COMPARISONS OF LATINOS, AFRICAN AMERICANS, AND CAUCASIANS WITH MULTIPLE SCLEROSIS

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Objective: Identify racial/ethnic differences among people with multiple sclerosis (MS) in demographics, MS disease characteristics, and health services received.

Participants: We analyzed enrollment data from the Registry of the North American Research Committee on Multiple Sclerosis (NARCOMS) Project to compare 26,967 Caucasians, 715 Latinos, and 1,313 African Americans with MS.

Design: Racial/ethnic analyses of NARCOMS data focused on descriptive characteristics, using ANOVA and chi-square tests to identify significant differences in means and frequencies among Caucasians, Latinos, and African Americans.

Results: We identified significant racial/ethnic differences in demographics, MS disease characteristics, and treatments. Caucasians were older when first MS symptoms were experienced (30.1 years) and at MS diagnosis (37.4 years) than Latinos (28.6 years and 34.5 years) or African Americans (29.8 years and 35.8 years). Larger proportions of Latinos reported normal function for mobility and bladder/bowel function compared to Caucasians. Larger proportions of Latinos (44.2 percent) and African Americans (45.8 percent) reported at least mild depression compared to only 38.7 percent of Caucasians. Larger proportions of Latinos never received mental health care or care from rehabilitation specialists than Caucasians or African Americans. A larger proportion of African Americans had never been treated by a neurologist specializing in MS and a smaller proportion of African Americans received care at a MS clinic than Caucasians or Latinos.

Conclusions: Our findings highlight the need for future analyses to determine if age, disease duration, MS symptoms, and disability levels provide additional insights into racial/ethic differences in the use of MS-related providers. (*Ethn Dis.* 2010;20:451–457)

Key Words: Multiple Sclerosis, African Americans, Latinos, Demographics, Symptoms, Treatments

INTRODUCTION

Multiple sclerosis (MS) is the most common neurological disease disabling young adults in the United States, with about 350,000 Americans diagnosed by a physician.[1] Multiple sclerosis is a demyelinating illness of the central nervous system which can lead to the expression of a range of symptoms, including spasticity, movement disorders, fatigue, bladder and bowel dysfunctions, pain, depression, and cognitive difficulties.[2] The clinical course of MS typically follows a variable pattern over time but usually is characterized by either episodic acute periods of worsening condition (relapses, exacerbations, bouts, or attacks), gradual progressive deterioration of neurological function, or combinations of each.[3] The disease is typified by episodes of neurological symptoms that are often followed by fixed neurological deficits, increasing disability, and medical and physical decline over 30 to 40 years.[4]

The Sonya Slifka Longitudinal Multiple Sclerosis Study follows about 2,000 people with MS, with this cohort broadly representative of the MS population in the United States.[5] African Americans comprise about 5 percent of Slifka Study participants, with Latinos comprising about 4 percent. We conducted a pilot study funded by the National Multiple Sclerosis Society to learn more about any ethnic or racial differences in demographics, MS characteristics and symptoms, and treatments for Latinos, African Americans, and Caucasians with MS. In addition, we highlight areas for future study and identify the special needs of minorities so that services can be developed and tailored to meet their needs.

We conducted a pilot study funded by the National Multiple Sclerosis (MS) Society to learn more about any ethnic or racial differences in demographics, MS characteristics and symptoms, and treatments for Latinos, African Americans, and Caucasians with MS.

African Americans with Multiple Sclerosis

Weinstock-Guttman et al found that African Americans were diagnosed with

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MS at a younger age, had greater disability with increased disease duration, and demonstrated a more rapid and severe cognitive decline than non-African Americans with MS.[6] A number of studies concluded that the course of MS is more aggressive among African Americans compared to Caucasians, with greater disability observed among African Americans.[6–10] Buchanan et al found that African Americans with MS were significantly more physically dependent and cognitively impaired than Caucasians with MS at admission to a nursing facility and one year after admission, as well as significantly younger at admission.[11,12] Minden et al observed that African Americans with MS had a significantly lower probability of receiving care from a neurologist than Caucasians with MS.[13]

