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Differences by Race/Ethnicity in the Delivery of the Resources for Enhancing Alzheimer's Caregiver Health (REACH II) Dementia Caregiver Intervention

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Abstract

Background/Objectives—Previous analyses of the Resources for Enhancing Alzheimer's Caregiver Health (REACH II) intervention have found that it was less effective for African American than for Hispanic or White caregivers. We examined whether there were race/ethnicity group differences in REACH II intervention delivery.

Design—Randomized controlled trial.

Setting—Community-based intervention delivered at 5 sites across the United States.

Participants—323 family caregivers of persons with dementia who were randomized to the active intervention condition.

Intervention—Nine in-home sessions (90 mins each) and 3 telephone sessions (30 mins each) were intended to be delivered and designed to reduce caregiver burden and depression, improve caregivers' self-care and social support, and help caregivers manage behavior problems in persons with dementia.

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Measurements—Interventionists recorded the type (home or telephone), start and stop times, and whether specific intervention content modules (e.g., stress management, social support) were administered in each session.

Results—Overall, REACH II intervention delivery was high, with over 80% of randomized caregivers completing at least 5 in-home sessions and receiving 8 or more hours of intervention contact. African American caregivers, however, completed fewer in-home sessions (M = 6.98) than either Hispanics (M = 7.84) or Whites (M = 8.25) and received less total intervention contact time (M = 683 mins) than either Hispanics (M = 842 mins) or Whites (M = 798 mins). No significant differences in exposure to content by race/ethnicity were found after controlling for demographic covariates.

Conclusion—African Americans in REACH II received significantly less intervention contact. Similar multicomponent interventions should examine whether there are systematic differences in intervention delivery across specific demographic subgroups and explore implications for treatment outcomes.

Keywords

dementia caregiving; intervention delivery; race

INTRODUCTION

An estimated 5.3 million Americans have Alzheimer's disease or a related disorder, and both African Americans and Hispanics are more likely than Whites to experience dementia in later life.¹ Most individuals with dementia receive daily, ongoing care from one or more family members, and the chronic stress and potential health effects of family caregiving for persons with dementia have received a great deal of research attention.^{2–4} This includes studies showing race differences in caregiver reactions and distress levels.^{5–7} To address the challenges and burdens that face dementia caregivers, over 200 randomized controlled trials have evaluated multicomponent interventions designed to improve caregiver adjustment, well-being, and the services they provide to their affected family members.⁸

Although significant progress has been made in intervention development, more research is needed to identify the optimal evidence-based services that are most acceptable and appropriate for specific subgroups within the diverse caregiving population. This includes understanding whether intervention doses, intensity, delivery characteristics, and therapeutic content are optimal for specific demographic subgroups. Although previous studies have examined potential racial differences in both the use of formal care services for dementia⁹ and the predictive significance of perceived needs for those services,¹⁰ more work is needed to determine if race or ethnic differences in service use will persist once reasonable access is made available. For caregiving intervention trials, this means sufficiently collecting and examining fidelity data to determine if interventions are delivered comparably across diverse race, ethnic, or other demographic subgroups. Unfortunately, differences in intervention delivery or fidelity across subgroups have been largely neglected in caregiving intervention research.^{11–13} Treatment delivery or participant adherence data are sometimes reported as descriptive information in outcome reports but are then typically ignored as irrelevant in the

standard intention-to-treat efficacy analysis. Nevertheless, an intervention's ultimate impact in the larger population is not simply a matter of its efficacy under controlled experimental conditions, but also depends on whether it is delivered, implemented, and utilized by persons to whom it is made available.^{13,14}

This report examines data from the multi-site REACH II initiative, which was designed to examine the efficacy of a multicomponent intervention for dementia caregivers from three race/ethnic groups.¹⁵ Family caregivers of persons with dementia who were randomly assigned to the active intervention condition were provided with education, skills training, role playing, problem solving, stress management techniques, and support services that addressed five different target areas: caregiver depression, burden, self-care and health behaviors, social support, and care recipient problem behaviors.^{15–17} All five target areas were addressed for all caregivers, but individual flexibility was allowed to tailor the relative emphasis of the treatment components based on caregiver risk profiles identified from an initial needs assessment and from joint planning and goal-setting activities between caregivers and their interventionists.^{15,18} This tailoring was allowed while still keeping the overall and session-specific contact targets the same in order to standardize total intervention contact time as much as possible. That is, there was still the expectation that all caregivers would receive the same dose of treatment in terms of the number of intervention sessions and total intervention contact time. In addition to possible intervention delivery differences by race/ethnicity, we also examined and controlled for the effects of other demographic predictors including caregiver gender, age, caregiving relationship (spouse vs. non-spouse), education, and employment status.

