RACIAL ANALYSES OF LONGER-STAY NURSING HOME RESIDENTS WITH MULTIPLE SCLEROSIS

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Objectives: Compare profiles of African Americans with multiple sclerosis (MS) to White residents with MS one year after admission to a nursing facility.

Methods: We used all admission assessments recorded in the national Minimum Data Set (MDS) from 1999 to 2001 as well as all MDS annual assessments recorded from 2000 to 2002. We matched admission assessments with first annual assessment for 3632 White residents with MS and 461 African-American residents with MS.

Results: African Americans with MS were admitted at a significantly younger age and with more aid to daily living (ADL) dependence and cognitive dysfunction than Whites with MS one year after admission. Despite significantly poorer physical performance, cognitive function, and more medical comorbidities, African Americans with MS did not receive significantly more therapies or medications than White residents with MS after one year in the facility.

Conclusions: Basic differences in MS expression and progression in African Americans appear to have to do with both genetic and environmental factors. Further study will help to clarify the reasons for these differences. (*Ethn Dis*. 2006;16:159–165)

Key Words: African Americans, Minimum Data Set, Multiple Sclerosis, Nursing Facilities

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INTRODUCTION

Multiple sclerosis (MS), a demyelinating disease of the central nervous system, is the most common disabling neurologic disease in younger adults; as many as 350,000 Americans have been diagnosed.[1,2] Symptoms of MS include spasticity, movement disorders, fatigue, bladder and bowel dysfunctions, pain, depression, visual disorders, cognitive difficulties, and dysphagia.[3] The clinical course of MS characteristically follows a variable pattern over time but typically is characterized by either episodic acute periods of worsening condition (relapses, exacerbations, or attacks), gradual progressive deterioration of neurologic function, or combinations of both.[4] Multiple sclerosis (MS) is distinguished by episodes of neurologic symptoms that are often followed by fixed neurologic deficits, increasing disability, and medical, socioeconomic, and physical decline over 30 to 40 years.[5]

Earlier studies produced conflicting conclusions about the incidence of MS among African Americans.[6] Some earlier studies found no significant differences in the frequency of MS between Whites and Blacks in the United States,[7,8] while other earlier studies found MS less common among African Americans.[9,10] Recent studies conclude that MS is more common among White Americans than African Americans.[11,12]

Approximately 20% to 25% of people with MS will need long-term care during the course of their disease, and an estimated 5% will eventually need care in a nursing facility.[13,14] Little is known about nursing-home care provided to African Americans with MS, especially those admitted to nursing facilities for longer stays (at least one year or more). The objective of this research is to create profiles of African-American residents with MS one year after admission and compare these profiles to profiles of White residents by using Minimum Data Set (MDS, Centers for Medicare & Medicaid Services, Baltimore, Md, USA).

African Americans and MS

Buchanan et al conducted comparative analyses of African Americans with MS and Whites with MS at admission to nursing facilities; they found that African-American residents with MS were more physically dependent and cognitively impaired.[15] That study included all MS residents of both races at admission who had either longer or shorter stays at the nursing facility. Other studies focused on African Americans with MS in general, but not on nursing-home residents. Weinstock-Guttman et al analyzed clinical characteristics of African-American patients with MS by using the New York State Multiple Sclerosis Consortium patient registry and found that African Americans were diagnosed with MS at a younger age, were more likely to have greater disability with increased disease duration, and demonstrated a more rapid and severe cognitive decline.[16] Weinstock-Guttman, et al found that MS follows a more aggressive course among African Americans, with shorter time from the onset of symptoms to diagnosis for African-American females with MS. Kaufman et al observed consistent evidence of more disability among African Americans with MS compared to Whites with MS.[17] Other studies also concluded that the course of MS is more aggressive among African

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Americans, with greater disability observed among African Americans compared to Whites.[18–20] Cree et al[20] recently reported that African Americans with MS are more likely to have a more aggressive disease course including opticospinal involvement and transverse myelitis. In addition, they concluded that genetic differences between African-American and African Blacks may cause the former to have a greater risk for developing MS.

