Positive Aspects of Alzheimer’s Caregiving: The Role of Race

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We examined differences in positive aspects of caregiving (PAC) among 275 African American and 343 Caucasian caregivers of individuals with Alzheimer’s disease from the National Institutes of Health Resources for Enhancing Alzheimer’s Care Health (REACH) study sites in Birmingham, Memphis, and Philadelphia. African Americans reported higher scores on PAC than did Caucasians. African Americans’ higher religiosity partially mediated the relationship between race and PAC. Additional variables that contributed to their higher PAC scores were African Americans’ lower anxiety, lower feelings of bother by the care recipient’s behavior, and lower socioeconomic status.


Although historically most dementia caregiving studies have focused on the majority population (Connell & Gibson, 1997), recent researchers have begun to consider the PAC reported by African American caregivers. Picot (1995a) examined rewards experienced by 83 African American Alzheimer’s disease caregivers and found the most frequently reported reward was the belief that “God will bless me.” She also found a negative correlation between caregiver education and perceived rewards and that older caregivers reported more perceived rewards than did younger caregivers. In another study based on the same sample, Picot (1995b) found perceived rewards to be related to use of a palliative coping strategy, which relies on prayer and faith in God.

The studies that have compared African American and Caucasian dementia caregivers on PAC have consistently found African Americans to report more benefits or gains than Caucasian caregivers (Farran, Miller, Kaufman, & Davis, 1997; Foley, Tung, & Mutran, 2002; Janevic & Connell, 2001; Lawton, Rajagopal, Brody, & Kleban, 1992; Picot, Debanne, Namazi, & Wykle, 1997; Rapp & Chao, 2000; White, Townsend, & Stephens, 2000). The examination by Lawton and colleagues (1992) of caregiving in African American and Caucasian families of Alzheimer’s disease patients found greater caregiving satisfaction and caregiving mastery among African Americans than among Caucasians, with African Americans perceiving less subjective burden and intrusion on their lives because of caregiving.

Farran and colleagues (1997) compared the provisional meaning (sense of purpose provided by day-to-day events) that African Americans and Caucasians derived from dementia caregiving and found that African Americans appraised their caregiving experiences more positively than Caucasians. Moreover, higher levels of provisional meaning predicted lower levels of depression in both groups. In a study of caregivers of older, disabled people (Picot et al., 1997), African American caregivers reported higher degrees of rewards than did Caucasians, with more highly educated caregivers of both races perceiving fewer rewards. The comfort participants reported receiving from religion “in times of suffering and distress” and the frequency with which they prayed mediated the relationship between race and caregiver rewards. White and associates (2000) studied daughters and daughters-in-law caring for impaired older relatives and found that African American women perceived more rewards in caregiving than did Caucasian women.

These and similar findings have led to attempts to explain why African Americans find caregiving for older persons more rewarding than Caucasians. Two studies (Foley et al., 2002; Lawton et al., 1992) examined whether having a traditional “taking care of one’s own” ideology explained the relationship between race and caregiver rewards. Neither found that having such an ideology was related to African Americans’ favorable views of caregiving. In fact, in both studies, having a traditional ideology of care was related to positive caregiver affect for Caucasians only.

Another explanation is that caregiving is seen as a more normative experience for African Americans (Dilworth-Anderson & Anderson, 1994; Haley et al., 1996). Positive appraisal may function in a different manner for different groups (Rapp & Chao, 2000) and may be a learned cultural pattern that has helped African Americans live through many difficult life experiences (Farran et al., 1997).

The most frequent explanation is that, for African Americans, religious meaning and expression are more significant sources of
cope that are tied to appraising caregiving more positively (Connell & Gibson, 1997; Farran et al., 1997; Segall & Wykle, 1988–1989; Wykle & Segall, 1991). Only Picot and colleagues (1997), however, have systematically shown religiosity to be a predictor or mediating variable to help explain the relationship between caregivers’ positive views of caregiving and race.

