Race and Gender Differences in 1-Year Outcomes for Community-Dwelling Stroke Survivors With Family Caregivers

David L. Roth, PhD; William E. Haley, PhD; Olivio J. Clay, PhD; Martinique Perkins, PhD; Joan S. Grant, DSN; J. David Rhodes, BSN; Virginia G. Wadley, PhD; Brett Kissela, MD; George Howard, DrPH

Background and Purpose—Previous research has reported worse outcomes after stroke for women and for African Americans, but few prospective population-based studies have systematically examined demographic differences on long-term stroke outcomes. Race and gender differences in 1-year stroke outcomes were examined using an epidemiologically derived sample of first-time stroke survivors from the national REasons for Geographic and Racial Differences in Stroke (REGARDS) study.

Methods—Participants of REGARDS who reported a first-time stroke event during regular surveillance calls were interviewed by telephone and then completed an in-home evaluation approximately 1 year after the verified first-time stroke event (N=1105112). A primary family caregiver was also enrolled and interviewed for each stroke survivor. Measures from the in-home evaluation included previously validated stroke outcomes assessments of neurological deficits, functional impairments, and patient-reported effects of stroke in multiple domains.

Results—African American stroke survivors were less likely to be living with their primary family caregivers than white participants. Analyses that controlled for age, education, and whether the stroke survivors lived with their primary family caregivers indicated that African Americans and women showed significantly greater deficits on multiple 1-year outcome measures compared to whites and men, respectively.

Conclusions—Among community-dwelling stroke survivors with family caregivers, women and African Americans are at heightened risk for poor long-term outcomes 1 year after first-time stroke events. Rehabilitation services and public health policies aimed at enhancing stroke recovery rates should address these disparities in poststroke outcomes. (Stroke. 2011;42:626-631.)

Key Words: family caregivers ■ gender differences ■ race differences ■ stroke outcomes

A number of studies have characterized the outcomes after stroke and identified variables that are associated with stroke outcome. Stroke survivors experience a variety of long-term problems after strokes, including impairments with activities of daily living,1,2 cognitive deficits,3 and reduced self-perceptions of their daily functioning.4 Although many factors are associated with long-term recovery from stroke, two major demographic factors—race and gender—have emerged as particularly important. Research suggests that African Americans experience more severe strokes, receive less evidence-based care, and recover more slowly and less completely, on average, than white stroke patients.5-7 Other studies have found that women tend to have poorer functional outcomes after stroke than men.5-10 Most of the previous studies on disparities in stroke outcomes, with the notable exception of Petrea et al,10 have identified and recruited stroke survivors after those participants have already experienced their index stroke events. This is a key concern because patients identified retrospectively through clinical registries or convenience samples may have more impairments or differ in other important ways from participants identified in epidemiological, prospective, population-based studies.11-13 Methodological differences between retrospective and prospective designs or convenience samples and population-based samples can become amplified when race and gender disparities are examined because these demographic groups can differ substantially on multiple dimensions, including marital status, socioeconomic factors, the prevalence of comorbidities, access to care, and the availability of assistance from informal family caregivers.10,14 Prospective, population-based studies offer much promise for minimizing the artificial biases that can be introduced by
these factors and can provide important confirmations or clarifications of effects observed from more retrospective, clinical, or convenience samples.

The purpose of this study was to examine race and gender differences in 1-year stroke outcomes in a sample of community-dwelling first-time stroke survivors from a large, national, prospective study of stroke incidence. We predicted poorer outcomes for women and for African American stroke survivors even after controlling for the availability of a primary family caregiver and other factors.

Materials and Methods

Participants

The participants in this study were 112 survivors of incident stroke events identified in the REasons for Geographic and Racial Differences in Stroke (REGARDS) project. REGARDS is an ongoing, national, epidemiological investigation of stroke incidence and mortality that enrolled 30,239 participants 45 years or older from 2003 to 2007.15 Large samples of both African Americans and whites were assembled in REGARDS, and follow-up surveillance interviews are conducted by REGARDS staff every 6 months to inquire about hospitalizations, outpatient visits, and symptoms that might indicate possible stroke events. Medical records for possible stroke events are then retrieved and examined by neurologist adjudicators. Once potential stroke survivors are identified, they are recruited, along with a primary family caregiver, to participate in the ancillary Caring for Adults Recovering from the Effects of Stroke (CARES) project.

