

HEALTH-RELATED QUALITY OF LIFE AMONG AFRICAN AMERICANS WITH MULTIPLE SCLEROSIS

Objective: Identify factors associated with health-related quality of life (HRQOL) among African Americans with multiple sclerosis (MS).

Design: A survey cohort was recruited from the Registry of the North American Research Committee On Multiple Sclerosis (NARCOMS) Project. Data were collected from 131 African Americans with MS, with 111 participants providing all data needed for analyses of physical domains and 103 participants providing all data needed for analyses of mental health domains of HRQOL using multiple linear regression models.

Results: Worsening MS symptoms and greater interference of MS symptoms with daily life were associated with significantly lower physical domains of HRQOL. Respondents reporting that their principal care physician who had a greater understanding of how MS symptoms affected their daily lives tended to have significantly higher physical dimensions of HRQOL. A previous diagnosis of depression and agreement that participants were sometimes embarrassed in public due to their MS were associated with significantly lower mental health aspects of HRQOL.

Conclusion: Findings highlight the importance of the positive association between the level of understanding by the principal care physician of how MS symptoms affect the lives of African Americans and their physical dimensions of HRQOL. Physicians treating African Americans with MS need to understand how MS symptoms impact the life of these patients as a key component to providing culturally competent care. (*Ethn Dis.* 2011;21(3):377-384)

Key Words: Multiple Sclerosis, African Americans, Health-related Quality of Life

From the Department of Political Science and Public Administration, Mississippi State University, Mississippi State (RB) and Department of Statistics, Indiana University, Bloomington, Indiana (CH) and Department of Health Care Administration and Health Sciences, Tennessee State University, Nashville (BC).

Address correspondence to Robert J. Buchanan; Department of Political Science and Public Administration, PO Box PC; Mississippi State University; Mississippi State, MS 39762; 662.325.9318; 662.325.2716 (fax); rbuchanan@pspa.msstate.edu

Robert J. Buchanan, PhD; Chunfeng Huang, PhD; Bonnie J. Chakravorty, PhD

INTRODUCTION

Between 3% and 5% of people with multiple sclerosis (MS) in the United States are African American.^{1,2} Weinstock-Guttman et al found that African Americans were diagnosed with MS at a younger age, more likely to have greater disability with increased disease duration, and demonstrated a more rapid and severe cognitive decline.³ In a later study Weinstock-Guttman et al concluded that African Americans with MS have more rapid disease progression than Caucasians with MS, with greater tissue damage and faster lesion volume accumulation possibly explaining this rapid clinical progression.⁴ Other studies observed that African Americans with MS are at risk for a more rapidly disabling disease course, with more disability compared to Caucasians with MS.^{5,6} Marrie et al found that African Americans experienced greater disability associated with MS than Caucasians but failure to adjust for socioeconomic differences overestimates these differences.⁷

The objective of our study was to identify factors affecting the health-related quality of life (HRQOL) of African Americans with MS. Previous studies analyzed HRQOL among peo-

ple with MS, identifying demographic, MS-disease characteristics, and treatments that impact HRQOL. However, no previous study focused on the HRQOL of African Americans with MS. We built on these earlier studies of HRQOL in adults with MS to determine whether there were unique factors associated with the HRQOL among African Americans with MS. Learning more about characteristics associated with better HRQOL among African Americans with MS will facilitate the development of services and programs that address this community's health needs, as well as identify areas for future study.