In summary, previous research that compared Caucasian and African American dementia caregivers has generally found African Americans to evaluate the caregiving experience more positively and to report more satisfaction and less burden. Previous work has been less successful, however, in explaining the reasons for these differences. Identification of the mediators of the relationship between an independent and dependent variable might help contribute to theory development by explaining how or why the relationship between the two occurs (Baron & Kenny, 1986).

This study is based on the sociocultural stress and coping model articulated by Knight, Silverstein, McCallum, and Fox (2000). In this model, ethnicity is seen as a cultural variable that influences how one has been socialized to view caregiving. It suggests that strengths of the African American family, especially religious beliefs and traditions and support, are hypothesized to reinforce the value of family caregiving and thus lead to caregiver rewards. Martin and Martin (2002), for example, discuss African American helping traditions at length, defining the caregiving personality as “the racial self and the communal self revolving around the spiritual self” (p. 6). From this perspective, spirituality and caregiving are conceptually linked in the African American helping tradition as positive values benefiting the community as a whole. This view is consistent with Ellison’s (1993) conceptualization of the African American church as a place that affirms understandings held within the community of a “good” family member and a place where the important values of family solidarity and African American culture are transmitted (Roberts, 1980).

Ellison’s (1997) finding that religiosity among African Americans was related to satisfaction in the performance of family roles is consistent with this perspective. As noted earlier, there is evidence to support the sociocultural importance of religiosity in explaining caregiver outcomes among African Americans (Connell & Gibson, 1997; Farran et al., 1997; Picot et al., 1997; Segall & Wykle, 1988–1989; Wykle & Segall, 1991). Similarly, Dilworth-Anderson, Williams, and Gibson (2002) highlighted the importance of cultural constructs in their review.

The sociocultural model of stress and coping also suggests that ethnicity might imply racial differences in the way social support would affect caregiving outcomes. A large number of studies have shown differences in the size, importance, and helpfulness of African American and Caucasian American caregivers’ social support systems, suggesting that social support might significantly influence the relationship between PAC and race (Haley et al., 1995, 1996; Miller & Guo, 2000; Mui, 1992; Smarglia, Deimling, & Barresi, 1998; Sterritt & Pokorny, 1998; Stommel, Given, & Given, 1998; Wallsten, 2000).

Other elements of the traditional stress and coping model include anxiety, depression, and behavioral bother. Previous work by Farran and colleagues (1997) and Haley and colleagues (1995, 1996) suggested the importance of caregiver anxiety and depression in understanding differences in African American and Caucasian caregiver outcomes. Prior research has also found African American caregivers to be less distressed by disruptive behaviors than their Caucasian counterparts (Haley et al., 1996; Miller et al., 1995), suggesting that perceptions of behavioral bother might influence the relationship between race and PAC.

A number of previous studies (e.g., Macera et al., 1992; Picot, 1995a; Picot et al., 1997) have found demographic characteristics of caregivers, particularly education and income, to be related to caregiver attitudes and outcomes, with persons of lower education and socioeconomic status (SES) reporting less burden and more positive attitudes toward caregiving.

In this study we had two aims. Our first was to determine if previous findings that African Americans experienced more positive feelings about Alzheimer’s disease caregiving than Caucasians would be supported in this large multisite sample that included large numbers of African American caregivers. Second, assuming these differences were found, we were interested in exploring variables that might contribute to African Americans’ more positive feelings about caregiving. What variables might help explain the relationship between race and PAC?

On the basis of previous literature and our conceptual framework, we predicted that African Americans would express more positive feelings about caregiving. We also predicted that the following factors would help explain African Americans’ more positive feelings about caregiving: (a) higher religiosity; (b) lower levels of anxiety, depression, and feelings of bother; (c) higher levels of social support; and (d) lower levels of education and SES.

