was impacted by adversity experienced currently or historically by their cultural group, including discrimination, prejudice, dislocation, or other types of hardship the group had faced collectively. For example, participants in the Native American group discussed at length the hardships that Native Americans have endured, including a history of discrimination, poverty, isolation, and displacement; they indicated that these experiences have resulted in an aggregate distrust of government and the dominant culture, and a reluctance to utilize caregiver support services. African-American participants described how racism and low socioeconomic status have hindered their ability to obtain needed services and also made it difficult for them to have sufficient resources to provide adequate support to their care recipients.

Group experiences with adversity were perceived as impacting caregiving in some positive ways, as well. Many participants described how their personal and historical experiences of adversity had brought them closer together as a family or as a community. In addition, some participants indicated that dislocation and other hardships had made

them more sensitive to the needs of others and more committed to providing care to persons who needed help. Group experiences with adversity also affected service utilization, as will be discussed under the construct of service barriers.

### *Us versus Them*

One issue that emerged consistently among all caregiver groups was a sense that one's own cultural community differed from the majority culture in the United States with regard to the ways in which they provide care or treat their elderly members. For example, Hispanic caregivers clearly differentiated themselves from Anglos, who were perceived as abandoning the care and protection of their loved ones into the hands of strangers in order to rid themselves of the burden of care: "I mean hey you take care of your parents, they live with you, the whole huge family is living together. It seems like Anglo families want to get grandma off into the nursing home where [they] don't have to be bothered with her." Another participant said: "We can't just put them somewhere else, that's the way we were brought up."

Vietnamese participants believed that providing care for family members was more important in their culture than in the Caucasian culture, reflecting strong family values not shared by the majority culture. Regarding the importance of caregiving in the African-American culture, one African-American participant had this to say: "We shouldn't be like white people, where the job is more important than our relatives."

### *Cultural Norms in Transition*

Another issue raised in many of the focus groups was the sense that changes were taking place in their cultural communities that impacted the availability of support for older adults and their caregivers. Participants in the Chinese and Korean groups cited changes in cultural norms that they attributed to the acculturation of later-born cohorts. In the Chinese group, participants worried that American-born Chinese would not have a sense of filial piety in caring for their elders and not fulfill traditional family obligations. One participant said: "There is a sense of tradition to take care of your parents, but it is uncertain whether your children would do the same for you." Participants of the Korean group also voiced similar concerns about whether or not the younger generation would take care of them. Older participants expressed the concern that younger Koreans might have a different conception of caregiving

responsibilities, especially with regard to living arrangements. Younger participants did not view living with the care recipient as necessary, while the older participants perceived this to be an important part of the caregiving role.

African-Americans and Native-Americans perceived their groups as ones undergoing significant changes as well. Participants in the African-American group indicated that drugs and violence have contributed to a lack of unity in the African-American community, affecting family cohesiveness and the availability of support for caregivers from within the African-American family and outside of it. The Native American participants also described how traditional Native American family values have changed as the tribes have become more and more decentralized.

### ***Service Barriers***

Focus group participants reported very limited use of existing formal support services. Themes that emerged regarding the limited use of outside services included the following: (1) reliance on informal support networks rather than formal services; (2) lack of knowledge of available services; (3) mistrust of formal service providers; (4) unavailability of culturally appropriate services.

### ***Utilization of Informal vs. Formal Supports***

When caregivers needed help, they turned primarily to family and friends, with limited reliance on secondary informal support networks and minimal use of formal support services. For example, participants in the Chinese, Filipino, and Vietnamese groups relied primarily on family members for assistance, seldom mentioning other informal networks or their cultural community as a source of support with caregiving. One Vietnamese participant was part of a seven-member family with each person appointed a certain service in caring for their mother. Participants in the African-American group also emphasized the importance of family when caring for loved ones, but extended it to include kinship networks and non-blood relations. They indicated that it was important that families maintain the primary responsibility of caring for ill family members instead of employing outside services.

Hispanic caregivers preferred to keep caregiving within the family; however, because these caregivers in a rural area, they often relied on neighbors simply because there was no one else around. As a result,

neighbors sometimes became as close as family members. As one participant said, "Well, in my neighborhood we are all pretty close and we are all pretty much like family. They will come by and visit. They provide a good lift, I mean we don't really ask them to, but they provide a good lift."

Social, cultural, and religious organizations were identified as sources of informal support for caregivers in a few of the focus groups. Some of the Hispanic, Filipino, and African-American caregivers identified the church as a major source of emotional or spiritual support. Native American caregivers frequently turned to tribal organizations. Many of the Filipino caregivers described attending social clubs for dancing, recreation, and companionship. Some of the Korean participants turned to Korean community organizations, such as the Korean Health Information Center, for services designed to assist the care recipient.