African Americans and Nursing Home Care

A larger number of studies analyzed the nursing-home care provided to African Americans in general, not focusing on African Americans with MS. Previous studies found that elderly African Americans are less likely to receive care in nursing facilities than elderly Whites.[21–23] In addition, African-American residents are significantly more likely than White residents to have dementia at admission to the nursing facility.[24] Another study found that African-American females in nursing facilities had worse mental status and worse ADL performance than White female residents.[25] African-American residents in nursing facilities receive life-sustaining interventions at higher rates than Whites,[26] while African-American residents are substantially less likely to implement advance-care plans.[27] However, minority residents are more likely to receive treatment by a mental-health specialist among nursing home residents who report a mental illness.[28] Minority residents in nursing facilities are at greater risk for the undertreatment of pain than White residents.[29]

METHODS

The MDS is a federally mandated assessment instrument that includes all nursing-home residents (regardless of payment source) in all Medicare and Medicaid-certified nursing facilities.[30] The MDS contains comprehensive assessments of nursing-home residents, including demographic characteristics, measures of health, behavior, physical function, cognitive performance, and treatments. Full MDS assessments are recorded at admission, annually, and upon significant changes in status.

Analyses of MS Residents

We used all MDS admission assessments recorded throughout the United States from 1999 to 2001 and all MDS annual assessments recorded from 2000 to 2002 for this study, including only residents with a diagnosis of MS. We matched MDS admission assessments with their first annual assessment for 3632 White residents (not of Hispanic origin) with MS and 461 African-American residents (not of Hispanic origin) with MS. These longer-stay residents with MS included in our analyses belong to a subset of all residents with MS, including only residents with MS who stayed in the nursing facility at least one year. As we matched MDS admission assessments with first annual MDS assessment, residents with MS who stayed in the nursing facility less than one year are not included in these analyses.

ADL Long Scale

Morris et al developed the ADL Long Scale by using MDS characteristics, with possible scores from 0 to 28.[31] The higher the score, the more physically dependent the nursing home resident. The ADL Long Scale is composed of seven items, including early-loss ADL items (dressing and personal hygiene), middle-loss items (transfer, locomotion, and toilet use), and late-loss items (eating and bed mobility).

Cognitive Performance Scale

The Cognitive Performance Scale (CPS) uses five MDS items to construct a measure of cognitive impairment.[32] These items are short-term memory, cognitive skills for daily decision making, comatose status, the ability of residents to make themselves understood, and full dependence in eating. The CPS categorizes residents into one of seven levels of cognitive performance, from intact to very severe impairment.

MDS Pain Scale

Fries et al used pain frequency and pain intensity from the MDS to develop a four-category MDS Pain Scale.[33] Residents with no pain or pain less than daily make up the first two categories of this pain scale. Residents with daily pain are divided into the other two categories based on pain intensity. Residents with daily pain that is horrible/excruciating form the highest category of pain and all other residents with daily pain form an intermediate category.

Statistical Analyses

Analyses of MDS assessments were conducted by using SAS (SAS Institute, Inc., Cary, NC, USA). Population characteristics, such as percentages, means, medians, and standard deviations, were computed. To test for differences of statistical significance between African-American residents with MS and White residents with MS, we used two sample tests for comparisons of proportion (eg, diagnosis of depression). We used the two-way contingency table chi-square test for categorical data (eg, pain index). Statistically significant differences are noted at the .05, .01, or .001 levels in tables

that summarize these racial comparisons of residents with MS. The MDS data displayed in this study are consistent with the Centers for Medicare and Medicaid Services' data release and privacy guidelines.

RESULTS

Demographic Characteristics at Admission

Table 1 compares demographic characteristics of longer-stay African-American and White residents with MS at admission to the nursing facility. Longer-stay African Americans with MS were significantly younger at admission than Whites (median age of 49.7 years compared to 56.0 years). More than one half of African-American residents were ≤50 years of age at admission compared to fewer than one third of White residents. In fact, approximately one in five African-American residents was ≤40 years of age at admission compared to only 1 in 14 White residents.

A significantly larger proportion of African-American residents with MS was admitted to the nursing facility from an acute-care hospital. Whites were more likely to be married when admitted, while African Americans were more likely to have never married. Significant racial differences existed in the payment sources for nursing-home care at admission among these MS residents; a larger proportion of African Americans had Medicaid coverage, and a larger proportion of Whites paid for their own care. White residents were significantly more likely to have advance-care plans in place at admission, while African-American residents were significantly more likely to have a family member responsible for decision making at admission.