Methods

Participants

The total sample (N = 618) for this study was 275 self-identified African American and 343 non-Latino Caucasian caregivers from the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) sites in Birmingham, Memphis, and Philadelphia. REACH was a unique 6-year multisite research program sponsored by the National Institute on Aging (NIA) and the National Institute of Nursing Research (NINR). Its purpose was to carry out social and behavioral research on interventions designed to enhance family caregiving for Alzheimer’s disease and related disorders. Six research sites (Birmingham, Boston, Memphis, Miami, Palo Alto, and Philadelphia) and a coordinating center (Pittsburgh) focused on characterizing and testing the most promising home- and community-based interventions for maintaining and improving the health and quality of life of Caucasian, African American, and Latino caregivers of dementia patients. Psychological distress was the primary outcome of interest. The study sites were allowed to choose whether their data would be included in the various papers generated from the REACH initiative. The Boston, Miami, and Palo Alto sites chose not to participate in this analysis.

Data for the study were collected through in-home interviews during the baseline phase. Of the 640 cases initially available, 22 were excluded because of missing data. Demographic characteristics of participants by race are presented in Table 1.
Recruitment

Family caregivers of community-dwelling individuals with dementia (care recipients) were recruited from community sites and health and social service agencies. Media outreach efforts to and referrals from memory disorder clinics, primary care clinics, and physician offices were also used to recruit participants. See Nichols, Malone, Tarlow, and Lowenstein (2000) and Tarlow and Mahoney (2000) for details about recruitment for the REACH cooperative agreement.

To be included in the study, care recipients had to have a medical diagnosis of probable Alzheimer’s disease or exhibit a Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975) score of less than 24. In addition, recipients had to have at least one basic activity of daily living limitation (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) or two instrumental activities of daily limitations (Lawton & Brody, 1969). At the Birmingham site, care recipients also had to exhibit at least three behavioral problems. All caregivers in the study had to be at least 21 years of age and live with the care recipient. They also must have provided an average of at least 4 hours of daily care for the recipient for at least 6 months.

Measures

Interviewers collected data at baseline and at 6, 12, and 18 months. All data were collected as part of the REACH core battery administered to all participants by interviewers who were trained with the same procedure and materials and certified by the Coordinating Center. Only the baseline data are included in this paper.

Positive aspects of caregiving.—We measured the dependent variable for this study with a nine-item instrument that assessed caregivers’ subjectively perceived gains from, desirable aspects of, or positive affective returns from providing care for their family member. The instrument is a modified version of the caregivers’ connections to a community of others and a personally satisfying and enriching) and “outlook on life” (ways the caregiver perceives that his or her caregiving has been important. The factors were labeled “self-affirmation” (how the caregiver perceives that his or her caregiving has been personally satisfying and enriching) and “outlook on life” (ways the caregiving experience has strengthened and enhanced the caregivers’ connections to a community of others and a philosophical stance that is sustaining and nurturing). These subscales were positively correlated \( r = .61 \). Thus we elected to undertake our analyses on the total PAC measure. The PAC mean was \( M = 34.64; SD = 8.74 \). Cronbach’s alpha was \( \alpha = .88 \) (Tarlow et al., in press).

Demographic characteristics.—Demographic variables included race, caregivers’ age, years of education, relationship to the care recipient, length of time living with the care recipient, and SES. As a marker for SES, we coded the primary employment situations of both the caregiver and his or her spouse (either currently or before retirement) by using the Nam–Powers Socioeconomic Status Scores (Nam & Terrie, 1988), and we used the higher of the two to determine SES. Scores could range from 0 to 100.

Caregiver anxiety.—A 10-item modified version of the Spielberger State-Trait Personal Inventory (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) measured anxiety. Response options ranged on a 4-point scale of intensity from 1 (not at all) to 4 (very much). Cronbach’s alpha was \( \alpha = .89 \).

Caregiver depression.—We used the Center for Epidemiological Studies–Depression (CES-D) scale (Radloff, 1977) as a measure of depression for caregivers. For each of the 20 items, caregivers rated the frequency of this symptom on a 0 (rarely) to 3 (most of the time) scale. Higher scores indicate greater depression, with a score of 16 or more considered to be clinically significant. Cronbach’s alpha was \( \alpha = .86 \) in the REACH sample reported in Burgio, Stevens, Guy, Roth, and Haley (2003).