Latinos with Multiple Sclerosis

The number of Latinos with MS in the United States will increase given estimates that the proportion of Latinos in the population will increase from 14 percent in 2005 to 29 percent by 2050.[14] However, a review of the literature found few studies focusing on Latinos with MS. The disease mortality rates and prevalence estimates among Hispanics are lower than among Caucasians.[15,16] One previous study analyzed MS management for low-income minorities in New York, with 31% of the women and 28% of the men in the study Hispanic or Latino.[17] That study found that these low-income New Yorkers with MS had difficulty accessing appropriate health care, with one third never treated by MS specialists or received immunomodulating drug therapy. Language, stigma, and lack of health insurance are significant barriers to mental health services for Latinos in general, resulting in insufficient use of mental health care.[18]

METHODS

The data analyzed in this study came from the Registry of the North American Research Committee On Multiple Sclerosis (NARCOMS) Project, which contained 35,000 people with MS by March, 2010.[19] Estimates place up to 10 percent of the American MS population in the NARCOMS Registry.[20] People with MS aged ≥18 years are invited to enroll in the registry through direct mailings, MS clinical centers, support groups, and the NARCOMS Registry website to participate in routine data collection.[21] Enrollment involves completing a questionnaire, which collects data on demographic characteristics, MS-related medical history, disease modifying (immunologic) and symptomatic therapies, and health services utilization, as well as a series of patient-assessed performance scales measuring disability in eight domains of function. Registry participants are assured confidentiality and that their names will never be disclosed to anyone without the participant's written permission.

Our study analyzed data from the NARCOMS Registry collected from 715 Latinos, 1,313 African Americans, and 26,967 Caucasians with MS who completed the enrollment questionnaire from November, 1995 through April 1, 2009. These analyses included demographics, MS characteristics and symptoms, and the use of MS-related providers and treatments as reported at the time of enrollment. These analyses of NARCOMS Registry data were completed by staff at NARCOMS to protect the privacy of registry participants. Institutional review board approval for these analyses was received from the Office of Regulatory Compliance at Mississippi State University in October, 2008.

Analyses of the NARCOMS data focused on descriptive characteristics of these people with MS to determine the range and distribution of values for the registry characteristics of interest. We used ANOVA and chi-square tests to identify any statistically significant differences in means (age) and frequencies (eg, MS symptoms, use of providers) among the groups of Caucasians, Latinos, and African Americans. In addition, we used logistic regression and a Wald Chi-Square test to identify any statistically significant differences in proportions among Caucasians, Latinos, and African Americans for selected NARCOMS Registry characteristics in preliminary age-adjusted analyses.

RESULTS

Demographic Characteristics

Table 1 presents racial/ethnic analyses of demographic characteristics of people with MS, demonstrating significant racial/ethnic differences for all demographics included. Caucasians were older at enrollment in the NARCOMS Registry, averaging 47.5 years compared to 42.3 years for Latinos and 44.5 years for African Americans. A larger proportion of African Americans (76.1 percent) was female compared with Caucasians (72.3 percent) or Latinos (72.4 percent). We identified significant racial/ethnic differences in marital status, with a larger proportion of Caucasians married and larger proportions of African Americans and Latinos never marrying. In addition, there were significant income differences, with larger proportions of Caucasians having higher incomes. More than 90 percent of each racial/ethnic group in our study had health insurance coverage, although the proportion of uninsured Latinos (8.1 percent) was about twice as high as the uninsured rate among Caucasians (4.3 percent). We found significant racial/ethnic differences in the type of health insurance coverage, with a larger proportion of Caucasians having private health coverage and larger proportions of Latinos and African Americans having only Medicaid coverage.

MS Symptoms/Disease Characteristics

Table 2 shows racial/ethnic comparisons of MS history and symptoms.