HEALTH-RELATED QUALITY OF LIFE AND MS

Multiple sclerosis has physical, psychological, and social impacts on the patient,⁸ with the unpredictability and stress of the disease affecting quality of life.⁹ The HRQOL measure reflects a person's total well-being, including measures of social roles, physical health and symptoms, emotional status, psychosocial factors, intellectual function, psychiatric conditions, and self-perceptions of health.⁸⁻¹¹ The measure provides a broader measure of disease burden than physical impairment or disability levels,¹² approximating the World Health Organization's definition of health as including physical, mental and social well-being and not just the absence of disease or infirmity.¹⁰

Demographic Characteristics

Studies show that men with MS have higher HRQOL than women for various dimensions of HRQOL.¹³ Another study found that age was not associated with HRQOL among people with MS.¹⁴ Employed people with MS

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have higher dimensions of HRQOL than those with employment problems or limitations.^{8,13} Forbes et al theorized that those factors contributing to problems with employment may also affect the ability of people with MS to perform daily activities.⁸

Multiple Sclerosis Characteristics

The clinical course of MS can influence HRQOL, with progressive types of MS having a more negative association with HRQOL than relapsing-remitting MS.^{9,15,16} The relationship between the duration of MS and HRQOL is not established, with some studies indicating that HRQOL improves over the course of the disease and other studies finding that disease duration is negatively linked with HRQOL.^{9,15} Earlier studies found that MS-related disabilities are associated with lower HRQOL across many domains.^{16,17}

Care and Treatments

Not having a usual provider of MS care has been associated with worse physical domains of HRQOL, while difficulty accessing mental health care and medical care were associated with lower mental health dimensions of HRQOL.¹⁶ Buchanan et al found that receiving MS care at an MS clinic was associated with better physical dimensions of HRQOL and having a neurologist as the principal care physician was associated with better mental health dimensions of HRQOL among people with MS.¹⁸ Studies of the impact that interferon beta and disease-modifying treatments have on HRQOL in people with MS have been inconclusive, with results ranging from worsening HRQOL, no effect, or significant improvement.^{19,20}

Mental Health

Studies demonstrate a strong relationship between depression or depressive symptoms in people with MS and HRQOL,^{9,15,21} while treatment of de-

pression improves HRQOL.^{22,23} Turpin et al observed that illness intrusiveness in people with MS (defined as the degree that MS interferes with important life domains) was the only MS-specific characteristic in their analyses that was significantly linked with mental health dimensions of HRQOL.²⁴ This literature review identified factors affecting the HRQOL of people with MS, helping to develop a questionnaire administered to African Americans with MS in a telephone interview.

METHODS

We surveyed 131 African Americans with MS for this pilot study, recruited from the Registry of the North American Research Committee On Multiple Sclerosis (NARCOMS) Project.²⁵ However, only 111 participants provided all data needed for analyses of the Physical Component Summary model and 103 participants provided all data needed for analyses of the Mental Component Summary model. The NARCOMS Registry contains 35,000 people with MS who volunteered to participate in data collection and possibly other research projects.²⁶ Participants are assured confidentiality. Estimates place up to 10% of the American MS population in the NARCOMS Registry.²

Survey Process

The Institutional Review Board at Tennessee State University approved this study during April, 2007 and the Office of Research Compliance at Texas A&M University approved the study in November, 2007. The computer-assisted, telephone interview was administered by the Public Policy Research Institute at Texas A&M. In December, 2007 the Mid-South Chapter of the National Multiple Sclerosis Society (NMSS) in Nashville recruited four African Americans with MS to preview the telephone interview process to assess

the clarity and acceptability of survey questions.

The NARCOMS Registry mailed recruitment letters in January, 2008 to all 720 African Americans in the registry. These letters described the purpose of the study and included a toll-free number to call to complete the interview. The letter requested that participants be prepared to tell interviewers their type of MS (with definitions provided), the practice specialties of their physicians, and any MS/disease modifying medications currently used (with a list of these drugs provided). The study design dictated the survey would end when no African American called to be interviewed during a two-week period. The survey ended in February, 2008, with 131 African Americans completing the interview (19% participation rate). Table 1 describes the African Americans with MS included in our regression models.

The Interview Questionnaire

The selection of independent variables was based on the literature review and factors affecting HRQOL identified in previous studies of people with MS, input and questions from MS clinicians with whom the authors have collaborated, and suggestions from national staff and staff at the local chapters of the NMSS. In addition, a draft of the questionnaire was previewed by four African Americans with MS recruited by the Nashville Chapter of the NMSS and two African American students with MS at Tennessee State University, with their input integrated into the final interview instrument.

