

African American Stroke Survivors More Caregiving Time, but Less Caregiving Burden

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Background—Blacks have higher stroke incidence and experience greater poststroke disability than whites. To optimize care for stroke survivors, it is important to understand the amount of care that they receive and the implications for stroke caregivers.

Methods and Results—Data from 2 nationally representative, population-based studies, the NHATS (National Health and Aging Trends Study) linked to the NSOC (National Study of Caregiving), were used to identify elderly stroke survivors and their caregivers. We compared hours of care received and unmet activity need among the 581 white and 225 black stroke survivors. We then performed racial comparisons of positive and negative aspects of caregiving reported by caregivers of black and white stroke survivors. Black stroke survivors were more likely than white stroke survivors to have a caregiver (62.5% versus 49.7%; $P<0.01$) and received on average more hours of help per week (31.7 versus 20.5; $P<0.01$). There was little racial difference in unmet need for assistance. Caregivers of black stroke survivors reported more positive aspects of caregiving than caregivers of white stroke survivors (6.8 versus 6.0; $P<0.01$). There was no racial difference in negative aspects of caregiving, depression, or anxiety.

Conclusions—Black stroke survivors received an average of ≈ 11 more hours of care than white stroke survivors without substantial differences in unmet need. Despite providing more hours of care, caregivers of black stroke were more positive about their caregiver role than caregivers of white stroke survivors. (*Circ Cardiovasc Qual Outcomes*. 2017;10:e003160. DOI: 10.1161/CIRCOUTCOMES.116.003160.)

Key Words: African Americans ■ depression ■ outcomes research ■ race ■ stroke ■ survivors

The number of stroke survivors in the United States is expected to increase from 6.6 million in 2012 to >10 million by 2030 as a consequence of population aging and continued declines in stroke mortality.¹ Because most people survive after their stroke, disability is a common challenge facing stroke survivors and their families. Most help with activities of daily living for community-dwelling stroke survivors is provided by unpaid family members; paid sources of care also serve an important supportive role.² A greater understanding of the care that stroke survivors receive on a national basis and the implications for both stroke survivors and their caregivers are needed to plan for the projected increase in stroke survivors.

It is well established that African Americans (Blacks) have a higher incidence and prevalence of stroke than non-Hispanic whites (Whites). Blacks also have a higher prevalence of disability in later life, suggesting the possibility of a disproportionate burden on caregivers of black stroke survivors.^{3–5} Black stroke survivors are more likely to receive help with activities of daily living compared with white stroke survivors,⁴ but the amount of care and whether the care is adequate is unknown. One measure of the adequacy of caregiving is whether there

are adverse consequences of unmet need for activity assistance. The presence of unmet need suggests that, regardless of how much help is received, additional or more skilled help may be needed. Black stroke survivors, given their greater disability and need for help with more activities, are at high risk for unmet activity need.⁴

In addition to the potential racial differences in time caring for stroke survivors, caregiving may have different social, emotional, and physical implications by race. The prevailing construct for many years was that caregiving is harmful to the caregiver to the point of increased mortality.⁶ However, subsequent population-based studies have found that caregiving may be associated with reduced caregiver mortality rates and psychological benefits.⁷ In this context, using data from 2 nationally representative, population-based studies, we explore care from the perspective of the stroke survivors, as well as the stroke caregiver. Specifically, we will (1) quantify racial differences in hours of care received by stroke survivors; (2) determine racial differences in unmet activity need among stroke survivors; and (3) explore racial differences in the caregiving experience.

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WHAT IS KNOWN

- Blacks have higher stroke incidence and experience greater poststroke disability than whites.

WHAT THE STUDY ADDS

- Black stroke survivors received more hours of care than white stroke survivors.
- Caregivers of black stroke survivors were more positive about their caregiver role than caregivers of white stroke survivors.
- There are only small racial differences in the proportion of stroke survivors with unmet caregiving need.