METHODS

Participants

Dyads (persons with dementia and their caregivers) were recruited and randomly assigned to either an active intervention condition or a usual care control condition. Data from 323 caregivers who were randomly assigned to the intervention condition were analyzed in this report (104 African American, 106 Hispanic, 113 White). The 106 Hispanic caregivers included 40 of Cuban origin, 24 of Mexican orgin, 21 of Puerto Rican origin, and 21 with other, mostly Central or South American origins (e.g., Salvadoran, Peruvian, Columbian). Caregiver inclusion criteria included: 1) living with or sharing cooking facilities with the person with dementia; 2) providing care for a relative diagnosed with Alzheimer's disease or a related disorder for 4 hours or more per day for at least the past 6 months; and 3) reporting some distress from caregiving. Caregivers were excluded if they had participated in REACH I or were participating in another caregiving intervention study. They were also excluded if they reported that their family member with dementia had a history of stroke with no progressive cognitive declines, Parkinson's disease, severe mental illness, or head injury; were bedbound; or scored 0 on the Mini-Mental State Examination (MMSE).

Intervention

All interventionists had at least a bachelor's degree and were specifically trained and certified in the REACH II procedures. The intervention was delivered over a 6-month period

in either English or Spanish. The intended dose of the intervention was 9 in-home sessions of about 90 minutes each and 3 telephone sessions of about 30 minutes each. The total amount of intended intervention contact time, therefore, was 900 minutes (15 hours) over a total of 12 intervention sessions. Adjustments were allowed such that two telephone sessions could be replaced with in-home sessions or two in-home sessions could be increased if caregivers were distressed or needed more opportunity to practice skills introduced, and telephone sessions could replace in-home sessions for caregivers who were unavailable for an extended period of time.¹⁸ Caregivers also had the opportunity to participate in group support sessions with other caregivers by telephone, but participation in these group sessions was not coded for data entry. The present analyses examined only the individual in-home and telephone intervention sessions.

Intervention Delivery Measures—Following completion of each intervention session, interventionists documented the type of session (face-to-face; telephone), start and stop times, and the specific intervention content modules (e.g., stress management, social support) provided. REACH II data are publically available through the Inter-University Consortium for Political and Social Research (ICPSR), and all analyses were based on data downloaded from their website (http://www.icpsr.umich.edu/icpsrweb/landing.jsp).

The following measures of the quantity of intervention services delivered were extracted: 1) total number of in-home sessions completed, 2) total time (in minutes) that caregivers participated in in-home sessions, 3) total number of telephone sessions completed, 4) total time participated in telephone sessions, 5) total number of either kind of session, and 6) total amount of intervention contact time across both in-home and telephone sessions. We also examined the percentage of sessions that included the following specific therapeutic content modules: 1) stress management, 2) pleasant events, 3) mood, and 4) social support.

Statistical Analyses

Descriptive comparisons of the three race/ethnicity groups were conducted using chi-square tests for categorical variables and one-way analyses of variance for quantitative measures. Linear regression analyses were used to examine intervention delivery variables as a function of caregiver race/ethnicity (African American, Hispanic, and White). During structured baseline interviews, caregivers reported on their gender, age, relationship with the person with dementia, number of years of education, and employment status (full- or part-time employment, retired, or unemployed). These variables were examined as covariates in the analyses. Raw or unadjusted analyses by race/ethnicity were conducted first followed by multivariable models that adjusted for the covariates. Pairwise comparisons were examined on the raw and the covariate-adjusted means after any significant omnibus effects in order to better describe any overall significant group differences.

RESULTS

Descriptive Characteristics

Descriptive characteristics of the sample are summarized in Table 1. There were significant differences across the three race/ethnicity groups on caregiver age, education, and caregiver-care recipient relationship. African-American and Hispanic caregivers were younger, had fewer years of education, and were less likely to be spouses and more likely to be adult children of the persons with dementia than White caregivers.

Overall, the large majority of REACH II intervention participants received more than half of the intended intervention dose. Of the 323 cargivers, 268 (83.0%) completed five or more of the intended 9 in-home sessions and 262 (81.1%) received at least 480 minutes (8 hours) of total intervention contact. However, there was also notable variability in the number of sessions completed and total intervention contact time as illustrated in Figure 1. Only a little over a third of caregivers received the full intended protocol: 123 caregivers (38%) received 900 or more minutes of intervention contact and 126 caregivers (39%) completed all 12 intervention sessions.