The data reported in this article were obtained from REGARDS stroke survivors who had adjudicated incident stroke events between November 15, 2004 and September 10, 2009 and who met the following inclusion criteria. First, REGARDS participants who indicated a history of stroke (6.4% of the REGARDS sample) were excluded from the present analyses so that these findings would apply to first-time stroke events only. Second, only those stroke survivors who reported experiencing a stroke <1 year before their biannual REGARDS surveillance interview were eligible to participate. Third, only stroke survivors who were residing in the community were eligible to participate. Fourth, each stroke survivor had to have a family member or close friend who was serving as an informal caregiver or had served in this capacity at some point after the stroke event and who was also willing to participate in the CARES study. The Figure summarizes the flow of potential participants. Only 11 of 204 screened stroke survivors were ineligible because there was no caregiver available to contact, and only 4 were deemed ineligible because of residence in a nursing home. Both members of the stroke survivor–family caregiver dyads agreed to participate in 138 of the 173 eligible dyads (79.8%), and 112 of these stroke survivors have completed their in-home evaluations as of August 31, 2010.

The final sample of stroke survivors consisted of 112 community-dwelling residents from 28 different states. Their ages ranged from 52 to 94 years. Medical records indicated that 103 participants had ischemic strokes and 9 had hemorrhagic strokes. Additional descriptive information is provided in Table 1.

Each participant received $20 for participating in this project, and all procedures were reviewed and approved by the Institutional Review Board of the University of Alabama at Birmingham.

Procedures

The data reported in this article were obtained from 3 sources. First, an initial baseline CARES interview was conducted by telephone ~9 months after the stroke event. After explaining the study, screening for eligibility, and obtaining verbal informed consent, trained research interviewers collected data on demographic information, general physical health, and psychosocial functioning. Education was coded into 4 ordinal categories (1=less than high school graduate; 2=high school graduate; 3=some college; 4=college graduate or more).

Second, medical records for the suspected stroke events were independently examined by at least 2 trained physician adjudicators, including at least 1 stroke neurologist, to confirm that these were stroke events and to determine stroke type (ischemic vs hemorrhagic). Other variables extracted from the medical records included the cerebral hemisphere affected (left, right, bilateral), the length of the acute hospital stay, and the discharge status of that hospitalization (eg, to home, a rehabilitation facility, or nursing home). The third and primary source of data consisted of an in-home evaluation of the stroke survivor conducted graduate and beyond).

Table 1. Demographic Information by Race and Gender Groups

<table>
<thead>
<tr>
<th>Variable</th>
<th>Black Men</th>
<th>Black Women</th>
<th>White Men</th>
<th>White Women</th>
<th>Total Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>12</td>
<td>28</td>
<td>43</td>
<td>29</td>
<td>112</td>
</tr>
<tr>
<td>Age,* mean</td>
<td>73.58</td>
<td>73.07</td>
<td>75.28</td>
<td>78.33</td>
<td>75.33</td>
</tr>
<tr>
<td>SD</td>
<td>4.17</td>
<td>7.74</td>
<td>7.90</td>
<td>7.28</td>
<td>7.57</td>
</tr>
<tr>
<td>Education,† mean</td>
<td>2.17</td>
<td>2.39</td>
<td>3.28</td>
<td>3.10</td>
<td>2.89</td>
</tr>
<tr>
<td>SD</td>
<td>1.27</td>
<td>0.99</td>
<td>0.88</td>
<td>0.94</td>
<td>1.05</td>
</tr>
<tr>
<td>Live with caregiver (% yes)</td>
<td>67</td>
<td>32</td>
<td>100</td>
<td>41</td>
<td>67</td>
</tr>
<tr>
<td>Type of stroke (% ischemic)</td>
<td>92</td>
<td>96</td>
<td>88</td>
<td>93</td>
<td>92</td>
</tr>
<tr>
<td>Length of hospital stay (d)</td>
<td>Mean</td>
<td>4.36</td>
<td>4.35</td>
<td>4.55</td>
<td>4.57</td>
</tr>
<tr>
<td>SD</td>
<td>2.11</td>
<td>2.95</td>
<td>3.94</td>
<td>2.73</td>
<td>3.21</td>
</tr>
</tbody>
</table>

*Age is the exact age at the date of the home visit.
†Education was coded as: 1=less than high school graduate; 2=high school graduate; 3=some college; 4=college graduate or more.
~1 year (mean=367 days; SD=93 days) after the incident stroke event. All in-home evaluations were conducted by trained examiners employed by Examination Management Services Incorporated.