Methods

Study Populations

This study draws from the NHATS (National Health and Aging Trends Study) and its companion the NSOC (National Study of Caregiving). NHATS is a population-based survey of over 8000 Medicare beneficiaries aged ≥ 65 years and oversamples Blacks and people in older age groups. The NHATS response rate is 71%. The NHATS survey weights used in this analysis account for nonresponse by a variety of individual, county, and tract-level factors. In 2011, initial face-to-face interviews were conducted by trained study personnel in study participants' place of residence. Proxy respondents were interviewed in cases where study participants were unable to respond for themselves. NHATS respondents who received help with mobility, self-care, or household activities because of health or functioning listed their caregivers. These caregivers were eligible for NSOC if they were family members or unpaid, nonrelative caregivers who helped with mobility, self-care, household activities because of health or functioning, transportation, medical activities, or money matters.⁸ NSOC respondents were interviewed by telephone. The final NSOC sample consisted of 2007 caregivers who provided help to 1369 NHATS respondents.

The current study population included stroke survivors living in the community (including residential care settings other than nursing homes) who were identified by an affirmative response to: "Has a doctor has ever told you that you had a stroke?"⁹ Race and ethnicity were self-reported. Because of small sample size of other race/ethnicities, we limited the sample for this analysis to stroke survivors who reported their primary race as white or black. NHATS included 806 stroke survivors, of which 581 reported their primary race as white and 225 as black. NSOC included 277 caregivers providing care to 187 white stroke survivors and 155 caregivers providing care to 100 black stroke survivors.

Characteristics of Stroke Survivors: NHATS

Demographic characteristics of stroke survivors were obtained, including age, race, sex, education, income, insurance status (Medicare Part D, employee drug coverage, Medigap, Medicaid, Tricare, Long-term care insurance), and living situation (traditional community housing versus residential care setting). A summary self-reported physical capacity measure was created from NHATS responses to questions about ability to perform pairs of harder and easier physical tasks: (1) walking 3 and 6 blocks; (2) going up 10 and 20 stairs; (3) lifting and carrying 10 and 20 pounds; (4) bending over and kneeling down; (5) reaching overhead and reaching overhead with a heavy object; and (6) open small objects and open sealed objects (Table I in the [Data Supplement](#)).¹⁰ The index was created by adding 1 point for every easy task and 2 points for every more challenging task performed (range, 0–12).¹⁰ Cognitive capacity was assessed with 2 tests. NHATS asked respondents to recall a list of 10 words immediately

and after a short delay. A clock-drawing test was also administered. Cognitive capacity was summarized as the sum of correct immediate and delayed recall words scores (0–20) and the categorical NHATS clock-drawing scoring system (0 unrecognizable to 5 accurate).

Stroke Caregiver Identification and Hours of Caregiving: NHATS

Stroke survivors who received help with any self-care (eating, bathing/showering, toileting, and dressing), mobility (getting outside, getting around inside, and getting out of bed), or household activity because of health or functioning (laundry, hot meals, grocery shopping, bills and banking, and handling medications) were identified as care recipients. Information on whether the stroke survivor had a caregiver, number of hours of help he/she received in the last month, whether he/she lived with a caregiver, and whether the caregiver was paid was obtained from NHATS. In accordance with other studies, we imposed a 16-hour limit on help per day for any given caregiver.^{11–13} For each stroke survivor, we calculated weekly hours of help from each caregiver and total hours of weekly help if there was >1 caregiver. To identify the most time-consuming activities, receipt of help was also divided into 3 categories: receipt of help for self-care or mobility activities, receipt of help for household activities only, and receipt of help for self-care or mobility and household activities.

We also explored unmet activity need among stroke survivors who were care recipients. For each activity, NHATS asked about unmet need to perform activities in the last month.¹⁴ Unmet needs related to self-care and mobility activities included going without eating, going without showering/bathing/washing up, accidentally wetting or soiling clothing, going without getting dressed, having to stay in bed, not being able to go places in one's home or building, and not being able to leave one's home or building. Unmet need related to household activities included going without clean clothes, going without groceries or personal items, going without a hot meal, or going without handling bills and banking matters. We created a summary indicator of the presence of one or more unmet needs for self-care, mobility, or household activity.