Table 1. Race/Ethnicity analyses of NARCOMS registry data: demographic characteristics

NARCOMS registry characteristic	Caucasian (*N*=26,967)	Latino (*N*=715)	African American (*N*=1,313)
Age			
Mean†	47.5 years	42.3 years	44.5 years
SD	11.0	10.9	10.5
Female*	72.3%	72.4%	76.1%
Marital status†			
Married	66.6%	58.2%	40.3%
Divorced or separated	18.0%	18.0%	26.2%
Never married	10.7%	19.9%	27.7%
Widowed	3.1%	1.6%	4.0%
Living with someone	1.6%	2.3%	1.9%
Currently employed†	47.5%	46.9%	38.6%
Income†			
<$15,000	14.3%	19.5%	29.3%
$15,000 to $29,999	18.1%	20.1%	24.2%
$30,000 to $49,999	23.7%	22.9%	22.9%
$50,000 to $100,000	27.7%	23.2%	16.0%
>$100,000	9.4%	7.2%	2.0%
Did not want to answer	6.9%	7.2%	4.7%
Education†			
High school diploma/GED	10.8%	15.5%	11.9%
Associate's degree	32.0%	29.7%	37.0%
Bachelor's degree	20.8%	22.3%	20.4%
Post graduate degree	21.5%	20.5%	18.4%
Technical degree	13.5%	9.9%	10.9%
Other	1.4%	2.1%	1.4%
Type of health insurance coverage†			
Private‡	72.3%	65.8%	57.6%
Medicare§	13.5%	11.2%	15.7%
Medicaid	3.7%	7.4%	10.8%
CHAMPUS or VA	5.1%	5.8%	9.5%
Other‖	1.1%	1.8%	.8%
No health insurance	4.3%	8.1%	5.6%

Note: Not all participants in the NARCOMS Enrollment Survey provided data for all characteristics in this table.

* $P<.05$.

† $P<.001$.

‡ Private insurance category includes those who responded that they have private insurance and Medicare and/or Medicaid, and also those who responded that they have private insurance and other.

§ Medicare category includes those who responded that they are dually eligible for Medicare and Medicaid.

‖ Other category includes responses of other and also responses of national insurance (non-United States).

We found significant racial/ethnic differences in the average age at MS diagnosis, with Caucasians averaging 37.4 years Latinos averaging 34.5 years and African Americans averaging 35.8 years. Similarly, we observed significant racial/ethnic differences in the average age when MS symptoms were first experienced, with Caucasians averaging 30.1 years, Latinos averaging 28.6 years and African Americans averaging 29.8 years. There were significant racial/ethnic differences in current overall MS symptoms, with larger proportions of Latinos (20.3 percent) and African Americans (19.1 percent) reporting that MS symptoms were currently better compared to Caucasians (12.7 percent). We found significant racial/ethnic differences in Patient-Determined Disease Steps (PDDS), mobility, fatigue, cognitive symptoms, bladder/bowel condition, spasticity, vision, and depression. We found no significant racial/ethnic differences in pain or tremor/loss of coordination. Noticeably larger proportions of Latinos had normal function compared to African Americans and Caucasians for PDDS, mobility, bladder/bowel function, and vision. However, larger proportions of Latinos (44.2 percent) and African Americans (45.8 percent) reported at least mild depression compared to only 38.7 percent of Caucasians.

Physician and Treatment Services

Table 3 presents racial/ethnic comparisons of the utilization of various types of physicians, other providers, and therapies related to MS care, with many significant racial/ethnic differences observed. There were significant racial/ethnic differences in care received at MS clinics, with a smaller proportion of African Americans (36.8 percent) treated or evaluated at a MS center or clinic compared to Caucasians (49.2 percent) or Latinos (47.0 percent). There were significant racial/ethnic differences in the use of alternative medicine, with noticeably larger proportions of Latinos never receiving these therapies presented compared to Caucasians or African Americans. We observed many significant differences in the proportions of African Americans, Latinos, and Caucasians who never received the physician services. For example, 56.1 percent of African Americans had never been treated by a neurologist specializing in MS care compared to only 47.2 percent of Latinos. A noticeably larger proportion of Latinos never received treatment from a physiatrist/MS specialist (39.2 percent) compared with African Americans (25.9 percent) or Caucasians (29.2 percent).

