Experiences of African American Women with Multiple Sclerosis

Alexa Stuifbergen, PhD, RN, FAAN; Heather Becker, PhD; Carolyn Phillips, PhD, RN, ACNP-BC, AOCNP; Shalonda Horton, PhD, RN; Janet Morrison, PhD, RN, MSCN; Francisco Perez, PhD

Background: Despite growing understanding that African American patients may have a more aggressive course of multiple sclerosis (MS) and experience disparities in diagnosis and treatment, fewer studies have examined how African Americans experience MS and its effect on their lives. This study explored the experiences of African American women with MS to inform future research and practice.

Methods: Face-to-face semistructured interviews were conducted with 19 African American women. Inductive content analysis was used to identify major categories and subcategories.

Results: The analyses yielded three major categories: no one could believe I had MS, it is tough living with MS, and you have to keep going. Many women reported that the MS diagnosis was a surprise to them and their doctors because of the common belief that MS is a “Caucasian disease.” For this reason, many women felt their diagnosis had been delayed while their physicians initially focused on other diseases considered more typical in African American individuals. Living with losses related to social and family activities, independence, and employment was especially challenging for them. Faith in God, coming to grips with the diagnosis, and health promotion behaviors were key strategies for dealing with their MS. Women also spoke of pushing forward, working through MS challenges, and taking care of themselves, thus preserving their identity as strong Black women, a culturally important construct in the African American community.

Conclusions: Future research should explore the interactions of culture with coping strategies and the development of useful and valued resources and supports for African American people with MS. *Int J MS Care*. 2021;23:59-65.

Awareness is increasing that multiple sclerosis (MS), typically diagnosed in young to middle-aged White women, occurs in many racial groups. Since 2005, research on African Americans with MS has increased, although it has focused largely on differences between White and Black patients in etiology, brain morphology, and clinical characteristics. African Americans tend to have a more aggressive course of MS and experience more disease burden, although differences between racial groups are attenuated when socioeconomic status is considered. Some studies have found that African American patients with MS were less likely to have been treated by a neurologist specializing in MS or to have received care at an MS clinic. Comorbidity risk was reported as higher for African American patients with MS, which may also contribute to disease burden. African Americans may experience MS differently than Whites because of differences in clinical presentation, genetic underpinnings, and/or sociocultural factors, and the substantial genetic heterogeneity among African American people may contribute to differences in clinical presentation. A few studies have begun to emerge examining the impact of MS on the lives of African Americans diagnosed as having MS. These studies have documented the negative effects of MS on their relationships, employ-
ment, and health-related quality of life.11-14 Many of these studies use surveys or large data sets rather than allowing African Americans with MS to describe their condition and its effect on their lives in their own words. We, therefore, interviewed African Americans with MS about their experiences to inform future research and practice concerning the health of this under-studied group.

Methods

Given the limited existing knowledge about the phenomenon of interest (the experiences of African Americans with MS), we used a qualitative descriptive approach15,16 characterized by minimally structured open-ended questions for data collection and textual analysis using inductive content analysis. Qualitative description analysis methods support the generation of findings that are close to the data, allowing participants’ perspectives and concerns to be directly reflected.16

A convenience sample was recruited from participants in an earlier multisite randomized controlled trial (RCT)18 who indicated their willingness to be contacted for subsequent studies. Inclusion criteria for the RCT included physician-verified MS, 18 to 60 years of age, able to understand and follow study protocols, clinically definite MS for at least 6 months, and concerns about cognitive symptoms. All 34 individuals who self-reported as being African American who participated in the RCT were invited by letter to participate in an in-person interview about their perceptions of living with MS. Those who expressed interest were contacted by research staff to explain the study and arrange the interview, some of whom then verbally consented by phone and completed a written consent form immediately before their interview. The in-person interviews, conducted in the participants’ homes or at mutually agreeable sites, lasted 60 to 90 minutes. Interviewees received a $50 money order by mail after the interview. Ethics approval was obtained from the institutional review board of The University of Texas at Austin.