Characteristics of Stroke Caregivers: NSOC

Sociodemographic characteristics (age, sex, marital, family, and employment status) of caregivers were obtained during the NSOC interview. In addition, caregivers were asked to report on positive and negative aspects of caregiving on a 3-point scale (from not so much [0] to very much [2]), which we used to form 2 scales (ranging from 0 to 8).¹⁵ The positive aspects of caregiving scale included more confidence in one's ability, learned how to deal with difficult situations, brought one closer to the recipient, and satisfaction that the recipient is well cared for.^{16,17} The items included in the negative caregiving scale included exhaustion when he/she goes to bed at night, more things to do than he/she can handle, insufficient personal free time, and disruption of an established routine when the care recipient needs a change (Table I in the [Data Supplement](#)). The Patient Health Questionnaire-2 and the Generalized Anxiety Disorder-2 questionnaire were used to measure depressive and anxiety-related symptoms in caregivers.^{18,19} We also explored whether caregivers restricted participation in valued activities because of care or experienced other changes in well-being. A participation restriction index was constructed by combining responses to 4 activities in the last month: visiting in person with friends or family; attending religious services; participating in clubs, classes, or other organized activities; and going out for enjoyment. Participation restrictions occurred if the caregiver rated the activity as somewhat or very important and if providing care limited participation in the activity in the last month. To assess subjective well-being, questions assessing positive (cheerful, full of life) and negative (bored, upset) emotions and 3 reflecting self-realization metrics (extent of disagreement with statements about purpose in life, self-acceptance, and environmental mastery) were combined (0–22).²⁰ We also examined 3 items in which caregivers were asked whether they experienced financial, emotional, and physical difficulty as a result of caregiving.

Analyses

Characteristics of both stroke survivors (NHATS) and their caregivers (NSOC) were reported using survey-weighted means or percentages. Racial comparisons were made using Wald tests for continuous variables and χ^2 tests for categorical variables. Standard errors were adjusted to take into the complex survey design of NHATS and NSOC.

Given the frequent occurrence of zero hours of help, we fit a zero-inflated Poisson model to explore differences in weekly hours of care between stroke survivors and controls. The zero-inflated Poisson model simultaneously estimates by race (1) the probability of receiving help and (2) the expected weekly hours of care, among those receiving care. We estimated sequential models to explore what accounted for racial differences in hours of care received: (1) sociodemographic factors (age, sex, marital status, education, and income) and comorbidities, (2) physical capacity and cognitive capacity; and (3) living situation (ie, whether the stroke survivor lived with a caregiver or lived in a residential care setting). These models differentiate the association of capacity and a marker of caregiver availability. All analyses were done in STATA 12.0 and approved by the University of Michigan Institutional Review Board.

Results

Stroke Survivor Characteristics

There were no significant age or sex differences between the race groups. Black stroke survivors were less likely than white stroke survivors to be married and reported less education and income. Black stroke survivors were also less likely than white stroke survivors to live in a residential care setting (5.5% versus 10.5%; $P<0.08$). Racial differences in insurance status also were notable. Compared with whites, black stroke survivors were less likely to have a Medicare supplemental policy and long-term care insurance and were 3x more likely to be dually eligible for Medicare and Medicaid. Compared with white stroke survivors, black stroke survivors had lower physical capacity (5.1 versus 6.9; $P<0.01$) and cognitive capacity, including lower 10-word recall scores (5.9 versus 7.3; $P<0.01$; Table 1).

Care for Stroke Survivors

As shown in Table 2, black stroke survivors were more likely than white stroke survivors to have a caregiver (62.5% versus 49.7%; $P<0.01$), had on average more caregivers (1.6 versus 1.1; $P<0.01$), and received on average more hours of care per week (31.7 versus 20.5; $P<0.01$). Black stroke survivors were more likely than white stroke survivors to receive care from their children, grandchildren, and friends. After adjusting for sociodemographic factors and comorbidity, black stroke survivors received more hours of care than white stroke survivors (32.0 hours versus 20.3 hours; $P=0.01$; Table 3). The racial difference was no longer significant after adjusting for physical capacity and cognitive capacity (24.7 black stroke survivor versus 21.1 white stroke survivors; $P=0.26$) and further attenuated after accounting for living situation.