There were significant racial/ethnic differences in the use of rehabilitation/support therapies and mental health services; a noticeably larger proportion of Latinos never received occupational therapy (33.8 percent) than African Americans (21.1 percent) or Caucasians

(24.5 percent). In addition, more than 40 percent of Latinos had never used the services of a home health aide compared with only about 28 percent of African Americans or about 30 percent Caucasians. About 39 percent of Latinos had never been treated by a neuropsychologist compared with African Americans (23.9 percent) or Caucasians (26.8 percent).

Table 2. Race/Ethnicity analyses of NARCOMS registry data: MS history and symptoms

NARCOMS Registry Characteristic	Caucasian (*N*=26,967)	Latino (*N*=715)	African American (*N*=1,313)
Duration of MS			
Mean‡	10.2 years	8.1 years	8.8 years
SD	9.4	8.3	8.0
Age At MS Diagnosis			
Mean†	37.4 years	34.5 years	35.8 years
SD	9.8	9.7	9.5
Age at First MS Symptoms			
Mean†	30.1 years	28.6 years	29.8 years
SD	10.0	10.0	10.0
Reported relapse/exacerbation of MS within last year*	51.7%	57.9%	54.1%
Current overall MS symptoms†‡			
Better now	12.7%	20.3%	19.1%
Same as previous period	37.5%	31.4%	37.9%
Worse now	46.5%	44.7%	38.0%
Unsure	3.3%	3.6%	5.0%
Patient-determined disease steps†			
Normal (0)	15.6%	23.1%	14.1%
Mild disability (1)	11.3%	9.8%	8.7%
Moderate disability (2)	8.3%	8.0%	7.5%
Gait disability (3)	15.9%	15.4%	16.7%
Early cane (4)	14.2%	13.8%	16.8%
Late cane (5)	12.1%	10.7%	11.6%
Bilateral support (6)	8.1%	7.9%	8.7%
Wheelchair/scooter (7)	13.1%	10.7%	15.5%
Bedridden (8)	1.4%	.7%	.5%
Mobility†			
Normal (0)	19.5%	28.6%	16.8%
Minimal gait disability (1)	15.1%	14.4%	13.5%
Mild gait disability (2)	15.8%	14.2%	17.3%
Occasional use of cane/unilateral support (3)	16.9%	14.9%	17.2%
Frequent use of cane (4)	11.2%	10.8%	11.4%
Severe gait disability - bilateral support (5)	8.2%	7.1%	10.1%
Total gait disability or bedridden (6)	13.4%	10.1%	13.9%
Fatigue*			
Normal fatigue (0)	7.0%	10.0%	8.1%
Minimal fatigue disability (1)	12.0%	15.9%	13.6%
Mild fatigue disability (2)	20.7%	21.7%	20.3%
Moderate fatigue disability (3)	24.7%	21.4%	23.6%
Severe fatigue disability (4)	29.1%	25.3%	27.8%
Total fatigue disability (5)	6.6%	5.8%	6.7%
Cognitive symptoms*			
Normal cognition (0)	20.8%	22.6%	21.4%
Minimal cognitive disability (1)	32.1%	32.4%	32.9%
Mild cognitive disability (2)	20.3%	17.9%	17.5%
Moderate cognitive disability (3)	17.5%	18.6%	16.7%
Severe cognitive disability (4)	7.6%	6.5%	8.5%
Total cognitive disability (5)	1.7%	1.9%	3.1%
Bladder/bowel†			
Normal bladder/bowel (0)	17.9%	25.1%	18.0%
Minimal bladder/bowel disability (1)	31.0%	30.9%	34.5%
Mild bladder/bowel disability (2)	22.8%	18.0%	18.0%
Moderate bladder/bowel disability (3)	14.1%	14.7%	15.6%

> *Latinos and Africans Americans were younger at MS diagnosis and when first symptoms were experienced than Caucasians.*

DISCUSSION

We found significant and interesting racial/ethnic differences in the demographic characteristics of people with MS, their disease history and symptoms, and the health services utilized. Latinos and Africans Americans were younger at MS diagnosis and when first symptoms were experienced than Caucasians. These age differences were largest between the Latinos and Caucasians included in our study. Future research is needed to identify possible explanations for this younger age for MS symptom onset and disease diagnosis among minorities, especially Latinos.