Religiosity.—We assessed religiosity with three items: importance of religious faith or spirituality (0, not important, to 4, very important), attendance at religious services or activities (1, never, to 6, nearly every day), and frequency of prayer or meditation (1, never, to 6, nearly every day). The resulting index was the sum of respondents’ standardized responses to each item. Cronbach’s alpha was \( \alpha = .80 \).

Behavioral bother.—The Revised Memory and Behavior Problem Checklist (RMBPC; Teri et al., 1992) consists of 24 items that we used to inquire about problem behaviors the care recipient might have exhibited in three specific areas: memory-related problems, depression, and disruptive behaviors. In the REACH version of the measure, caregivers were asked to indicate whether the problem behavior had or had not occurred during the past week. If the problem behavior had occurred, the caregivers rated the degree to which they were bothered or upset by the behavior. Response options range from 0 (not at
all) to 4 (extremely), with a 0 given to any behavior not present. We obtained a behavioral bother score by averaging these ratings across all reported problems. Cronbach’s alpha was $\alpha = .87$. Complete psychometric data on the RMBPC are available in Roth and colleagues (2003).

Social support.—A 17-item measure of social support was developed specifically for the REACH project. The scale was designed to measure multiple dimensions of social support known to affect health and well-being. It included the 4-item Krause (1995) measure of negative interactions (e.g., “How often have others taken advantage of you?”), 10 items based on questions from the Lubben Social Network Index (Lubben, 1988) asking about specific help received (e.g., “How often has someone helped you with shopping?”), and 3 items measuring satisfaction with tangible, emotional, and informational support received (Krause, 1995; Krause & Markides, 1990). Cronbach’s alpha for the combined scale was $\alpha = .80$.

RESULTS

We found a clear relationship between race and PAC, with African Americans scoring higher than Caucasians on positive aspects of caregiving; $M = 36.74$ for African Americans and $M = 32.95$ for Caucasians, $F(1, 616) = 30.07, p < .001, R^2 = .05$. There was no evidence of a Site $\times$ Race interaction; $F < 1.0$.

The primary goal of our study was to evaluate possible explanations for why African American caregivers were more positive about their caregiving roles than Caucasian caregivers. To assess the effects of race and potential mediating variables, we followed the four-step logic outlined by Baron and Kenny (1986), Judd and Kenny (1981), and MacKinnon and Dwyer (1993). Having established a statistically significant correlation between race and PAC, we followed the four-step logic outlined by Baron and Kenny (1986), Judd and Kenny (1981), and MacKinnon and Dwyer (1993). We were able to determine that each of these variables was individually a significant mediator of the relation between race and PAC.

When we included all four of the mediator variables (SES, behavioral bother, anxiety, and religiosity) simultaneously in a multiple regression equation with race, the standardized regression coefficient for race remained statistically significant, $F(5, 612) = 18.09, R^2 = .13$ (see Table 3). The relationship between race and PAC is thus partially explained by African Americans’ lower SES, lower behavioral bother, lower anxiety, and higher religiosity when compared with Caucasians. By using Sobel tests (Sobel, 1982), we were also able to determine that each of these variables was individually a significant mediator of the relation between race and PAC.

**DISCUSSION**

Our first aim in this study was to identify differences between African American and Caucasian Alzheimer’s disease caregivers in the degree to which they experienced PAC. Consistent with previous research (e.g., Farran et al., 1997; Picot et al., 1997; Lawton et al., 1992), African American caregivers, compared with Caucasian caregivers, reported more PAC. This finding provides additional support for the conclusion that African Americans perceive Alzheimer’s disease caregiving more favorably than do Caucasians.