Demographics and MS Characteristics

The interview included questions on age, sex, marital status, employment, income, and health insurance coverage. Participants were asked about their MS and symptoms, such as type of MS, age when MS symptoms first appeared, and age at MS diagnosis. Interviewers asked participants if their "MS symptoms in

general affect your activities or lifestyle,” with a 0 to 10 scale provided for responses. A response of 0 indicated that MS symptoms had no interference at all and a response of 10 signified “that your MS symptoms prevent you from doing many of your daily activities each day.” Interviewers asked respondents to compare current MS symptoms to MS symptoms experienced one year earlier.

Physician Care

Interviewers asked about the care participants received from physicians, including their principal care physician, defined in the NARCOMS recruitment letter and by the interviewer as the physician “you see most often and who knows you best.” Respondents were asked to identify the practice specialty of their principal care physician. Interviewers asked how well the principal care physician understood how MS symptoms affected the participant’s daily life, with a response of 0 indicating no understanding and a response of 10 indicating complete understanding. Respondents were asked if they went to an MS clinic for the majority of their MS-focused health care.

Mental Health

Interviewers asked participants if they had ever been diagnosed with depression. If diagnosed with depression, interviewers asked if they had received treatment and the type of treatment received. The interview included two questions that Mohr et al found to identify depressive symptoms in people with MS.²⁷ These questions asked if during the past two weeks respondents had: (1) “often been bothered by feeling down, depressed, or hopeless?” and (2) “often been bothered by little interest or pleasure doing things?” Mohr et al found that a positive response to either question could identify almost all MS patients meeting criteria for major depressive disorder.²⁷ We used in our analyses a

positive response to either question to indicate the presence of current depressive symptoms.

Feelings/MS Experiences

The interview collected information from respondents concerning their feelings about having MS, their experiences with the illness, and how they thought MS affected various relationships based on their agreement or disagreement with a number of statements about MS. For example, the interviewers read the statement, “I do not have as good a social life as most people my age because of my MS.”

SF-8 Health Survey

The interview included the SF-8 Health Survey, an 8-item instrument designed to provide a HRQOL profile.^{11,28} The SF-8 HRQOL profile also includes a Physical Component Summary (PCS) and a Mental Component Summary (MCS), with higher scores indicating better health status. Previous studies documented the validity of the SF-8²⁸ and the SF-8 meets standard evaluation criteria for content, construct, and criterion-related validity.¹¹

Multiple Regression Models

Multiple linear regression models were utilized to analyze survey data, with the PCS and the MCS from the SF-8 serving as dependent variables. Other survey characteristics were included as independent variables. Independent variables utilized in these analyses, with coding explained, are presented in Table 2. The results of the PCS model are presented in Table 3 and the results of the MCS model are presented in Table 4.

RESULTS

Physical Component Summary Model

Characteristics of African Americans with MS collected during the interviews

were included in the PCS multiple regression model (see Table 3). The $R^2 = .6218$ indicates that the PCS model has an excellent ability to explain variability of the PCS among the African Americans with MS. Demographic characteristics and the relapsing-remitting course of MS were not significantly associated with physical dimensions of HRQOL among the African Americans. However, African Americans reporting that their MS symptoms had greater interference with their ability to perform daily activities tended to have significantly lower physical dimensions of HRQOL. Similarly, African Americans reporting that their MS symptoms were worse at the time of the interview than one year earlier tended to have significantly lower physical-related HRQOL. Typically, the more strongly survey participants agreed that their social life was not as good as most people their age due to their MS, the lower their PCS scores. There was no significant association between the duration of MS or the presence of current depressive symptoms and the PCS. African Americans reporting that their principal care physician had a greater understanding of how MS symptoms affected their daily lives tended to have significantly higher physical dimensions of HRQOL. However, having a neurologist as principal care physician, being treated at an MS clinic or by a mental health professional, or receiving disease-modifying therapies were not significantly associated with the PCS.