The study’s recruitment letter and interview questions were first reviewed with an African American woman with MS, whose experiential insights led to slight changes for subsequent studies. Inclusion criteria for the RCT included physician-verified MS, 18 to 60 years of age, able to understand and follow study protocols, clinically definite MS for at least 6 months, and concerns about cognitive symptoms. All 34 individuals who self-reported as being African American who participated in the RCT were invited by letter to participate in an in-person interview about their perceptions of living with MS. Those who expressed interest were contacted by research staff to explain the study and arrange the interview, some of whom then verbally consented by phone and completed a written consent form immediately before their interview. The in-person interviews, conducted in the participants’ homes or at mutually agreeable sites, lasted 60 to 90 minutes. Interviewees received a $50 money order by mail after the interview. Ethics approval was obtained from the institutional review board of The University of Texas at Austin.

The study’s recruitment letter and interview questions were first reviewed with an African American woman with MS, whose experiential insights led to slight changes for subsequent studies. The final semistructured interview guide, based on a review of the literature and our team’s earlier research with persons with MS, included broad, open-ended questions about what it was like to live with MS, the greatest challenges of living with MS, and how participants addressed those challenges. Open-ended probes (eg, “Can you tell me more about that?”) were used to elicit more details. Table 1 lists the questions that generated the responses described later herein.

The study’s qualitative descriptive methods included inductive content analysis15 and constant comparison.17 The audio recordings of the interviews were transcribed verbatim by a professional service, checked for accuracy, and entered into qualitative data analysis software (NVivo; QSR International). Two researchers (C.P. and J.M.) independently read, reread, and extracted meaningful data from the transcribed narratives. They then met to discuss codes from each transcript and began to generate a list of categories. Decisions about categorization were recorded as an audit trail. Next, discussion with our larger team as well as secondary analysis by the primary investigator (A.S.) led to final categories and higher-order headings. Categories were named using content-characteristic words. To enhance cultural sensitivity and trustworthiness, the final analysis included transcript review and discussion of general findings with a doctorate-prepared African American public health nurse (S.H.).

Results

Twenty-one individuals expressed interest in participating, and 19 women completed the study process. The women (average age, 48 years; average education, 15 years) were diagnosed at a mean age of 35.8 (range, 22-48) years (Table 2). Our qualitative findings yielded three major categories and related subcategories. These are presented in the following subsections with illustrative quotations.

No One Could Believe I Had MS

This category included responses from all the participants about the experiences leading up to their eventual diagnosis of MS. Findings in this category included their own difficulty believing that they had MS (one described it as “a White people’s disease”) and perceptions that physicians were slow to consider MS as a plausible diagnosis. Initial symptoms reflected the disease’s variability: several participants experienced optic neuritis, weakness, fatigue, numbness, and a pattern of milder symptoms that subsided and then returned. As one woman stated, “You just explain it away, especially as a Black woman … we’re used to just doing above and beyond where we need to do and so that’s what I did.” Friends (often nurses) and family played important roles in convincing these women to seek professional care and often helped them navigate the system when they were dismissed by health care providers.

Many felt that their diagnosis was delayed because doctors initially believed they had “other more common diseases in Blacks.” These conditions included lupus, sickle cell disease, arthritis, fatigue, stress, Parkinson dis-

Table 1. Interview questions

1. Can you tell me what it is like for you to live with MS?
2. What have been your greatest challenges living with MS?
3. Can you tell me how you have dealt with challenges related to living with MS?
4. What suggestions would you have for others like yourself who have problems with their MS?

Abbreviation: MS, multiple sclerosis.
It Is Hard to Function with MS Symptoms

Participants described many symptoms characteristic of MS (fatigue, pain, weakness, and difficulties with coordination, balance, and cognition) primarily in terms of how they affected functional activities. Weakness, for example, made it impossible to lift pans on the stove; fatigue and coordination issues led to falls. When specifically asked about cognitive challenges related to MS, many mentioned memory concerns as well as problems with attention and concentration, numeracy, and processing speed: “I just can’t focus”; “not ... able to think like I used to think.” To function with these symptoms, participants included avoiding multitasking, following a routine and being very organized, and using written and phone reminders.