Black stroke survivors were more likely than white stroke survivors to receive assistance with both self-care or mobility activities and household activities, the category of assistance for which the most hours of help were provided (Table 4). Black stroke survivors had more unmet self-care needs (27.5% versus 24.9%; $P=0.04$) than white stroke survivors. There was no significant

Table 1. Sociodemographics, Physical and Cognitive Capacity, and Living Situation of Stroke Survivors by Race

	White (n=581), %	Black (n=225), %	P Value
Sociodemographics			
Age, y			0.22
65–69	16.7	21.7	
70–74	19.9	25.0	
75–79	19.4	17.7	
80–84	22.0	16.3	
85–89	14.1	13.3	
90+	7.9	5.9	
Women	56.6	61.8	0.27
Married/partner	48.1	30.7	<0.01
Education			<0.01
Less than high school	24.8	45.9	
High school graduate/some post high school	57.8	45.1	
College graduate/advanced degree	16.3	8.5	
Income			<0.01
<\$12 000	17.0	40.0	
\$12 101–\$21 000	24.2	26.3	
\$21 001–\$34 409	21.1	14.2	
\$34 410–\$60 000	22.0	13.4	
>\$60 001	15.7	6.1	
Insurance			
Medicare part D	63.1	70.7	0.15
Employee drug coverage	23.7	17.5	0.11
Medigap or Medicare supplement	61	36.9	<0.01
Medicaid	13.1	42.4	<0.01
Tricare	6.9	4.4	0.41
Long-term care insurance	14.9	8.3	0.03
Physical and cognitive capacity			
Physical capacity index, mean (0–12 best)	6.9	5.1	<0.01
Cognitive capacity			
10 word recall, mean	7.3	5.9	<0.01
Clock drawing			<0.01
0: not recognizable as clock	1.1	0.9	
1: severely distorted	4.2	7.7	
2: moderately distorted	10.9	16.5	
3: mildly distorted	23.2	28.4	
4: reasonably accurate	37.2	19.3	
5: accurate	10.4	2.2	
Living situation			
Reside in residential care setting	10.5	5.5	0.08

Table 2. Racial Differences in Characteristics of Care Received by Stroke Survivors

	White Stroke Survivors, %	Black Stroke Survivors, %	P Value
Caregiver	49.7	62.5	<0.01
Unpaid caregiver	48.8	61.2	<0.01
Paid caregiver	10.1	17.3	<0.01
Average number of caregivers, n (SE)	1.1 (1–1.2)	1.6 (1.4–1.8)	<0.01
Average amount of care received, h/wk (SE)	20.5 (17.6–23.4)	31.7 (24.9–38.6)	<0.01
Unpaid, h/wk (SE)	17.7 (15–20.4)	27.2 (20.7–33.7)	0.01
Paid, h/wk (SE)	2.8 (1.8–3.8)	4.6 (2.5–6.6)	0.13
Lives with caregiver	32.6	39.6	0.13
Relationship of caregiver and stroke survivor			
Spouse	21.4	14.5	0.08
Child	30.1	43.4	<0.01
Grandchild	5.0	14.9	<0.01
Friend	6.2	11.6	0.03
Paid aide/housekeeper	6.6	9.6	0.18

racial difference in unmet mobility (38.8% versus 34.4%; $P=0.07$) or household needs (17.6% versus 19.1%; $P=0.68$).

Caregivers of Stroke Survivors

Caregivers of black stroke survivors were less likely to be married (28.4% versus 44.8%; $P<0.01$) and more likely to have children under the age of 18 years (20.0% versus 11.9%; $P=0.03$) than caregivers of white stroke survivors (Table 5). Caregivers of black stroke survivors reported more positive aspects of caregiving than caregivers of white stroke survivors (6.8 versus 6.0; $P<0.01$). There were no racial differences in negative aspects of caregiving, participation restrictions, depressive symptoms, anxiety symptoms, well-being, or financial, emotional, or physical difficulty. Few caregivers of stroke survivors used a service to enable them to take some time away from caregiving.