Mental Component Summary Model

Survey characteristics of African Americans with MS were included in the MCS multiple regression model (see Table 4). The $R^2 = .3815$ indicates that the MCS model has good ability to explain variability of the MCS among the African Americans with MS. There were no significant associations between demographic characteristics and the

Table 1. Demographics, MS characteristics and health and support services (N = 111)

Independent Variables	African Americans with MS
Sociodemographics	
Mean age (SD)	51.3 years (10.5)
Female	82.0%
Married	46.0%
Full-time employment	30.6%
Income	
<\$25,000	33.3%
25,000 to 49,999	18.0%
50,000 to 74,999	22.5%
75,000 to 99,999	13.5%
100,000 and over	12.6%
MS/health characteristics	
Relapsing-remitting MS	66.7%
Years with MS, Mean (SD)	14.5 years (10.1)
MS symptoms worse than one year ago	35.1%
MS symptoms affect daily life	
Minimal interference (survey response of 0 to 3)	27.9%
Moderate interference (survey response of 4 to 7)	43.2%
Major interference (survey response of 8 to 10)	28.8%
Received a diagnosis of depression	39.8%
Current depressive symptoms	50.5%
MS and psychosocial characteristics	
Sometimes feel embarrassed in public due to MS	
Strongly disagree	36.9%
Disagree	23.3%
Neither agree or disagree	2.9%
Agree	29.1%
Strongly agree	7.8%
Concerned MS will affect marriage or opportunities for long term relationship	
Strongly disagree	22.3%
Disagree	33.0%
Neither agree or disagree	10.7%
Agree	24.3%
Strongly agree	9.7%
MS affects career advancement	
Strongly disagree	17.5%
Disagree	17.5%
Neither agree or disagree	13.6%
Agree	33.0%
Strongly agree	18.5%
Not as good a social life as other people my age due to MS	
Strongly disagree	26.2%
Disagree	25.2%
Neither agree or disagree	3.9%
Agree	35.0%
Strongly agree	9.7%
Health services	
Neurologist is principal care MD	36.0%
Principal care MD understands how MS symptoms affect life	
Poor understanding (survey response of 0 to 3)	4.5%
Good understanding (survey response of 4 to 7)	21.6%
Excellent understanding (survey response of 8 to 10)	73.9%

MCS. African Americans with a previous diagnosis of depression and agree that participants were sometimes embarrassed in public due to their MS tended to have significantly lower mental dimensions of HRQOL. None of the other MS disease characteristics, MS symptoms, or health and support services included in the MCS model were significantly associated with mental-health dimensions of HRQOL.

DISCUSSION

Having a previous diagnosis of depression and sometimes feeling embarrassed in public due to MS were significantly associated with lower mental health dimensions of HRQOL among African Americans with MS. To facilitate treatment and counseling of these African Americans, future research needs to learn more about public occasions that cause embarrassment. Importantly, African Americans who reported that their principal care physician had greater understanding of how MS symptoms affected their daily lives tended to have significantly higher physical dimensions of HRQOL.

Sensitivity to how MS symptoms affect the daily lives of African Americans with MS should be a key component of culturally competent MS care. Providing culturally competent care

Sensitivity to how multiple sclerosis symptoms affect the daily lives of African Americans with multiple sclerosis should be a key component of culturally competent multiple sclerosis care.