Participants also found nonvisible symptoms difficult: “My greatest challenge … is the fact that really for most of the time, I don’t have any visible symptoms … Unless people know me, they are like, ‘what’s wrong with you?’ They just see me as the quirky lazy individual.” Another said that “people always tell me, ‘oh, you don’t even look like you’re sick. You look like there’s nothing wrong with you.’ … But you know, they don’t know … because they can’t see it.” The women spoke most about the variability of MS symptoms in their personal experiences: “It’s different every day … I guess it’s just a surprise every day.”

I Am Angry and Afraid

Most of the women described emotional aspects of living with MS. Frustration and anger were common, as was fear about the future: “Living with MS, the best word is frustration … and just being mad at myself. Don’t be lazy. Just push through.” One participant, who had worked in a rehabilitation setting, feared getting worse and knew that her mother would not be able to care for her if she became bedbound: “I pray God he don’t put me there. I pray that he takes me first before that ever happens.”

So Many Losses

This subcategory included women’s responses about living with painful losses, primarily those related to independence, social and family activities, and employment. The women were able to work through some but not all of the losses related to living with MS.

Table 2. Demographic characteristics of sample (N = 19)

| Characteristic            | Value                   |
|---------------------------|-------------------------|
| Female sex                | 19 (100)                |
| Age group                 |                         |
| 20-35 y                   | 1 (5)                   |
| 36-50 y                   | 10 (53)                 |
| 51-60 y                   | 8 (42)                  |
| Age, y                    | 46.7 ± 7.80 [34-60]     |
| Education                 |                         |
| High school graduate      | 4 (21)                  |
| Associate degree          | 8 (42)                  |
| Bachelor’s degree         | 4 (21)                  |
| Graduate degree           | 3 (16)                  |
| Marital status            |                         |
| Married                   | 10 (53)                 |
| Unmarried                 | 9 (47)                  |
| Employment status         |                         |
| Employed (full or part-time) | 7 (37)              |
| Unemployed-disability     | 7 (37)                  |
| Full-time homemaker and part-time at another job | 1 (5) |
| Fired/laid off            | 3 (16)                  |
| Full-time student         | 1 (5)                   |
| Time since diagnosis, y   | 10.7 ± 6.70 [2-24]      |
| Multiple sclerosis type   |                         |
| Benign sensory            | 1 (5)                   |
| Relapsing-remitting       | 12 (63)                 |
| Secondary progressive     | 2 (11)                  |
| Progressive-relapsing     | 1 (5)                   |
| Unable to choose one/don’t know | 3 (16)       |
| Expanded Disability Status Scale total score | 5.1 ± 2.05 [1.0-8.0]  |

Note: Values are given as number (percentage) or mean ± SD [range].

ease, and stroke. As one woman said, “I went through so much hell to be diagnosed with this … you’re testing me for all these things that are ‘Black diseases.’”

Participants who knew of MS before their diagnosis were surprised that they could have it: “I’ve always been told it’s really kind of a Caucasian disease and truly, that’s not true.” “I’m going along this MS journey and people are still telling me … ‘Black people don’t have that.’” “If there is anything that I think ... may be misunderstood about the Black culture and MS, I would say … people’s horizons need to be expanded. That this is an ‘every people’s disease’ now.”

It Is Tough Living with MS

This major category of responses included experiences that these women found challenging in living with their MS. This category included comments about the difficulties living with nonvisible symptoms and their effect on functional activities; the emotional effect of living with MS; the multiple losses experienced in independence, relationships, and employment; and how difficult it was to access care.