Table 3. Unadjusted and Adjusted Averages of Hours of Care Received by Stroke Survivors

	White Stroke Survivors, h/wk	Black Stroke Survivors, h/wk	P Value
Unadjusted	20.5	31.7	<0.01
Adjusted for sociodemographic factors and comorbidities	20.3	32.0	0.01
Adjusted for sociodemographic, comorbidities, physical capacity and cognitive capacity	21.1	24.7	0.26
Adjusted for sociodemographic, comorbidities, physical capacity, cognitive capacity and living situation	21.2	23.9	0.24

Discussion

We found that black stroke survivors receive an average of 11 more hours of care per week than white stroke survivors. At the same time, only small racial differences in unmet activity need were found. These results suggest that the increased amount of care provided to black stroke survivors is, on the whole, relatively well calibrated to the increased needs of black stroke survivors. Furthermore, in spite of the greater time commitment of caregivers of black stroke survivors, there was no evidence that caregivers of black stroke survivors perceived this time commitment as burdensome compared with caregivers of white stroke survivors. In fact, caregivers of black stroke survivors reported more positive aspects of caregiving than caregivers of white stroke survivors.

Actual hours of care received by stroke survivors are a product of the hours of care needed and caregiver availability. Black stroke survivors have lower physical and cognitive capacity than white stroke survivors, suggesting a greater need for care. After accounting for these differences, there was no significant racial difference in the amount of care received. Differential caregiver availability may also exist. We found that white stroke survivors were almost twice as likely to live in a residential care facility compared with black stroke survivors. Residential care settings often provide staff assistance with household activities, such as meals or housekeeping; such hours are not accounted for in this study.²¹ Thus, this differential living situation, which may underestimate the hours of care received by white stroke survivors, may account for some of the observed racial differences in caregiving hours. Currently, an estimated 4.5 million elderly Americans live in residential care settings, the vast majority of whom are white.²¹ Closer attention to racial differences in residential care settings and the impact on stroke survivors and caregivers is needed.

Important differences by race in the characteristics of care providers were identified. For both black and white care recipients, caregivers are predominately women, but caregivers of black stroke survivors are younger and nearly twice as likely to have a young child compared with caregivers of white stroke survivors. For black stroke survivors, care was

Table 4. Hours of Care Received Among Stroke Survivors With a Caregiver by Level of Assistance, National Health and Aging Trends Study

Level of Assistance	Stroke Survivors, % (n=464)		Help, h/wk, (95% CI)	
	White	Black	White	Black
Only self-care or mobility activities	12.3	5.8*	23.5 (14.1–33)	33.8 (7.9–59.7)
Only household activities (because of health/functioning reason)	30.6	21.6*	24.4 (17–31.7)	21.3 (13.1–29.5)
Self-care or mobility and household activities (because of health/functioning reason)	57.1	72.6*	54.1 (46–62.2)	60.9 (50–71.8)

* $P<0.05$.

Table 5. Caregiver Demographic Characteristics and Attributes, National Study of Caregiving

	Caregiver of White Stroke Survivor (n=277), %	Caregiver of Black Stroke Survivor (n=155), %	P Value
Women	66.4	71.0	0.33
Married	44.8	28.4	<0.01
Children under the age of 18 years	11.9	20.0	0.03
Worked for pay in the last week	30.9	38.7	0.10
Hours worked in the last week, mean (95% CI)	36.2 (32.6–39.8)	37.1 (33.8–40.4)	0.72
Caregiver attributes			
Positive aspects of caregiving, mean (95% CI)	6.0 (5.8–6.2)	6.8 (6.6–7.0)	<0.01
Negative aspects of caregiving, mean (95% CI)	2.6 (2.3–2.8)	2.5 (2.1–2.9)	0.79
Depressive symptoms	15.8	13.6	0.53
Anxiety symptoms	16.2	17.4	0.74
Participation restriction summary index (0–4), mean (95% CI)	0.2 (0.1–0.3)	0.2 (0.1–0.3)	0.84
Well-being summary index (0–22), mean (95% CI)	15.4 (15.1–15.7)	15.4 (15.1–15.8)	0.87
Helping financially difficult to caregivers	25.0	21.3	0.39
Helping emotionally difficult to caregivers	50.4	49.7	0.89
Helping physically difficult to caregivers	29.0	29.0	0.998
Used service to take time away from caregiving	17.7	14.2	0.19

CI indicates confidence interval.