Table 1. Sociodemographic characteristics of admission

Characteristic	White (not Hispanic)	African American
Female[4]	71.2%	72.9%
Age		
Mean[1]	57.7 years	50.7 years
Standard deviation	13.1	12.2
Median	56.0 years	49.7 years
Age distribution[1]		
30 years or younger	0.6%	3.5%
31 to 40 years	6.5%	15.0%
41 to 50 years	23.1%	32.4%
51 to 60 years	30.4%	28.0%
61 to 70 years	18.8%	13.3%
71 to 80 years	14.6%	6.5%
81 years or older	6.0%	1.3%
Admitted to Nursing Home from[1]		
Acute Care Hospital	30.5%	42.0%
Nursing Home	24.9%	21.3%
Private home/apt. with no home health services	16.5%	14.8%
Private home/apt. with home health services	15.9%	13.3%
Board and care/assisted living/group home	7.5%	3.7%
Other	4.7%	5.0%
Lived alone prior to admission[4]		
No	64.2%	69.2%
Yes	14.1%	13.0%
Other facility	21.7%	17.8%
Marital status[1]		
Married	32.6%	19.6%
Divorced	30.3%	24.0%
Widowed	17.8%	10.5%
Never married	16.5%	38.6%
Separated	2.7%	7.0%
Payment source		
Medicaid per diem[1]	53.5%	65.3%
Self pay/family per diem[1]	26.1%	7.8%
Private Health Insurance per diem[4]	13.8%	13.7%
Other per diem[2]	5.2%	8.7%
Medicare per diem[4]	4.4%	5.2%
VA per diem[4]	2.9%	2.8%
Responsibility/legal guardian (more than one may apply)		
Family member responsible[1]	52.3%	61.2%
Patients responsible for themselves[4]	49.5%	45.6%
Durable Power of Attorney/Health Care[1]	29.2%	8.9%
Durable Power of Attorney/Financial[1]	21.3%	4.8%
Advance directives (more than one may apply)		
Do not resuscitate[1]	35.4%	13.5%
Living Will[1]	18.0%	5.2%
No advance directives[1]	52.9%	80.5%

[1] =<.001; [2] =<.01; [3] =<.05; [4] =not significant (>.05).

Physical Dependency and Disability

Table 2 presents selected ADL scores and other measures of physical disability for residents with MS one year after admission. African Americans averaged a significantly higher score on the ADL Long Scale, which indicates greater ADL dependency after one year in the facility. Similarly, significantly higher proportions of African Americans were totally dependent in the self-perfor-

Table 2. ADL dependence, physical disability, co-morbidities, and pain

Characteristic	White (not Hispanic)	African American
ADL long scale		
Mean[3]	19.3	20.2
Standard deviation	7.5	8.1
Median	20	22
Percentage with maximum score/total dependence (28)	18.4%	29.3%
ADL—total dependence*		
Bed mobility[3]	37.2%	42.5%
Walk in room[4]	85.5%	84.6%
Dressing[1]	45.6%	54.5%
Eating[1]	26.7%	38.2%
Toilet use[3]	64.3%	70.1%
Personal hygiene[1]	44.1%	55.5%
Range of motion—arm[2]		
No limitation	53.4%	49.7%
Limitation on one side	15.1%	11.7%
Limitation on both sides	31.6%	38.6%
Range of motion—leg[4]		
No limitation	31.0%	29.3%
Limitation on one side	10.0%	7.6%
Limitation on both sides	59.0%	63.1%
Loss of voluntary movement—leg[4]		
No loss	21.0%	21.3%
Partial loss	40.3%	39.7%
Full loss	38.7%	39.1%
Wheelchair primary mode of locomotion[1]	83.1%	73.3%
Incontinent		
Bowel[1]	46.1%	62.7%
Bladder[1]	29.2%	45.1%
Most common diseases one year after admission		
Depression[1]	56.8%	42.5%
Hypertension[2]	25.4%	32.1%
Allergies[2]	19.3%	14.1%
Dementia (other than Alzheimer's disease)[4]	13.8%	15.6%
Seizure disorder[2]	12.4%	17.4%
Anxiety disorder[1]	12.3%	4.3%
Anemia[1]	11.8%	18.7%
Diabetes[1]	11.6%	19.1%
Arthritis[3]	11.3%	8.2%
Osteoporosis[1]	11.3%	5.4%
No pressure ulcers[3]	79.8%	74.8%
Distribution of MDS pain index[3]		
No pain	52.2%	59.4%
Mild pain (pain less than daily)	25.9%	21.0%
Moderate pain (daily pain)	18.4%	18.2%
Excruciating pain (daily pain)	3.5%	1.3%

* Responses of ''activity did not occur'' were combined with total dependence. This approach was used by Morris J.[31]

[1] =<.001; [2] =<.01; [3] =<.05; [4] = not significant (>.05).

mance of individual ADLs after one year compared to White residents with MS. No significant racial difference was found in the ability of these residents to walk in their rooms after one year in the facility, with more than four in five residents of either race totally dependent.