Race/Ethnic Differences in Intervention Delivery

The means and standard deviations of the intervention delivery variables are displayed in Table 2. Unadjusted analyses indicated significant omnibus effects across the three race/ ethnicity groups on 5 of the 6 variables assessing the quantity of invervention contact. As indicated in Table 2, pairwise comparisons revealed that African American caregivers completed fewer in-home sessions, fewer total sessions, and had less in-home and total contact time than either Hispanic or White caregivers. Furthermore, Hispanic caregivers participated in significantly fewer telephone sessions than either African American or White caregivers. For the 306 caregivers who completed at least one intervention session, Hispanics had a higher percentage of sessions with pleasant event content and a lower percentage of sessions with stress management content than White caregivers, whereas African Americans had a lower percentage of their sessions including mood or emotional distress content.

The adjusted analyses that controlled for the effects of the other demographic covariates (gender, age, caregiving relationship, education, employment status) indicated that none of the race/ethnicity effects on the intervention quantity measures could be explained by these covariates. That is, statistically significant race/ethnicity effects (ps < .05) were maintained on all measures of intervention quantity in Table 2 except the amount of time spent in telephone sessions. The covariate-adjusted means for total intervention contact time, for example, were very similar to the unadjusted means in Table 2 with African Americans (adjusted M = 699.33 mins) receiving significantly less intervention contact than either Hispanics (adjusted M = 852.64 mins) or Whites (adjusted M = 805.19 mins). For the module variables, however, the covariates did account for the unadjusted race differences such that no systematic differences by race/ethnicity were evident after accounting for gender, age, relationship, education, and employment status.

The covariates themselves had very few statistically significant effects on intervention delivery. There were two statistically significant adjusted effects for caregiver age such that older caregivers completed more in-home sessions (b = 0.03, p = .047) but participated in fewer total minutes of telephone sessions (b = -0.56, p = .043). That is, for every 10 additional years of age, participants completed 0.3 more in-home sessions, on average, but 5.6 fewer minutes of telephone contact.

DISCUSSION

This study examined whether there were race or other demographic group differences in the amount and type of intervention services delivered as part of the REACH II initiative. The findings indicate that the intervention was delivered in such a way that most caregivers in all demographic subgroups received more than half of the intended intervention contact. On average, caregivers completed 86% of the intended 900 minutes, and 83% of the caregivers completed more than half of the intended 9 in-home sessions. African American caregivers, however, received significantly less total intervention contact time and in-home intervention than either Whites or Hispanics.

The race differences in intervention delivery brings into question why this might have occurred and whether variations in treatment delivery affect treatment outcomes. More specifically, because African Americans are at higher risk for developing dementia than other race or ethnic groups, it is important to better understand why African American families participated less in the REACH II intervention compared to their White and Hispanic counterparts. It is also important to determine if similar disparities in intervention delivery are evident for other behavioral and non-pharmacological interventions for persons with dementia and their family caregivers. One possibility is that African American caregivers may experience less emotional (e.g. depression, distress) effects from caregiving compared to other race or ethnic groups^{6,7,19} while still showing the same or even more physical health effects of caregiving.⁷ To the extent that the REACH II intervention was perceived as being targeted to more emotional or distress-related concerns, it may have been less appealing to African Americans. The reduced percentage of sessions that were devoted to mood concerns in REACH II for African Americans is also consistent with this hypothesis.

The REACH II study is consistent with many other dementia caregiving studies in showing that African American caregivers are less likely to be spouses and more likely to be adult children than White caregivers.^{9,10} Because adult children may be employed or have other care responsibilities, differences by relationship or employment status could potentially explain race differences in intervention delivery. However, race differences were largely maintained even after controlling for these covariates. In fact, the obtained race effects are rather striking when compared to the relative lack of differences associated with other demographic variables (gender, spouse vs. non-spouse, education, employment). Thus, race/culture has a unique relationship with intervention delivery that was distinctly different from other sociodemographic factors, but the reason for this difference remains unclear. Future research should consider conceptual, methodological, and measurement strategies that are culturally relevant and resonate with the needs, preferences, and choices of caregivers.

There are several limitations to the present study. First, we are unable to discern why African Americans received fewer visits. It may be related to a lack of interest or a view that intervention sessions were not helpful or targeted to their unique needs, as discussed above. Other factors, such as a greater expectation to care for family members, competing time demands related to providing care to other family members, an increased reliance on prayer or religious support, or a lack of trust in more formal care providers, may have all contributed to the observed lower participation rates of African Americans and should be more carefully examined in future studies. Second, although some analyses have concluded that the REACH II intervention was less effective for African Americans than for other race /ethnicity groups,¹⁵ other analyses have not yielded differential efficacy findings by race.¹⁶ It is also not clear if fewer sessions or less intervention contact time are, in fact, linked to poorer outcomes.