Table 1. Continued

Independent Variables	African Americans with MS
Ability to get MS-focused care in the previous 12 months	
Minimum satisfaction (survey response of 0 to 3)	8.1%
Moderate satisfaction (survey response of 4 to 7)	23.4%
High satisfaction (survey response of 8 to 10)	68.5%
Go to MS clinic for MS care	49.6%
Sought access to a mental health professional in previous 12 months	43.2%
Participates in MS support group	26.2%
Receiving disease modifying medications at time of survey	75.7%
Health-related quality of life	
Physical component summary (N=111)	
Mean (SD)	42.1 (10.7)
Median	42.8
Minimum	17.2
Maximum	67.7
Mental component summary (N=103)	
Mean (SD)	47.4 (10.2)
Median	49.0
Minimum	11.8
Maximum	64.4

includes having knowledge and respect for diverse cultural perspectives, as well as providing care and using appropriate practices for diverse patient groups.²⁹ Cultural competency requires an understanding and respect for the beliefs and priorities of the patients receiving care, including sensitivity to the patients' reality, social organization, and social processes.³⁰ Culturally competent care also is a set of behaviors and attitudes that enable physicians and other providers to effectively treat culturally diverse patients.²⁹

Limitations

This research presents the results of a pilot study that surveyed 131 African Americans with MS, with participants selected from the NARCOMS Registry. The NARCOMS Registry is not a random sample of people with MS but comprises voluntary participants who

Table 2. Independent variables used in the quality of life analyses for African Americans with MS

Independent Variables	Description/coding of Independent Variables
Sociodemographics	
Age	Age, using date of birth and 9/2007
Female	no=0; yes=1
Married	no=0; yes=1
Full-time employment	full-time, no=0; yes=1
Income	5 ascending categories of income
MS/health characteristics	
Relapsing-remitting MS	no=0; yes=1
Years with MS	current age minus age when MS diagnosed
MS symptoms currently worse than one year ago	no=0; yes=1
MS symptoms affect daily life	0 – 10 scale, with 0=no interference; 10=most severe interference*
Current depressive symptomst	no=0; yes=1
Received a diagnosis of depression‡	no=0; yes=1
Sometimes feel embarrassed in public due to MS‡	1 to 5 scale
Concerned MS will affect marriage or long-term relationship	1 to 5 scale
MS affects career advancement	1 to 5 scale
Not as good a social life as most people my age because of my MS	1 to 5 scale
Health and support services	
Neurologist as principal care physician	no = 0; yes = 1 (everyone else=no)
Principal care physician understands how MS symptoms affect life	0 – 10 scale, with 0=no understanding; 10=complete understanding*
Ability to get MS-Focused care past 12 months	0 – 10 scale, with 0=total dissatisfaction; 10=complete satisfaction*
Go to MS clinic for MS care	no=0; yes=1
Sought access to a mental health professional in previous 12 months	no=0; yes=1
Participates in MS support group‡	no=0; yes=1
Receiving disease modifying medications at time of survey	no=0; yes=1

* For the analyses this 0 to 10 scale was collapsed into three groups: 0 to 3 = 1; 4 to 7 = 2; and 8 to 10 = 3.

† This independent variable used only in the Physical Component Summary Model.

‡ This independent variable used only in the Mental Component Summary Model.

Table 3. Factors associated with the physical health dimensions of HRQOL among African Americans with MS

Independent Variables	Coefficient Estimate	Standard Error	P
Demographic characteristics			
Age	-.156	.083	.0636
Female	-2.252	1.994	.2616
Married	-1.026	1.756	.5605
Full-time employment	.049	2.033	.9810
Income	.614	.668	.3601
MS/health characteristics			
Relapsing-remitting MS	2.994	1.866	.1121
Years with MS	.032	.089	.7214
MS symptoms currently worse than one year ago	-5.910	1.666	.0006
MS symptoms affect daily life	-5.575	1.387	.0001
Current depressive symptoms	.812	1.673	.6287
Not as good a social life as other people my age due to MS	-1.756	.645	.0077
Health services			
Neurologist as principal care physician	-1.624	1.783	.3645
Principal care physician understands how MS symptoms affect life	2.954	1.456	.0453
Ability to get MS-focused care in previous 12 months	-.430	1.233	.7283
Go to MS clinic for MS care	-.053	1.488	.9716
Sought access to a mental health professional in past 12 months	.360	1.679	.8305
Receiving disease modifying medications at time of survey	-1.129	1.930	.5600

R² = .6218.