The primary purpose of the in-home evaluation was to obtain objective measures of functional 1-year outcomes after stroke. Most of the spontaneous recovery after stroke occurs within the first year, and these evaluations were considered to be relatively stable assessments of long-term stroke outcomes. Each domain outlined by Kasner was covered in this in-home evaluation, and the following instruments were administered.

**Mini-Mental State Examination**
The Mini-Mental State examination is a common screening tool that was used to assess general cognitive functioning and to screen for dementia. Scores can range from 0 to 30, with higher scores representing better cognitive functioning.

**National Institutes of Health Stroke Scale**
The National Institutes of Health Stroke Scale (NIHSS) is a comprehensive 15-item assessment of neurological deficits subsequent to stroke. Though typically used in the more acute recovery phases, it is well-suited to identify persistent, long-term, neurological deficits after stroke. Each Examination Management Services Incorporated examiner completed a web-based training and certification program on the administration and scoring of the NIHSS (www.nihrokescale.org) before conducting the in-home evaluation. Inter-rater reliability studies of the NIHSS indicate comparable scores are obtained across neurologists, non-neurologist physicians, research nurses, and trained research staff. Higher scores indicate more neurological problems subsequent to stroke.

**Barthel Index**
The Barthel index was used to measure functioning in 10 basic self-care and mobility activities (feeding, bathing, grooming, dressing, continence of bowels, bladder control, toilet use, transferring, mobility on level surfaces, and climbing stairs). It ranges from 0 to 100, with higher scores indicating greater functional independence, and has been shown to have high intra-observer and inter-observer reliabilities.

**Modified Rankin Scale**
At the end of the in-home evaluation, the Examination Management Services Incorporated examiner provided a modified Rankin scale rating of general physical function, activity, and participation. Scores range from 0 (no symptoms) to 5 (severe disability).

**Stroke Impact Scale**
The Stroke Impact Scale (SIS; version 2.0) is an instrument that consists of 64 Likert-type rating scales and obtains stroke survivors’ self-assessments of 8 domains of functioning: strength, memory, emotion, communication, activities of daily living and instrumental activities of daily living, mobility, hand function, and social participation. Each subscale ranges from 0 to 100, with higher scores indicating better functioning. The SIS supplemented the other measures from the in-home evaluation by providing self-report measures of emotional well-being, communication, and social functioning. Deficits in these areas can be common and persistent among stroke survivors who are otherwise deemed fully recovered on measures such as the Barthel index.

**Statistical Analyses**
Descriptive analyses and associations among the demographic variables were examined using χ² tests and 1-way analyses of variance. Race and gender differences on the stroke outcome measures were examined in series of ordinary least-squares multiple linear regression analyses. Indicator variables for stroke survivor race (African American=1, white=0) and gender (female=1, male=0) were included as the primary independent variables, and covariates included age (in years), education, and whether the stroke survivors lived with their primary family caregiver (1=yes, 0=no).

**Results**
The descriptive characteristics for this sample are summarized in Table 1. There was a strong association between race and gender (χ²(1)=9.09; P=0.003), with 70% of the African American stroke survivors compared to 40% of the white stroke survivors being women. Most of the men (93%), including all of the white men, lived with their primary family caregivers, whereas only a minority of the women (37%) lived with their caregivers. This gender difference was highly significant (χ²(1)=38.08; P<0.0001). Similarly, across genders, whites (76%) and African Americans (43%) differed significantly in terms of whether they lived with their caregivers (χ²(1)=12.86; P=0.0003).

The African American stroke survivors were significantly younger than white stroke survivors (mean=72.80 and 76.03 years, respectively; F(1,110)=4.88; P=0.03) and had significantly less education (mean=2.33 and 3.21, respectively; F(1,110)=21.50; P<0.0001). There were no statistically significant gender differences in age or education.

The results of the multiple linear regression analyses are summarized in Table 2. The covariate-adjusted estimates represent the effect of each independent variable on the outcome variable after controlling for all other covariates in the model. African Americans, for example, had Barthel scores that averaged 8.51 points lower than those of whites after controlling for gender, age, education, and co-residence status. Overall, the pattern of the findings indicated that African Americans had worse outcomes than whites and women had worse outcomes than men. The race and gender effects were both statistically significant (P<0.05) for the Barthel index and for 4 of the SIS subscales (activities of daily living/instrumental activities of daily living, mobility, hand function, and social participation). Additional race differences were observed on the Mini-Mental State examination and the SIS memory subscale, whereas additional gender differences were observed for the NIHSS, modified Rankin score, and the SIS strength subscale. There were no statistically significant race or gender effects on the emotion or communication subscales of the SIS.