No significant racial differences were seen in limitations in the range of leg motion or in the loss of voluntary leg movement after one year in the facility. However, African Americans were significantly more likely to have limitations in the range of arm motion. A significantly larger proportion of White residents used a wheelchair as their primary mode of locomotion one year after admission. Significantly larger proportions of African-American residents were bowel or bladder incontinent than White residents with MS after one year in the facility.

Comorbidities

Table 2 also shows that a much larger proportion of Whites had a diagnosis of depression one year after admission. Significantly larger proportions of African-American residents had a diagnosis of hypertension, seizure disorder, diabetes, or anemia after one year. In contrast, White residents were significantly more likely to have a diagnosis of allergies, anxiety disorder, arthritis, or osteoporosis. A significantly larger proportion of African-American residents had pressure ulcers after one year in the facility. White residents were significantly more likely to experience pain one year after admission.

Cognitive Ability and Mental Health

Table 3 demonstrates significant racial differences in cognitive performance among MS residents; African Americans had poorer cognitive performance after one year in the facility. For example, one year after admission, African Americans were almost twice as likely to have very severe cognitive impairment, as measured by the CPS

Table 3. Cognitive ability, mental health, psychosocial well being, and communication

MDS Characteristic	White (not Hispanic)	African American
Cognitive Performance Scale Distribution[2]		
Intact	33.6%	27.6%
Borderline intact	19.4%	20.6%
Mild impairment	16.1%	16.5%
Moderate impairment	20.3%	19.7%
Moderately severe impairment	4.4%	5.6%
Severe impairment	1.6%	1.1%
Very severe impairment	4.7%	8.9%
Memory		
Short term memory problem[4]	44.8%	48.0%
Long term memory problem[4]	25.4%	29.0%
Memory/recall ability (resident can recall)		
Staff names/faces[3]	88.5%	84.9%
Current season[1]	77.2%	67.9%
Location of own room[1]	81.4%	74.5%
Psychiatric diagnoses		
Depression[1]	56.8%	42.5%
Anxiety disorder[1]	12.3%	4.3%
Indicators of depression, anxiety, or sad mood		
Sad, pained, or worried facial expressions[2]	24.9%	19.4%
Persistent anger[1]	20.1%	11.1%
Repetitive anxious complaints[1]	17.9%	8.5%
Crying[1]	11.6%	5.9%
Repetitive health complaints[1]	14.4%	7.0%
Mood persistence[1]		
No mood indicators	53.7%	64.6%
Indicators present, easily altered	25.8%	22.5%
Indicators present, not easily altered	20.4%	12.9%
Psychosocial well-being (sense of involvement)		
At ease interacting with others[3]	87.6%	83.4%
Self-initiated activities[1]	64.6%	52.8%
At ease in planned activities[2]	56.1%	48.7%
Establishes own goals[1]	33.3%	24.5%
Accepts invitations to group activities[4]	25.7%	22.9%
Pursues life in facility[3]	25.7%	21.2%

[1] =<.001; [2] =<.01; [3] =<.05; [4] =not significant (>.05).

(the highest level of impairment). In addition, Whites had better recall ability one year after admission. Table 3 also shows significant racial differences in indicators of depression, anxiety, or sad mood and mood persistence. However, larger proportions of White residents demonstrated psychosocial well-being or a sense of involvement in the nursing facility after one year.

Therapies and Treatments

Table 4 demonstrates significant racial differences in medication use among MS residents one year after admission; White residents averaged more medications, and significantly larger proportions of White residents received antianxiety, antidepressant, and diuretic medications on a daily basis. While African-American residents were more ADL dependent and more likely to have limitations in the range of arm motion, Table 4 shows no significant racial differences in the use of various therapies after one year in the facility. For example, Whites averaged 7.0 minutes of physical therapy after one year compared to 6.5 minutes for African Americans. A small proportion of either racial group of MS residents had been evaluated by a licensed mental-health specialist within 90 days of their annual MDS assessment, even though the proportion of MS residents of each racial group with a diagnosis of depression increased dramatically after one year in the facility. One year after admission, approximately three in four African-American residents still had not executed advance directives compared to fewer than 4 in 10 White residents. The proportion of both White and African-American residents who received Medicaid coverage of their nursing home per diem increased dramatically after one year in the facility.

DISCUSSION

While no significant racial difference was found in the ability to ambulate in their rooms after one year in the facility (about 85% of each group was totally dependent in the ability to walk in their rooms), a significantly larger proportion of White residents with MS depended on wheelchairs. However, a larger proportion of African Americans with MS was totally ADL dependent, as measured by the ADL Long Scale, compared to Whites with MS one year after admission. This greater ADL dependency among African Americans could explain why a larger proportion of Whites could use a wheelchair as the primary mode of locomotion. MS in African Americans may progress differently and cause more disability over time.