Overall, the ethnic minority caregivers were low users of formal support services. Other than a few participants in the African-American group, who reported using caregiver information and respite programs, the only services mentioned by focus group participants were directed at the elderly care recipients rather than the caregivers themselves. Although Chinese caregivers reported relying mostly on their children and other family members as their primary source of support in helping to take care of the care recipient, a few had used formal services such as IHSS, Meals-on-Wheels, Paratransit, or Adult Day Care. Some African-American caregivers had used Meals-on-Wheels or the state's In-Home Supportive Services program (IHSS). Some of the Russian caregivers reported that their care recipients attended an Adult Day Health Care (ADHC) or a Regional Center program for persons with developmental disabilities. Some Vietnamese participants reported using IHSS, but no other services. Some Hispanic participants had looked into getting In-Home Supportive Services (IHSS), but had become discouraged as a result of burdensome paperwork and no assurance of eligibility.

In describing the kinds of services they might find helpful (i.e., "to make it easier for you to provide care, alleviate strain, or otherwise improve your caregiving situation"), participants typically described services to alleviate the needs of the care recipient, seldom mentioning their own concerns and needs. Even when asked for recommendations for an ideal support program for caregivers, most of the recommendations concerned services for the care recipient rather than the caregiver. The lack of a clear differentiation of care recipient and caregiver needs

was especially apparent in the focus groups with Filipino, Chinese, Native American, and Korean participants.

### *Lack of Knowledge*

Focus group participants indicated that lack of knowledge about available services contributed to their limited use of formal support services. The Chinese caregivers were the only participants who were aware of an extensive range of formal services designed to help older persons, such as the state's In-Home Supportive Services program, Meals-on-Wheels, Lifeline, Adult Day Care, and Paratransit, and they also seemed the most up-to-date regarding relevant state budget and policy issues, program funding sources, and service criteria. The African-American and Korean participants were aware of a limited number of services and used these services only when necessary, as noted above. In addition, a number of African-American participants knew how to obtain additional information and referrals from their local Area Agency on Aging (AAA) if needed.

Participants in the remaining five focus groups reported not being aware of many formal services. None of the Native American, Filipino, or Russian participants were aware of what services existed for themselves or for the care recipient, nor did they know how to access this information. Participants in the Vietnamese group did not know about any services other than IHSS for their care recipients. The Hispanic caregivers seemed to know that information about needed support services was "out there somewhere," but did not know how to access it. Some did not even know how to apply for Medi-Cal for themselves or their care recipients.

### *Mistrust*

One reason given for low service use was mistrust of formal service providers. Many focus group participants felt that they could not trust non-family members to care for their care recipients. Many of the Filipino participants, for example, did not want to employ outside help because they felt that it was "too dangerous." As one participant in the Korean group said, "I want to take care of my mother and mother-in-law myself particularly if they become ill because I couldn't trust them in other people's hands. Nurse's aides don't even understand Korean and don't really care."

For Native American participants, avoidance of formal services was rooted primarily in a mistrust of government agencies. As one Native American participant explained, "A hundred years ago they (Americans of European origin) were the conquerors and slaughtered us. . . . Each one of us can tell of somebody that has been attacked by this dominant culture so it says something about not wanting to trust."

#### *Services Unavailable or Inappropriate*

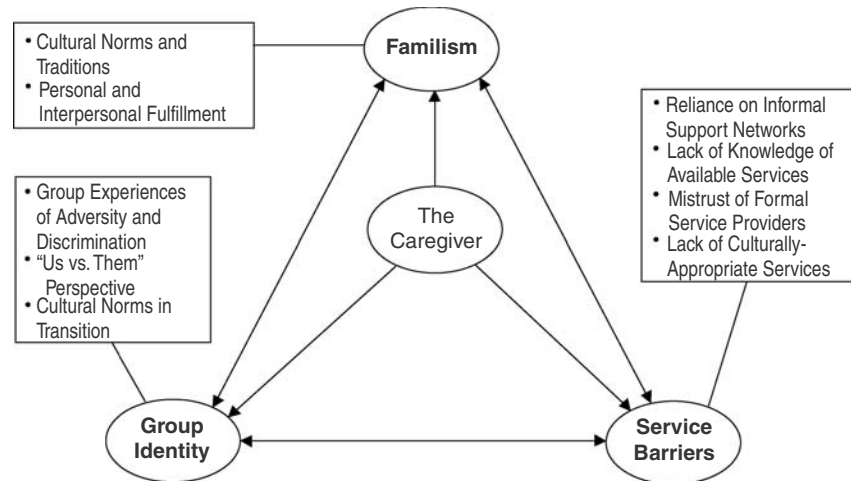
Another reason frequently given for not using services was that services were either not available or not culturally appropriate. For many of the ethnic minority groups, available services were considered inappropriate or inaccessible because of problems such as language barriers, lack of culturally-specific services, or economic barriers. Services especially desired included care training and respite.