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Independence. Women emphasized their desire to remain as independent as possible, difficulties in accepting help, not wanting to depend on others, and fears about progression and needing more assistance. One exemplar was a woman in her late 30s diagnosed as having MS 5 years earlier: “The challenge I have now to do those things and be able to maintain my dignity and not get stressed out about everything … having help, it means that they’re demeaning me. They’re treating me like an invalid and I don’t like to be treated that way … my mom even helps me and … she’s my mother … I’m supposed to be helping her but she’s helping me. … And I’ve always been a strong person. … My independence has just blown out the window.”

Social and Family Activities. Responses from these women emphasized how disease symptoms and a lack of certainty about how one might feel or function on any particular day limited spontaneity. The women often struggled with family members and coworkers who could not understand why they were unable to do activities that others expected. It was especially difficult when close family members (spouses, parents, siblings) seemed to minimize the experience of MS. As one woman described her experience: “Yeah, nobody in my family think I’m … they think the prayer done worked.” Another said, “They can disbelieve. They don’t think that it’s really as serious as it is, some of them, because they don’t see me down like this … they feel like, well, I’m faking it.”

Employment Losses. As seen in Table 2, seven of the participants were employed. Only four of the participants, diagnosed for 4 to 11 years, were able to continue full-time work without major difficulty. Others struggled with the impact of no longer being able to work or of being able to work only part-time. Employment was important to these women, not only to provide for those who depended on them but also to use their knowledge and skills acquired through education. Some saw employment as a way to compete with the challenges of MS. This condition didn’t have me. I had it. … My goal is to get back to work in some capacity. … I didn’t graduate from college to sit at home and watch junk TV like what I do right now.” The women described “fighting to stay employed,” negative effects of work on their symptoms, and difficulties with cognitive aspects of their employment as their disease progressed.

One woman in her 30s who had been fired from a job stated, “I’m fighting to stay employed. … I don’t want to be on disability. … I’m way too young. No, I don’t want to sit at home.” Participants were reluctant to disclose their experiences to their employers because, as one said, “I feel like they’ll use it against me.” Women tried to limit their time off from work, gave limited explanations to supervisors, and sought accommodations to maintain employment.

Several participants described the need to quit work due to MS symptoms’ negative effects: “I had to quit. The MS and then the stress of the job was becoming too much. Regardless of how I felt, I always went to work. Even if I was moving slow, my body was hurting. I still went to work.” “You know, you work and then you get home late … you’re tired and frustrated and then exacerbation starts and then it goes back into a circle because you’re trying to get better so you can go to work, but you’re not feeling well … it was just like a circle.”

Access to Care

Eleven participants commented on challenges accessing care. Several spoke of the difficulty in finding a “good neurologist” who understood MS and of difficulties when neurologists were no longer able to see them due to changes in insurance plans or a move. It was also difficult to get appointments with neurologists, especially for those who were employed and had less flexible schedules. Their comments about the importance of their health care provider relationship reaffirms the finding of Buchanan et al that African American patients who reported that their principal care physician understood how MS symptoms affected their daily lives reported higher physical quality of life.

You Have to Keep Going

This major category included responses from all the participants describing many strategies for dealing with the everyday challenges of living with MS. They stressed that it was a “personal thing” and that being a “Black woman” influenced the way they managed their lives with MS. Subcategories included taking care of yourself; finding others to support you; accepting “it,” stay positive, and look to God; and culture makes a difference.

Taking Care of Yourself

Almost all the participants (n = 18) spoke about self-initiated strategies to promote their health and manage their MS and about what they would recommend to someone newly diagnosed. It was, they stressed, “really a personal thing”; each person with MS must determine
what personally worked. Seeking information and educating oneself about MS were important, as was how to best take care of oneself. Practicing health and wellness behaviors (exercise, stress management, rest, cognitive stimulation) were emphasized. The need to set priorities and say “no” when necessary was highlighted: “You’ve got to pre-plan and you’ve got to say ‘no.’… And although you want to do a whole lot, you have to realize that you can’t. You can’t, not and be a functioning human being.” As another woman realized, “I’m doing more harm than help in pushing through.”