We observed that larger proportions of Latinos compared to Caucasians had normal function or disability levels for almost all of the various MS symptoms included in our study, while smaller proportions of African Americans had normal levels of disability or function for many of these symptoms than Caucasians. We also found that noticeably larger proportions of Latinos

Table 2. Continued

NARCOMS Registry Characteristic	Caucasian (*N*=26,967)	Latino (*N*=715)	African American (*N*=1,313)
Severe bladder/bowel disability (4)	10.2%	8.0%	8.9%
Total bladder/bowel disability (5)	4.2%	3.3%	5.0%
Spasticity Symptoms*			
Normal spasticity (0)	16.8%	19.8%	14.8%
Minimal spasticity disability (1)	31.1%	29.7%	28.5%
Mild spasticity disability (2)	18.1%	15.2%	17.7%
Moderate spasticity disability (3)	16.5%	17.5%	19.5%
Severe spasticity disability (4)	13.3%	13.8%	13.9%
Total spasticity disability (5)	4.2%	4.0%	5.7%
Vision†			
Normal vision (0)	26.9%	30.6%	24.1%
Minimal visual disability (1)	30.8%	26.1%	24.6%
Mild visual disability (2)	24.1%	26.7%	28.2%
Moderate visual disability (3)	11.2%	11.0%	13.5%
Severe visual disability (4)	6.2%	5.0%	8.4%
Total visual disability (5)	.9%	.6%	1.2%
Pain			
Normal (0)	24.1%	21.2%	20.2%
Minimal pain (1)	24.8%	26.6%	24.9%
Mild pain (2)	18.0%	16.2%	14.8%
Moderate pain (3)	18.3%	20.1%	22.2%
Severe pain (4)	11.9%	12.7%	15.2%
Total disabling pain (5)	3.0%	3.1%	2.7%
Depression†			
Normal (0)	24.7%	24.0%	26.0%
Minimal depression (1)	36.6%	31.5%	28.4%
Mild depression (2)	19.5%	21.2%	22.2%
Moderate depression (3)	13.9%	13.3%	13.5%
Severe depression (4)	3.9%	6.8%	6.6%
Total depression (5)	1.4%	3.2%	3.5%
Tremor/loss of coordination			
Normal/no tremor or loss of coordination (0)	25.7%	26.9%	22.5%
Minimal tremor or loss of coordination (1)	34.3%	31.5%	32.2%
Mild tremor or loss of coordination (2)	16.3%	19.0%	17.3%
Moderate tremor or loss of coordination (3)	12.9%	12.9%	16.3%
Severe tremor or loss of coordination (4)	8.3%	6.8%	10.0%
Total disabling tremor/Loss of coordination (5)	2.6%	2.9%	1.7%

Note: Not all participants in the NARCOMS Enrollment Survey provided data for all characteristics in this table.

* $P<.01$.

† $P<.001$.

‡ Enrollees before 2005 compared symptoms to one year earlier; enrollees after 2005 compared symptoms to six months earlier.

compared to Caucasians and African Americans never received the alternative therapies, most of the specialized physician services, mental health care, or rehabilitation /support therapies included in our study.

We found significant racial/ethnic differences in depression, with larger proportions of Latinos (44.2 percent) and African Americans (45.8 percent) reporting at least mild depression compared to only 38.7 percent of Caucasians. However, larger proportions of Latinos, compared to African Americans or Caucasians, had never received the various mental health services included in our study. Consistent with many of our findings for Latinos, a recent study observed that racial/ethnic minorities tend to have disproportionately poor mental health, face barriers to care, and receive lower quality mental health care.[22] Another recent study found that Mexican Americans and African Americans meeting major depression criteria had significantly lower odds of receiving any depression therapies than non-Latino Caucasians.[23] Future research is needed to assess the impact of stigma, psychosocial characteristics, and culture on the use of MS-related care and mental health services by Latinos with MS.