Language barriers were identified frequently as an obstacle to service utilization. Participants in the Chinese group, for example, complained of substantial difficulty finding local community organizations where staff members spoke Cantonese; consequently, many of these caregivers felt discouraged to even apply for services. Participants in the Russian and Vietnamese also expressed frustration about the lack of information and services in their native languages.

Many participants said that the lack of culturally-specific services was another barrier to service use. Hispanic caregivers were especially vocal in describing the need for care systems based on Mexican cultural traditions of family care rather than apparent Anglo patterns of formal care provision. Participants in the Native American, African-American, and Vietnamese groups also expressed the notion that their issues and concerns were different from those of the dominant culture, and that community agencies needed to reflect the special needs of their group. Native American participants, for example, felt that existing service providers did not and could not understand their special needs, and they wanted to see the services provided by people like themselves. Chinese participants also indicated that services would be more useful if they were more tailored to care recipients' cultural traditions, such as having an option of getting Chinese food with Meals-on-Wheels instead of the typical American dishes usually provided by the program.

Economic factors were another barrier to service use. Financial burdens associated with caregiving were a recurrent theme in all of the focus groups, and mentioned by every participant in the Hispanic group. African-American caregivers emphasized that services should be more

FIGURE 1. Themes Identified by Family Caregivers



affordable and that more monetary support should be provided to caregivers to ease the financial strain placed on these families. Filipino caregivers desired financial aid from service providers as well as monetary support from the government. Reimbursement for home care, including salary and health benefits for family caregivers, was seen as particularly important by participants in the Hispanic and Vietnamese groups.

Focus group participants also noted the need for training in order to better fulfill their care responsibilities. African-American caregivers, for example, indicated that training could enable them to provide better care and be less reliant on outside assistance. Chinese and Vietnamese participants identified the need for training classes as well as counseling regarding how to provide better care. Russian participants indicated that a 1-3 day training course for caregivers would be ideal. Korean participants indicated that training for service providers also would be helpful, particularly with regard to eligibility, program availability, and Korean language and culture.

Participants in a number of groups mentioned the need for respite care. Hispanic caregivers, while adamant about not wanting to rely on formal services, said that they would welcome having someone for a couple of hours per day to help the care recipient with basic necessities, such as cleaning, cooking, helping with bathing and dressing, or trans-

portation, so that the caregiver could have a break. Russian and Vietnamese caregivers also said that they would benefit from a break for a few hours or a few days a week. For the Chinese participants, an ideal service would include a private day care provider in the care recipient's neighborhood so that caregivers could take a break, and a backup system for the care recipient if the caregiver became ill.

### **DISCUSSION**

Our findings, like those of numerous other studies, provide evidence that caregiving experiences, care-related values and beliefs, and care practices differ across racial and ethnic groups (Aranda & Knight, 1997; Connell & Gibson, 1997; Dilworth-Andersen, 2002; Janevic & Connell, 2001). Our findings also reveal a number of striking consistencies across the eight racial and ethnic groups in our study, as reflected in the cross-cutting constructs of familism, group identity, and service barriers. These findings are discussed below in terms of their implications for existing knowledge regarding family responsibility, resource utilization, and program and service implications for caregivers from racial and ethnic minority populations.

#### ***Family Responsibility***

Family responsibility emerged as a central theme, with caregiving seen as an enactment of cultural traditions regarding family care roles and activities. Help-giving to the care recipient was described as a natural extension of one's responsibility to the family as a whole, and to ancestral traditions often handed down from generation to generation. Individual caregivers pictured themselves as a link in an historic trans-generational chain, providing continuity with ancestors and family members yet to come. From this perspective, caring for a disabled family member was experienced not so much as a choice but as a duty. Family responsibility was manifested in norms of familism, mutual support, reciprocity, and filial obligation (Becker, Beyene, Newsom, & Mayen, 2003), which pervaded the focus group participants' discussion of their care experiences. Moreover, these norms were perceived as differentiating these non-White and Hispanic caregivers from the majority culture, which "doesn't care." Levkoff and colleagues (1999) also found that non-White caregivers believed that their way of taking care of elders "is much better than the American way" (p. 350), and saw their

ethnicity as a major reason for not admitting a relative into a nursing home.