**Finding Others to Support You**

Seeking and receiving emotional support were important. Sources of such support included family and friends, the MS community and support groups, and participants’ church communities. One participant suggested that those with MS should “let people around you know about what’s going on so they can help guide you.” Another referred to “getting over myself, my pride, asking for help and just making others aware … don’t be ashamed or too proud to ask for help. Acknowledge it. It’s better to go ahead and state it before it occurs than to just try and fake it.”

Family was broadly defined and included parents, children, husbands, and ex-husbands. Family members who educated themselves about MS were perceived as more supportive and more able to provide relevant assistance. One woman said that she would advise someone newly diagnosed to “get a good support system.” Others with MS were thought helpful: “We can understand each other, where the average person does not, they really don’t.” One woman described her response when she was invited to join a specifically African American support group: “I was actually invited to be in a support group … but it’s all Black people. No, not for me. For me it doesn’t make any difference to me … I don’t see the color thing. Yes, I see color, but … it’s the person … I just want to join a supporting group.”

**Accept “It,” Stay Positive, and Look to God**

Approximately half of the women said that acceptance and acknowledgment of living with MS was important: “Once you get used to it you kind of figure your way to work through and work with it.” “I just accept … and keep on moving.” “I mean, trying to step into it and make it change isn’t going to work, so just step back, step to the side and go a different way.” As one participant noted, “I have to realize my life is not over. Because I can’t do certain things as before, that doesn’t mean I can’t enjoy life.” Thirteen of the women (including some who spoke of acceptance) stressed the need to be determined and to keep pushing in daily life: “I just try not to think about it … I’ve got to push forward.” “Just because you are diagnosed with it don’t mean you’re receiving it.” “That’s how I cope, just keep pushing.”

The importance of keeping a positive attitude (“Just think positive. Try to focus on the good and then not the negative.”) was emphasized by almost three-fourths of the participants as an important coping strategy that they would share with someone newly diagnosed: “I think to have a positive outlook. Even if you’re in pain … be positive about everything.” As another said, “That positivity will make all the difference, and if you let it bother you, it will. … Stop and step back and say to yourself, ‘this is not going to change’ … and find a different path.” One suggested, “Every day it’s like be thankful for the things you can do.”

Almost all the women described faith in God and prayer as important for managing the challenges of MS: “So the only one who I believe totally understands is God. … I rest my hope in that, you know, he’s not going to give me more than I can bear.” “I know the Lord. He doesn’t put on you more than you can bear without an escape hatch. So, MS has slowed me down a whole lot, but I’m not going to let it put me under.”

Several women turned to God with the belief that they would be healed from MS: “I truly believe in God … I am going to be healed and I’m going to be healed on this side. And I believe it’s going to happen. When, I don’t know. … So, I’m going to keep on living my life—however I have to live it—until that healing comes.” Another said that “[i]t was never God’s original purpose for us to get sick and be like this. So, this is not the way it’s always going to be. There’s something better; it’s going to be better. … I keep remembering that the Bible says there’s going to be a time when nobody is going to say, ‘I’m sick.’ And so, I’m not going to be sick and I just keep my eyes focused on what’s going to happen in the future and not what’s happening with me right now and I say this is just temporary.”

Others believed that God had a plan for them and that they were learning from living with MS: “I believe in the power of God and prayer and everything … because there’s some days when that’s all you can do is just get on your knees and pray.” “I believe in God. And I know that God does not want anything ill for me. …
Maybe he gave me MS so that I can give other people the opportunity to help me.” “God gives me strength. … Nothing’s in our control and … he’s teaching me that I’m not in control.”

Culture Makes a Difference

This subcategory included responses where women spoke of how their culture (being African American or being raised “in the country”) influenced their way of managing their MS. As one exemplar said, “I think it’s women—not even—but its Black women really … that Black female thing of just push through it all.” “We were raised in the country … anything you want out there you work for it … you don’t got to take it from nobody … you just work for it. … And that’s why I don’t ask nobody for nothing.”