Another finding is that African Americans have higher religiosity than Whites, and higher religiosity is associated with more favorable appraisals of caregiving. Therefore African Americans’ more favorable appraisal of caregiving is explained in part by their higher levels of religiosity. This is consistent with what Picot and colleagues (1997) found in their study conducted in an urban area in the Midwest and with others’ (Wykkle & Segal, 1991; White et al., 2000) speculations about race differences in PAC. For African American caregivers, the importance of religious practice and belief is a common theme and a potential strength upon which service providers can build in their interventions with family caregivers (e.g., provide respite services so that caregivers can attend religious services).

As hypothesized, higher PAC among African American caregivers also appears to be partially attributable to their lower levels of anxiety and bother by the care recipient’s behavior than their Caucasian counterparts. This finding suggests the importance of efforts to promote and sustain African American

### Table 2. Correlations Among Race, Mediator Variables, and PAC

<table>
<thead>
<tr>
<th>Variable</th>
<th>Race</th>
<th>SES</th>
<th>Anxiety</th>
<th>Religious</th>
<th>PAC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>1.00</td>
<td>0.25*</td>
<td>0.16*</td>
<td>-0.28*</td>
<td>-0.22*</td>
</tr>
<tr>
<td>SES</td>
<td>1.00</td>
<td>0.08*</td>
<td>-0.01</td>
<td>-0.07</td>
<td>-0.15*</td>
</tr>
<tr>
<td>Behavioral bother</td>
<td>1.00</td>
<td>0.47*</td>
<td>-0.07</td>
<td>-0.20*</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>1.00</td>
<td>-0.13*</td>
<td>0.22*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious</td>
<td>1.00</td>
<td>0.24*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAC</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Notes: PAC = positive aspects of caregiving; SES = socioeconomic status. *p < .05.

### Table 3. Standardized Regression Coefficients and Sobel Test

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Regression Coefficient</th>
<th>t</th>
<th>p</th>
<th>Sobel Test Statistic</th>
<th>p*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race alone</td>
<td>-2.22</td>
<td>-5.48</td>
<td>.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race with mediators</td>
<td>-0.11</td>
<td>-5.06</td>
<td>.011</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SES</td>
<td>-0.20*</td>
<td>2.24</td>
<td>.025</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>-0.13*</td>
<td>3.16</td>
<td>.002</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious</td>
<td>.18</td>
<td>4.52</td>
<td>.000</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Notes: PAC = positive aspects of caregiving; SES = socioeconomic status. *If we were to apply the conservative Bonferroni correction factor for multiple comparisons to these results, the significance level would be set at $\alpha = .0125$. In this case, the test for SES would fall just outside the cut point ($p = .025$). The reader should consider this information when interpreting these results.
caregivers’ positive mental health, coping and behavioral skills training, and cognitive restructuring of problems confronted as caregivers.

African Americans’ more positive appraisals of caregiving are also partially associated with their lower levels of SES. One possible explanation is that previous experience with adversity may help some lower income, African American caregivers to reframe difficult life experiences such as caring for a loved one with dementia more positively (Gallagher-Thompson et al., 2000; Gibson, 1992; Wood & Parham, 1990).

On the basis of previous work, we had anticipated that African Americans would report higher social support and lower levels of depression than Caucasians and that these factors would help explain higher PAC among African Americans. In this study, African Americans and Caucasians did not differ significantly on these variables, and thus they do not emerge as explanatory variables.

Similarly, there was no significant race difference in educational levels among this study’s participants. Thus, this study was unable to support the findings of Picot (1995a) and Picot and colleagues (1997) that lower education levels among African Americans were related to their more favorable views of caregiving.

In summary, our results corroborate earlier findings that African American caregivers express more positive appraisals of caregiving than their Caucasian counterparts and that religiosity partially mediates this relationship. In addition, our data indicate other variables that contribute to the relationship between race and PAC include anxiety, behavioral bother, and SES.

Although others have considered these factors in studies of African American and Caucasian caregivers’ attitudes, they have not been identified in these previous studies as mediators of the relationship between race and PAC. Researchers need to investigate these and other potential mediators so that a more complete picture of the relationship between race and PAC can be drawn.

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