Family-centered cultural norms also provided a context for positive perceptions of the caregiving experience. Indeed, focus group participants seldom mentioned strain or burden, most often describing caregiving as a source of personal satisfaction and emotional fulfillment. Satisfaction was found in carrying out expected roles, in honoring and being honored, in relationships with family members, and in connections with the past and the anticipated future. The well-being of the care recipient, and of the family as a whole, transcended the personal demands experienced by the individual. This emphasis on traditional norms and family well-being suggests that, for some non-White and Hispanic caregivers, measures of individual emotional and physical strain typically used with White caregivers may not adequately reflect the most salient dimensions of the caregiving experience, perhaps contributing to the relatively low levels of caregiver strain sometimes found among non-White caregivers (Farran et al., 1997; Miller et al., 1995; Mui, 1992). African-American caregivers, for example, have been found to appraise their caregiving roles more positively and report greater satisfaction than do White caregivers (Roff et al., 2004; Lawton et al., 1992). Rather, for some racial and ethnic groups, satisfaction and distress in caregiving roles may be rooted more deeply in one's self-perceived assessment of the extent to which one is fulfilling culturally-mediated family care expectations. More research is needed to assess this hypothesis more fully.

Existing cultural norms regarding family responsibility were not seen as static, however. Focus group participants consistently expressed concern that cultural norms were weakening. Younger cohorts were seen as having less cultural identification and commitment, coupled with the breakdown of traditional community support structures and values, prompting concerns regarding the availability and commitment of family members to provide care when the caregivers themselves needed help. Indeed, a number of writers have suggested that a shift from "filial piety" to "filial autonomy" may be underway among immigrant families (Pang et al., 2003; Silverstein, 2000), with relatively few middle-aged children able to enact the traditional practices associated with filial piety (Sung, 1998). Mausbach and colleagues, for example, found that more-acculturated Latinas are less likely to identify positive aspects of caregiving than are their less-acculturated counterparts (Mausbach et al., 2004). Contextual factors, such as decreasing neigh-

borhood cohesiveness and geographic decentralization, may also be contributing to changing cultural norms among some non-immigrant groups.

### ***Resource Utilization***

Focus group participants seldom used formal services, and displayed markedly little knowledge of outside sources of support. Mistrust of potential service providers, rooted in experiences of discrimination and actual or perceived vulnerability, was a recurrent theme in each of the focus groups. A common history of adversity, prejudice, and dislocation contributed to a sense of group identity but also vulnerability. While prior and contemporaneous hardships experienced by members of minority groups may decrease the likelihood that caregiving demands will be perceived as unusually difficult or stressful (Knight & McCallum, 1998), discrimination and dislocation can also serve to isolate caregivers from potential sources of outside support. Investigations of disparities in health care service use among racial and ethnic minority populations have cited the reluctance to obtain help from outsiders as a potentially important barrier to seeking needed services (Dunlop et al., 2002). Latino families, for example, frequently have been found to be wary of professionals whom they do not already know (Ruiz-Beltran & Kamau, 2001).

Low rates of service utilization by non-White and Hispanic caregivers also may reflect deficits with regard to the actual availability of needed resources. Services for non-White and Hispanic caregivers may be limited with regard to their accessibility, affordability, and appropriateness. For example, Latino caregivers have been found to be especially likely to experience difficulties due to language barriers and a lack of culturally-competent services (Levkoff et al., 1999). Financial barriers to service use also are likely to be important (Wallace et al., 1994), although several studies have found that the cost of services and geographic access to services are not necessarily predictive of formal service use (Strain & Blandford, 2002; Fortney, Chumbler, Cody, & Beck, 2002; Toseland, McCallion, Dawson, Gieryic, & Guilamo-Ramos, 1999). Even when services are available, immigrants may find eligibility and service information confusing or intimidating (Pang et al., 2003). Moreover, even highly-aculturated, middle-class, well-educated immigrants often prefer to speak their native language when discussing personal matters such as family care (Echeverry, 1997).

Low rates of service utilization sometimes have been seen as a reflection of cultural “strength” and solidarity (Bengtson et al., 1996). For example, Latina caregivers have been found to delay institutionalization significantly longer than do Caucasian caregivers (Mausbach et al., 2004). However, in maintaining care for a longer period of time, these caregivers may be experiencing service needs that are not being met adequately. Indeed, non-White and Hispanic caregivers have consistently been found to experience higher levels of unmet service needs than do White caregivers (Ho et al., 2000; Hinrichsen & Ramirez, 1992; Naivaie-Waliser et al., 2001).