Other comments reflected participants’ thoughts that being African American influenced their particular approach or response to living with MS. One referred to the difficulty of asking others for help: “It’s something that’s ingrained in the culture. I don’t know, some deep-rooted pride I was like, ‘no, ask for help.’ There’s nothing wrong with that. It’s worse if you just suffer quietly.” Another stated that “a lot of African Americans think you can go to the church and pray this away. They mean well, but sometimes they just don’t give you the right advice … even had people tell me that if you have enough faith in God you can just not—don’t claim that disease.”

Discussion

In this study, African American women with MS provided rich detail about their experiences of living with MS. Many of their responses were similar to those in studies with White samples, but they also described how their cultural and racial/ethnic background influenced their experience of diagnosis, the challenges they faced, and their strategies for self-management.

Many participants felt that health care providers were reluctant to consider MS as a diagnosis because they were African American, and several admitted that they were also surprised that Blacks could have MS. Their experience with delays in diagnosis is consistent with the report by Dong et al of delayed diagnosis leading to worse outcomes for African American patients. In addition, given the presumed rarity of MS in the African American population, the present participants tended to encounter skepticism and lack of awareness and understanding from friends and families who knew little about MS and found it hard to believe that a Black person could have it.

Consistent with the findings of Chakravorty et al, living with losses related to independence and employment was especially challenging for these women. The idea of the strong, resilient Black woman has been glorified in Black communities and can either serve as a positive coping mechanism or create stress that affects health behaviors and mental health. Participants spoke of pushing forward, working through MS challenges, and taking care of themselves—all consistent with the strong Black woman’s attributes. They found it hard to request help, and loss of independence was particularly painful. The women said that they sucked up and kept going, pushed forward, and didn’t give up. Although loss or limitations in employment were financially difficult, that difficulty was all the greater because many had struggled hard to acquire a college education and a job that they were proud of and that enabled them to support others. Many tried to keep working, and some did not tell supervisors or coworkers about their condition, despite difficulties managing their symptoms. Their concerns about the impact of MS on employment are well founded; non-Hispanic Black individuals with MS are significantly less likely to be employed than their White counterparts. Moreover, Wang et al found that employment status was one of the strongest correlates of fatigue, depression, and anxiety among African Americans.

Faith in God and spirituality were important for participants’ MS self-management. For several of the

PRACTICE POINTS

• African American women (mean age, 46.7 years) felt that health care providers were reluctant to consider MS as a diagnosis; in addition, they tended to encounter skepticism and lack of awareness and understanding from friends and families.

• Spirituality and faith in God were important ways in which many of the women in this study coped with their MS, although they varied in what faith in God meant in the context of their health.

• Maintaining employment (even part-time) was especially important, not only to provide financially but also to allow use of knowledge and skills acquired through a hard-sought education.
women, faith seemed to be the foundation of their lives; it permeated their lives and gave them hope. One participant said that she did not know what would happen without her faith, and several asserted that they were able to face challenges related to having MS because the Lord “don’t put on you more than you can bear.” Such spiritual coping is not unusual in those with serious illness. However, some women in this sample also described a strong belief that with prayer and faith, God would take MS away. Others felt that sometimes members of their faith or cultural community were less supportive because they expected them to be healed by prayer. Although the women did not mention it, in the African American faith community PUSH is an acronym for “pray until something happens.” Future research might explore the relationship between the cultural construct of the strong Black woman “pushing through” and faith.

Although all these women identified themselves as African American, we do not want to imply that they all had the same experience. Individual differences are clearly present within racial and ethnic groups with this disease, which manifests itself differently in each individual. This study’s convenience sample was small, recruited from African Americans who had participated in a cognitive rehabilitation intervention study. This well-educated selected sample’s experiences and perceptions may not reflect those of people diagnosed more recently, people with more limited resources, males, people with more severe or progressive MS, or people living in different geographic locations; these limitations should be considered when interpreting the findings.

Findings from this exploratory study can begin to inform researchers, health care providers, and others with MS about the unique experiences of African American people living with MS. Future research should explore the interactions of culture with coping strategies and the development of useful and valued resources and supports for them.

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