1.5× more likely to be provided by a child, 3× more likely to be provided by a grandchild, and nearly 2× more likely to be provided by a friend. Despite the positive aspects of caregiving noted by caregivers of black stroke survivors found in our study, given the magnitude of the time commitment, further research is needed to determine if other negative consequences such as decreased health or restricted economic opportunities accrue to caregivers of black stroke survivors.

Despite the greater hours of care provided, there were no racial differences in negative aspects of caregiving, depression, or anxiety. Our findings add to those of a national sample of stroke caregivers that found no racial difference in caregiver mental health–related quality of life and concluded that caregivers of black stroke survivors may have a heightened resilience to caregiver stress.²² Our findings suggest a complimentary interpretation. Not only were caregivers of black

stroke survivors no more likely to report negative aspects of caregiving than caregivers of white stroke survivors, but they also reported greater positive aspects of caregiving. Rather than conceptualizing caregiving as a necessarily burdensome activity, our findings suggest that caregiving may be a valued and important activity, particularly among caregivers of black stroke survivors.²³

Our study has several limitations. We relied on self-reported stroke, although, while some misclassification certainly exists, self-reported stroke has reasonably high accuracy even in older populations.²⁴ We cannot determine the duration of time since stroke, which may influence hours of care. However, duration of time since stroke is unlikely to vary by race and, therefore, is unlikely to alter our conclusions regarding racial differences in hours of care. There is no measure of stroke severity at the time of the stroke. Thus, we were unable to determine if the racial differences in capacity are related to greater stroke severity or poorer stroke recovery among black stroke survivors. Prior research, however, has suggested that stroke severity does not vary by race, and so it is more likely that it reflects differences in stroke recovery rather than differences in stroke severity.^{25,26} NHATS is limited to adults aged ≥65 years. Thus, our results may not generalize to the middle-aged stroke population. Finally, at baseline, NHATS does not interview adults living in nursing home facilities. If anything, this omission is likely to understate the magnitude of the racial differences in caregiving, given that nursing homes care for the most severely impaired stroke survivors, and blacks are disproportionately represented in nursing homes.²⁷

Conclusions

In conclusion, although black stroke survivors receive substantially more hours of care, this increase seems to be well calibrated to their increased need, given there was little racial difference in unmet need. Furthermore, caregivers of black stroke survivors had a more positive perception of caregiving than caregivers of white stroke survivors. Further study to define the factors facilitating the positivity of caregivers of black stroke survivors may provide insight into strategies to decrease or prevent caregiver burden among at-risk caregivers.

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Disclosures

None.

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African American Stroke Survivors: More Caregiving Time, but Less Caregiving Burden

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Supplemental Material

Table: Stroke survivor and caregiver measures

Measures	Score	Construct
Stroke Survivor		
Physical tasks	0-12 (best)	Physical capacity ¹
Immediate and delayed recall	0-20 (best)	Cognitive capacity ²
Clock draw	0-5 (best)	Cognitive capacity ³
Self-care activities (eating, bathing/showering, toileting, dressing)	No help vs. help	Activities ¹
Mobility activities (getting outside, getting around inside, and getting out of bed)	No help vs. help	Activities ¹
Household Activities (laundry, hot meals, grocery shopping, bills and banking, and handling medications)	No help vs. help	Activities ¹
Stroke Caregiver		
Positive aspects of caregiving	0-8 (greater)	Caregiver perspective ⁴
Negative aspects of caregiving	0-8 (greater)	Caregiver perspective ⁴
Patient Health Questionnaire (PHQ-2)	% PHQ-2 \geq 2	Depressive symptoms ⁵
Generalized Anxiety Disorder (GAD-2)	% GAD-2 \geq 2	Anxiety symptoms ⁶
Well-being index	0-22 (greater)	Well-being summary index ⁷
Participation restriction	0-4 (greater)	Participation restriction summary index ¹

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