The US Latino population is expanding rapidly, implying that the number of Latinos with MS will also increase. However, few studies have focused on Latinos with MS. We found significant and important differences that warrant additional analyses among Latinos, African Americans, and Caucasians with MS in disease history and disease characteristics, as well as health services utilized. Although beyond the scope of this initial descriptive study, future analyses should determine if the average younger age of Latinos and African Americans at enrollment in the NARCOMS Registry compared to Caucasians could affect symptoms and disability levels. For example, when we adjusted for age in preliminary analyses, we found no significant racial/ethnic differences in relapses/exacerbations of MS within the last year, fatigue, or cognitive symptoms. Conversely, we found significant race/ethnic differences in pain and tremor/loss of coordination when we adjusted for age. In addition, racial/ethnic differences in the utilization of a number of health services, such as holistic medicine, neurologists specializing in MS, urologists, and psychologists were no longer significant when we adjusted for age. Although beyond the scope of this descriptive study, future analyses could determine if age, disease duration, and MS symptoms/levels of disability can provide additional insight into these racial/ethic differences in the use of MS-related providers and therapies.

Study Limitations

There is a possibility of selection bias in our study as we did not use a

Table 3. Race/Ethnicity analyses of NARCOMS registry data: MS providers and therapies

NARCOMS registry characteristic	Caucasian (*N*=26,967)	Latino (*N*=715)	African American (*N*=1,313)
Has been treated/evaluated at MS center/clinic*	49.2%	47.0%	36.8%
Never received these types of alternative medicine:			
Massage therapist‡	24.4%	33.4%	21.4%
Acupuncturist‡	26.2%	35.0%	24.3%
Holistic medicine‡	27.6%	39.0%	24.0%
Never received these physician services:			
Neurologist - MS specialist‡	50.4%	47.2%	56.1%
Neurologist - non-MS specialist‡	36.2%	31.6%	34.1%
Rehabilitation specialist (physiatrist) - MS specialist‡	29.2%	39.2%	25.9%
Rehabilitation specialist (physiatrist) - non-MS specialist‡	27.2%	36.2%	24.2%
Internal medicine	30.8%	33.6%	33.1%
Urologist†	30.3%	34.9%	28.3%
Ophthalmologist‡	21.6%	28.0%	26.5%
OB/GYN (% of women only)‡	21.4%	27.1%	20.6%
Never received these mental health services:			
Psychologist‡	24.6%	34.1%	21.8%
Psychiatrist‡	27.0%	35.8%	24.1%
Neuropsychologist‡	26.8%	39.2%	23.9%
Social worker/counselor‡	26.8%	37.8%	25.7%
Never received these rehabilitation/support therapies:			
Physical therapy‡	21.5%	27.2%	22.4%
Occupational therapy‡	24.5%	33.8%	21.1%
Home health aide‡	29.5%	40.1%	27.5%
Disease modifying therapies (DMT) *§			
Currently taking DMTs	61.5%	62.1%	66.1%
Not currently, but have taken DMTs	25.6%	23.1%	23.9%
Never took DMTs	11.1%	12.3%	8.5%
Not sure	1.9%	2.5%	1.6%

Note: Not all participants in the NARCOMS Enrollment Survey provided data for all characteristics in this table.
* $P<.05$.
† $P<.01$.
‡ $P<.001$.
§ DMTs include Avonex, Rebif, Betaseron, or Copaxone.

random sample of people with MS but NARCOMS Registry data in our analyses. Participation in the NARCOMS Registry is voluntary and participants may not represent the entire MS population in the United States. The Registry population is large, however, and people in the NARCOMS Registry have comparable demographic characteristics, as well as age at symptom onset, to MS patients from the National Health Interview Survey and the Slifka Study cohort.[5,20,24] A second possible limitation to our study is the use of self-reported data in the NARCOMS Registry, with misclassification possible.[20] However, the validity of the performance scales for eight domains of disability utilized to collect data for the NARCOMS has been established.[25] In addition, other previous studies have validated diagnosis data, as well as pain and fatigue assessment in the NARCOMS Registry.[26–28]

CONCLUSIONS

This is the first descriptive analysis comparing Latinos, African Americans, and Caucasians for a comprehensive range of MS-related disease characteristics, symptoms, and treatments using national data. Our findings highlight the need for future expanded analyses to determine if age, disease duration, MS symptoms, and disability levels can provide additional insights into racial/ethic differences in the use of MS-related providers and therapies.

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