Table 4. Factors associated with the mental health dimensions of HRQOL among African Americans with MS

Independent Variables	Coefficient Estimate	Standard Error	P
Demographic characteristics			
Age	-.110	.104	.2933
Female	-.132	2.650	.9603
Married	-2.210	2.657	.4078
Full-time employment	-3.645	2.749	.1886
Income	.068	.935	.9424
MS/health characteristics			
Relapsing-remitting MS	1.885	2.359	.4264
Years with MS	.219	.115	.0601
MS symptoms affect daily life	-2.552	1.812	.1627
MS symptoms currently worse than one year ago	-1.205	2.135	.5739
Received a diagnosis of depression	-7.101	2.125	.0013
Sometimes feel embarrassed in public due to MS	-1.869	.772	.0176
Concerned MS will affect marriage or long term relationship	-1.248	.870	.1554
Not as good a social life as other people my age due to MS	.513	.965	.5963
MS affects career advancement	.496	1.014	.6260
Health services			
Principal care physician understands how MS symptoms affect life	-.344	1.955	.8609
Ability to get MS-focused care in previous 12 months	2.262	1.632	.1697
Go to MS clinic for MS care	-1.123	1.938	.5639
Sought access to a mental health professional in past 12 months	-2.396	2.041	.2440
Participates in MS support group	.581	2.310	.8019
Receiving disease modifying medications at time of survey	-.091	2.557	.9716

R² = .3815.

may not be representative of the larger MS population in the United States. However, the registry population is large, with estimates of up to 10 percent of the American MS population in the registry.² In addition, registry participants have comparable age at onset of MS symptoms and similar demographic characteristics to people with MS in the Sonya Slifka Longitudinal Multiple Sclerosis Study (which created a representative sample of people with MS) and the National Health Interview Survey.^{1,2}

Given our response low rate of 19%, we wanted to compare African Americans with MS from the registry who participated in our study to African Americans with MS from the registry invited to participate but did not. Participants and non-participants did not significantly differ by age, sex, marital status, time since diagnosis, impaired mobility, bladder or bowel dysfunction, or pain. Non-participants, however, were significantly more likely to have annual incomes below \$15,000 and to have activity limitations due to physical or emotional problems than participants. Non-participants were significantly less likely to experience very good health and to report normal or minimal disability in cognition or spasticity than participants.²⁵

Our survey collected self-reported data, such as the type of MS or practice specialties of physicians. Self-reported patient data can have accuracy problems. For example, do participants know their type of MS or the practice specialty of their physicians? However, we attempted to minimize self-reporting problems by asking in the recruitment letter that participants be prepared to discuss during the interview their type of MS and the practice specialty of their physicians.

Another limitation of our study is the possibility of sample bias due to the low response rate (19%). A possible unrepresentative sample causes concern about the comparability of our cohort of African Americans to other African

Americans with MS. The possibility of an unrepresentative sample in our study limits the inferences and conclusions we can draw from our results and apply to the larger population of African Americans with MS. However, this is a pilot study intended to identify areas for future research into the HRQOL among African Americans with MS, including how health, treatment, social, and cultural factors affect their quality of life.

CONCLUSIONS

Our findings highlight the importance of the positive association between the level of understanding by the principal care physician of how MS symptoms affect the daily lives of African Americans and their physical dimensions of HRQOL. Physicians treating African Americans with MS should understand how MS symptoms impact the daily life of these patients as a key component of providing culturally competent care.

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AUTHOR CONTRIBUTIONS

Design concept of study: Buchanan, Huang, Chakravorty

Acquisition of data: Chakravorty

Data analysis and interpretation: Buchanan, Huang, Chakravorty

Manuscript draft: Buchanan, Huang, Chakravorty

Statistical expertise: Buchanan, Huang

Acquisition of funding: Chakravorty

Administrative: Chakravorty