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Table 4. Medications, therapies, mental health care, and special treatments

MDS Characteristic	White (not Hispanic)	African American
Medications		
Mean[1]	9.8 medications	8.5 medications
Standard deviation	4.8	4.5
Median	9 medications	8 medications
First quartile	7 medications	5 medications
Third quartile	13 medications	11 medications
Specific medications (% of residents taking these medications daily)*		
Antipsychotic medications[4]	12.8%	14.8%
Antianxiety medications[1]	17.2%	10.9%
Antidepressant medications[1]	60.1%	41.4%
Diuretic medications[1]	20.6%	12.6%
Therapies**		
Physical therapy[4]		
Mean	7.0 minutes	6.5 minutes
Standard deviation	35.8	31.3
Median	0 minutes	0 minutes
90th percentile	0 minutes	0 minutes
Occupational therapy		
Mean[4]	5.3 minutes	4.1 minutes
Standard deviation	30.0	23.9
Median	0 minutes	0 minutes
90th percentile	0 minutes	0 minutes
Psychological therapy		
Mean[4]	1.3 minutes	0.8 minutes
Standard deviation	21.6	5.9
Median	0 minutes	0 minutes
90th percentile	0 minutes	0 minutes
Evaluation by Licensed Mental Health Specialist (last 90 days)[4]	18.2%	19.1%
Advance directives (more than one may apply)***		
Do not resuscitate[1]	45.7%	17.8%
Living Will[1]	21.0%	6.5%
Feeding restrictions[1]	11.6%	3.7%
Other treatment restrictions[1]	8.5%	2.4%
No advance directives[1]	42.6%	74.6%
Payment source***		
Medicaid per diem[1]	71.4%	83.3%
Self pay/family per diem[1]	19.0%	5.0%
Private Health Insurance per diem[4]	7.1%	5.4%

* In addition, small percentages of these MS residents received these medications, but less than daily.

** The total minutes these therapies were administered for at least 15 minutes per day in the last seven days prior to the admission assessment (counting only post admission therapies).

[1] =<.001; [2] =<.01; [3] =<.05; [4] =not significant (>.05).

*** One year after admission.

African Americans with MS continued to have poorer cognitive performance after one year in the facility and were approximately twice as likely as Whites with MS to have very severe cognitive impairment. Consistent with our observations for cognitive impairment, African Americans had significantly greater problems with recall ability, such as the current season. However, no significant racial differences were found in long-term or short-term memory. Memory is only one aspect of cognition. Other aspects of cognition include judgment, abstraction, problem solving, executive decision making, and right brain functions such as orientation in space, ability to locate and direct oneself in the environment, constructional ability, or form recognition. Significantly smaller proportions of African Americans than Whites were able to recall the location of their rooms in the facility.

Our observations support the findings of previous investigators that the clinical course of MS may be different and more aggressive in African Americans.[15,18–20] Although the MDS identifies differences in functional abilities between these racial groups, it is not designed to identify specific neuroanatomic differences between groups that might explain functional discrepancies. Inclusion of additional data, such as findings on neurologic examination and neuroimaging studies, would be necessary to further corroborate the specific differences between these racial groups. Nevertheless, our findings support the observation of a racial difference between African Americans and Whites with MS in disease expression and that African Americans with MS may suffer a more aggressive disease course after one year in the nursing facility. Referral bias could account for these observations in our study if African-American residents were referred to nursing facilities once they had developed greater disability than Whites. However, we think this bias unlikely because African Americans with MS tended to be admitted to nursing facilities at a younger age than White residents with MS (50.7 years vs 57.7 years), and almost one in five African-American residents with MS was <40 years of age at admission.

Racial differences existed in comorbidities; a greater proportion of African Americans had comorbid diseases such as hypertension, seizure disorder, diabetes, and anemia one year after admission. These comorbid diseases could also impair functional ability and may worsen impairments due to MS alone. Additional observations were that despite significantly poorer physical performance, cognitive function, and more medical comorbidities among African Americans with MS, they did

not receive significantly more therapies or medications than White residents with MS one year after admission.

Specific investigative tools will have to be developed to investigate what accounts for these differences. In summary, basic differences in MS expression and progression in African Americans may have to do with both genetic and environmental factors. Further study and refinement of investigational tools may help to further clarify the reasons for these differences.

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Data analysis and interpretation: Buchanan, Martin, Wang, Kim
Manuscript draft: Buchanan, Martin
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Acquisition of funding: Buchanan,
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