Future research should examine relationships between intervention delivery and outcomes using suitable analytic methods that extend beyond the standard intention-to-treat approaches. Techniques such as the complier-average causal effect model²⁰ and other postrandomization moderator analysis approaches²¹ might be particularly useful for examining process variables, such as adherence, and effects on outcomes simultaneously without reintroducing potential confounds due to self-selection biases. Future caregivers of persons with dementia will be more culturally diverse²² and thus will require interventions that are tailored to be responsive to both differences and cultural or ethnic variations. Supplementing measures of race with those of culture will specifically incorporate cultural knowledge and cultural action in future caregiver interventions.¹¹ These innovations will guide how interentions fit within the cultural beliefs of people and how they fit within their use of time and limited resources. Cultural adaptation, defined as the systematic modification of evidence-based treatments to consider language, culture, and context in a way that it is compatible with the client's meanings and values,²³ is a central challenge for interventionists seeking to help persons with dementia and their families.²⁴ The findings from this study highlight the significance of attending to fidelity and evaluating why delivery can differ systematically in relationship to key demographic characteristics.

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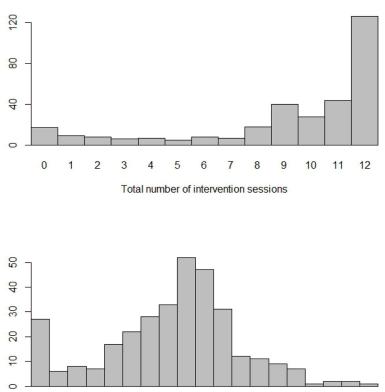




Figure 1.

Frequency

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Frequency distributions of REACH II intervention delivery as measured by the number of intervention sessions completed (1a) and the total minutes of intervention contact time (1b).

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Sample Characteristics of Caregivers Assigned to the REACH II Intervention Condition by Race Group

	African-American $(n = 104)$ Hispanic $(n = 106)$ White $(n = 113)$ <i>P</i> -Value	Hispanic $(n = 106)$	White $(n = 113)$	<i>P</i> -Value
Female gender, <i>n</i> (%)	87 (83.7)	85 (80.2)	92 (81.4)	.805
Age in years, Mean (SD)	60.34 (13.42)	58.81 (14.21)	63.41 (12.08)	.033
Relationship to person with Dementia				<.001
Spouse, <i>n</i> (%)	32 (30.8)	43 (40.6)	66 (58.4)	
Adult Child or Child-in-Law, n (%)	55 (52.9)	54 (50.9)	43 (38.1)	
Other, n (%)	17 (16.4)	9 (8.5)	4 (3.5)	
Years of education, Mean (SD)	12.99 (2.34)	11.42 (4.13)	13.79 (2.05)	<.001
Employment Status				.226
Full- or part-time, n (%)	36 (34.6)	37 (34.9)	32 (28.3)	
Retired, n (%)	42 (40.4)	31 (29.3)	47 (41.6)	
Unemployed, <i>n</i> (%)	26 (25.0)	38 (35.9)	34 (30.1)	

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Intervention Delivery Measure	African-American (Mean \pm SD) Hispanic (Mean \pm SD) White (Mean \pm SD) <i>P</i> -Value	Hispanic (Mean ± SD)	White (Mean ± SD)	P-Value
Intervention Quantity:				
# of in-home sessions	$6.98^{a}{\pm}\ 3.38$	$7.84^{b\pm} 3.18$	$8.25^{b\pm} 2.69$.010
Total time of in-home sessions (mins)	$631.45^{a}\pm341.99$	$794.75^{b}\pm 386.05$	744.78 ^b ± 314.12	.003
# of telephone sessions	$1.88^{a\pm}$ 1.70	$1.08^{b\pm} 1.44$	$1.95^{a}\pm 1.50$	<.001
Total time of telephone sessions (mins)	51.97 ± 52.36	47.49 ± 68.40	53.42 ± 53.32	.739
Total # sessions (in-home + telephone)	$8.69^{a}{\pm}~4.10$	$8.86^{a}\pm 3.71$	$10.00^{b\pm} 2.95$.014
Total time (in-home + telephone)	$683.42^{a\pm}$ 361.88	$842.25^{b\pm} 411.14$	$798.19^{b\pm} 321.67$	900.
Modules: % of sessions including:				
stress management	$55.20^{ab\pm} 24.07$	$51.68^{a\pm} 20.60$	$59.84^{\rm b}\pm19.53$.023
pleasant events	$29.25^{ab\pm} 22.72$	$32.22^{a\pm} 21.43$	25.42 ^b ± 22.78	.089
Mood	$12.31^{a}\pm 18.26$	$18.07^{\rm b\pm} 18.68$	$19.20^{b\pm} 22.04$.032
social support	70.31 ± 30.98	68.74 ± 26.49	69.12 ± 28.25	.923

Note. P-values from one-way analysis of variance – F(2, 320) for intervention quantity measures and F(2, 303) for module measures. Means that do not share the same superscript are significantly different (p < .05) on posthoc pairwise comparisons.