The covariate-adjusted estimates were divided by the overall standard deviation for each measure to create a standardized effect sizes, and these ranged from −0.47 to −0.66 for the statistically significant race effects and from −0.46 to −0.88 for the significant gender effects. These effect sizes are in the medium (0.50) to large (0.80) range according to conventional standards.

There were no statistically significant covariate-adjusted effects for age or education on any of the outcome measures. Participants who lived with their primary family caregivers had significantly worse covariate-adjusted outcomes than those who did not live with their caregivers on 4 measures: the NIHSS, Barthel index, Mini-Mental State examination, and SIS strength subscale. Similar effects that closely approached significance (P<0.06) were obtained on several other measures. However, because all 43 white male stroke survivors lived with their caregivers, these comparisons...
Table 2. Results of Multiple Linear Regression Analyses of 1-Year Stroke Outcomes (N=112)

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Descriptive Statistics for Total Sample</th>
<th>Covariate-Adjusted Regression Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>National Institutes of Health Stroke Scale</td>
<td>1.78</td>
<td>3.05</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−0.30, 2.45</td>
<td>(0.00, 2.77)</td>
</tr>
<tr>
<td>Barthel Index</td>
<td>89.20</td>
<td>16.67</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−15.84, −1.17</td>
<td>(−16.69, −1.90)</td>
</tr>
<tr>
<td>Modified Rankin scale</td>
<td>1.34</td>
<td>1.28</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−0.19, 0.97</td>
<td>(0.11, 1.28)</td>
</tr>
<tr>
<td>Mini-Mental State examination</td>
<td>27.54</td>
<td>3.32</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−3.65, −0.71</td>
<td>(−1.16, 1.80)</td>
</tr>
<tr>
<td>SIS, Strength</td>
<td>75.73</td>
<td>25.00</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−19.84, 1.48</td>
<td>(−32.84, −11.35)</td>
</tr>
<tr>
<td>SIS, Memory</td>
<td>79.18</td>
<td>19.13</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−20.66, −3.77</td>
<td>(−14.09, 2.93)</td>
</tr>
<tr>
<td>SIS, Emotion</td>
<td>77.88</td>
<td>16.72</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−13.16, 2.06</td>
<td>(−10.65, 4.69)</td>
</tr>
<tr>
<td>SIS, Communication</td>
<td>88.14</td>
<td>15.15</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−11.85, 1.97</td>
<td>(−7.18, 6.75)</td>
</tr>
<tr>
<td>SIS, Activities of Daily Living/</td>
<td>82.72</td>
<td>19.09</td>
</tr>
<tr>
<td>Instrumental Activities of Daily Living</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−19.62, −3.39</td>
<td>(−20.87, −4.51)</td>
</tr>
<tr>
<td>SIS, Mobility</td>
<td>76.44</td>
<td>23.15</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−20.91, −1.91</td>
<td>(−29.60, −10.45)</td>
</tr>
<tr>
<td>SIS, Hand</td>
<td>75.67</td>
<td>29.86</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−26.94, −1.17</td>
<td>(−35.95, −9.98)</td>
</tr>
<tr>
<td>SIS, Social</td>
<td>75.84</td>
<td>24.87</td>
</tr>
<tr>
<td>(95% CI)</td>
<td>−22.21, −0.98</td>
<td>(−31.70, −10.31)</td>
</tr>
</tbody>
</table>

SIS indicates Stroke Impact Scale.

*P<0.05.
†P<0.01.
All 5 predictor variables were included in each multiple regression model.

reflected differences between co-residing and not co-residing stroke survivors in the other 3 race–gender groups only.

Supplemental analyses examined race by gender interaction effects, ischemic vs hemorrhagic type of stroke effects, and hemispheric location effects on the outcome measures after controlling for the same demographic covariates. No statistically significant race by gender interactions were found, although an effect that closely approached significance was observed on the Barthel index (F(1,105)=3.66; P=0.06). White men tended to have better Barthel index scores (adjusted mean=99.02) than African American men, white women, and African American women (adjusted mean=82.50, 85.00, and 81.34, respectively). No statistically significant effects were found for the type of stroke or the hemispheric location of the stroke after controlling for covariates on these outcome measures.