In this study, service gaps apparently were not filled by ethnic-specific communal organizations and resources. Indeed, focus group participants made little mention of church, social and cultural organizations, or other potential community resources. Instead, these non-White and Hispanic caregivers relied mainly on family members and friends for support and assistance. Indeed, families have been found to be not only the first, but in many cases the only, place that non-White and Hispanic individuals turn to for help with personal problems (Phillips et al., 2000; Sotomayor & Randolph, 1988). This may be especially true in immigrant families, where family members and friends typically are called upon to assist with providing transportation and overcoming language barriers (Pang et al., 2003), prerequisites to formal service use.

### ***Program and Service Implications***

When asked to identify services that would assist them in their caregiving roles, most focus group participants talked primarily about services for the care recipient rather than for themselves. This was consistent with participants’ general pattern of discussing the care recipient and the care situation rather than their personal reactions to it. To some extent, this could have resulted from a concern that acknowledging dissatisfaction in the caregiving role could be seen as culturally dystonic and bring disapproval from cultural peers (Gallagher-Thompson et al., 2003). However, the tendency to focus on the care recipient and their needs also reflected the participants’ general family-centered approach, whereby family well-being took precedence over personal considerations. It is not surprising, therefore, that programs and services targeted “to best meet the needs of the *individual* caregiver” [emphasis added] (NFCSP, 2001) rather than the family system, are underutilized by Hispanic and non-White caregivers.

Our findings point to the importance of a family-centered approach to meeting the needs of Hispanic and non-White caregivers, in terms of what services are offered and how they are presented. Focus group participants indicated that they would use caregiver support services if those services were seen primarily as benefiting the care recipient rather than themselves. Training and counseling regarding care provision, for example, were seen as potentially useful to the extent that they could help caregivers to provide better care and be less reliant on outside assistance. Similarly, many caregivers mentioned the need for in-home respite care, primarily as a mechanism for enabling them to provide better care over a longer period of time rather than for alleviating their own caregiver strain. It also was seen as very important that service providers be as similar as possible to the care recipient, in order to overcome mistrust of "outsiders" and other linguistic and cultural barriers (Levkoff et al., 1999). Finally, a family-centered approach to caregiver support involves strengthening the capabilities and resources that families bring to the provision of care. This includes reimbursement for home care and health benefits, in order to overcome the financial hardships experienced by more economically challenged Hispanic and non-White care providers (NAC/AARP, 2004).

Given the lack of trust in majority cultural institutions expressed by these focus group participants, stemming from histories of adversity and discrimination, strengthening the capacity of their existing communal organizations and institutions would appear to be an essential component of any effort to provide needed support to these caregivers and their families. For example, a central tenet of culturally-competent service provision is that services need not only to be culturally appropriate, but also need to be provided and organized in collaboration with members of the particular cultural community (AoA, 2001).

Community partnerships between the aging network and accepted ethnic-specific community-based entities which already are trusted by and familiar to Hispanic and non-White caregivers can also help to overcome recruitment barriers and enhance service participation by minority caregivers, as has been shown for Chinese American caregivers and Hispanic caregivers (Gallagher-Thompson et al., 2003; Arean et al., 2003; Levkoff et al., 1999). Community partnerships also enhance the social capital of the communities in which services are provided, thereby potentially improving the long-term ability of those communities and their institutions for meeting the needs of disabled persons and their families.

### ***Study Limitations***

While these findings generally are consistent with those of other studies of individual ethnic groups and their service needs, their generalizability may be somewhat limited by the nature of the focus group methodology utilized in this study. Focus group participants were selected using local publicity and snowball techniques, and their views are not necessarily representative of the entire population of caregivers from each racial or ethnic group. Moreover, each racial and ethnic group is highly heterogeneous, including many diverse subgroups. Caregiving-related attitudes, values, and behaviors undoubtedly will vary based on caregivers' country of origin, number of years or generations in the United States, acculturation, generational status in the family, and other individual characteristics. Ultimately, these findings point to the need for additional research to better understand the ways in which cultural norms and racially- and ethnically-mediated experiences (e.g., discrimination and adversity) affect the care experiences, attitudes, and support needs of family caregivers.

### ***CONCLUSION***

The findings presented here add to existing knowledge regarding the experiences and perspectives of diverse groups of family caregivers. Data from the eight different racial-specific and ethnic-specific groups in this study revealed three common cross-cutting constructs (familism, group identity, service barriers), reflecting nine underlying themes. These findings have implications for understanding family responsibility and caregiver supports among racially and ethnically diverse family caregivers, and for developing culturally-relevant family- and community-centered caregiver support services.

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