Discussion

The results from this population-based study of first-time stroke survivors who were residing in the community 1 year after their stroke events are consistent with previous findings of race and gender differences in stroke outcomes.6,7,10 After adjusting for the effects of age, education, and whether the stroke survivors lived with their primary family caregivers, African Americans and women consistently showed poorer outcomes than whites and men, respectively, on multiple subscales from the SIS and on other functional outcome measures. The SIS is particularly sensitive to subtle deficits and measures the person’s perception of the impact of stroke on several domains of daily functioning. The race and gender effects reported here were adjusted not only for differences in age and education but also for the associations observed among race, gender, and caregiver co-residence in this population-based sample.

There were no methodological goals to balance race or gender groups by other demographic factors, and we sought to include all REGARDS participants who were first-time stroke survivors and who met the other inclusion criteria, including the availability of a family caregiver to participate
in the study. It is interesting that these race and gender differences emerged even though each stroke survivor in this sample had a family caregiver and received some informal care from this person during the recovery period. The present results indicate that the female stroke survivors were much less likely to be living with their informal caregivers, and previous findings from the REGARDS sample indicate that both groups report being less likely to have a co-residing informal caregiver available to them. Caregiver unavailability and other aspects of social isolation have been previously suggested as possible mechanisms that might explain poorer outcomes after stroke in women and ethnic minorities. However, because all of our stroke survivors had family caregivers, and because we statistically controlled for the co-residence status of those caregivers, it appears that other mechanisms are also involved in explaining race and gender differences in stroke outcomes. Interestingly, the role of caregiver presence was complicated by the fact that all of the white men in our sample co-resided with their caregivers, which may still partly explain the better functioning found in this group, whereas having a co-residing caregiver was associated with worse outcomes in the other race–gender groups. This suggests that mere caregiver presence is a complex variable that is associated with race, gender, and stroke outcomes in multiple ways. A married stroke survivor may be more likely to use outpatient rehabilitation or other therapy services, and the spouse–caregiver can respond more readily to daily changes and serve as a gatekeeper to get the patient additional assistance as needed. For unmarried or widowed stroke survivors, greater stroke severity or worse outcomes may persuade a nonspouse caregiver to move in with the stroke survivor, which would result in the associations between caregiver co-residence and outcomes observed here. Other demographic and cultural factors may also contribute to race and gender differences in caregiver co-residence status and poststroke service utilization, and these factors deserve additional investigation.

Our study does have some important limitations that should be noted. The sample size is smaller than optimal, especially when subgrouped by race and gender, and this limited our power to detect smaller group differences. Although the study has the strength of identifying participants from a population-based investigation, the CARES sample still may not be fully representative of the larger population because of the sampling design, differential retention across time, and differential ascertainment of medical records in REGARDS. In addition, because the stroke survivors were not assessed through a single center or clinic, there are measures that ideally might be available from the acute recovery phase, such as acute NIHSS scores, that were not available in our data.

Conclusions

In summary, our results show that previously found race and gender differences in long-term stroke outcome are apparent even when studied in a prospective population-based sample, and even when a family caregiver is available to all participants. Future research should more closely examine the mechanisms behind these differences, including more detailed assessments of the involvement of family caregivers and other local and cultural demographic factors that may affect service utilization and recovery from stroke.

Acknowledgments

The authors thank the other investigators, the staff, and the participants of the REGARDS study for their valuable contributions. A full list of participating REGARDS investigators and institutions can be found at http://www.regardsstudy.org. The authors also gratefully acknowledge the contributions of Michelle Henry for conducting data collection interviews and Martha Hovater and Kristine Baker for assistance with the statistical analyses.

Sources of Funding

The research reported in this paper was supported by an investigator-initiated grant (R01 NS045789, David L. Roth, PI) and by a cooperative agreement (U01 NS041588) from the National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH), Department of Health and Human Services. The content is solely the responsibility of the authors and does not necessarily represent the official views of NINDS or NIH. Representatives of the funding agency were involved in the review of the manuscript but were not directly involved in the collection, management, analysis, or interpretation of the data.

Disclosure

None.

References

Race and Gender Differences in 1-Year Outcomes for Community-Dwelling Stroke Survivors With Family Caregivers

David L. Roth, William E. Haley, Olivio J. Clay, Martinique Perkins, Joan S. Grant, J. David Rhodes, Virginia G. Wadley, Brett Kissela and George Howard

Stroke. 2011;42:626-631; originally published online January 21, 2011; doi: 10.1161/STROKEAHA.110.595322

Stroke is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2011 American Heart Association, Inc. All rights reserved.
Print ISSN: 0039-2499. Online ISSN: 1524-4628

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://stroke.ahajournals.org/content/42/3/626

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Stroke can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Stroke is online at:
http://stroke.ahajournals.org//subscriptions/