

The Lived Experiences of Adults with Multiple Sclerosis

KAYLA K. HAUBRICK, MPH; EMILY A. GADBOIS, PhD; SUSAN E. CAMPBELL, MA; JESSICA YOUNG, MSW;
TINGTING ZHANG, MD, PhD; SYED A. RIZVI, MD; THERESA I. SHIREMAN, PhD; RENEE R. SHIELD, PhD

ABSTRACT

Multiple sclerosis (MS), a chronic, often disabling, nervous system disease, affects over 2.3 million people worldwide. This research examined the lived experiences of 46 community-dwelling adults with MS. We conducted five focus groups that covered topics such as diagnosis, decision-making regarding MS treatment, learning about and paying for assistance, and unmet needs. Focus group transcripts were qualitatively analyzed to identify overarching themes. Participants described how MS affects both current and future physical and financial security, how they often feel unheard or misunderstood by loved ones and healthcare providers, and how MS support organizations provide a vital collaborative and compassionate environment. Our findings reflect the importance of MS support organizations, and the incorporation of social workers in MS care teams, as they can foster communication and empathy between parties, provide psychosocial treatment, and link patients to needed services.

KEYWORDS: qualitative research, multiple sclerosis (MS), lived experiences, social support, communication

BACKGROUND

Multiple sclerosis (MS) is a chronic, often disabling, neurological disease with an onset typically between ages 20 and 40.¹⁻⁴ Although disease modifying therapies (DMTs) help prevent relapses, no cure is currently available.⁵⁻⁷ As a result, those who would ordinarily be in good health could find themselves physically impaired and dependent upon others.⁸ Symptoms such as unpredictable fatigue, reduced mobility, pain, cognitive dysfunction, incontinence, and depression limit employment, performing household chores, and completing activities of daily living.^{4,5,9,10,11} Research to capture the lived experiences of people with MS is imperative for greater understanding.

Existing research on the lived experiences of people with MS come from small qualitative samples,^{5,12} with few male participants,^{2,8,11,13} which reflect health care such as in Iran, Jordan, Sweden, Norway, and the United Kingdom,^{4,5,8,12-16} and are not always current.^{2,8,11,14,17}

Our focus group research among individuals living with MS updates the current literature as it showcases a diversity of experiences and illuminates how MS impacts daily life.^{18,19} Our findings should be of particular interest to social workers, families, and other health care providers, highlighting how those with MS struggle with their unmet needs and require friend and family support. These findings will hopefully lead to enhanced communication to improve services.

METHODS

We conducted five focus groups with a total of 46 community-dwelling adults living with MS in Rhode Island between May and October 2017. We collaborated with a local MS support organization and described the study to members who then let us know if they wished to participate. To be eligible, individuals needed to be 18 or older and have an MS diagnosis.

During the focus groups, we asked how participants received their diagnosis, made decisions about MS treatments, learned about and paid for assistance, and identified their unmet needs. Focus groups lasted 60–90 minutes and were held in a private room at the MS support organization. The study was approved by the affiliated Institutional Review Board, and written informed consent was obtained from each participant. Participants received lunch and a \$40 gift card.

Focus groups were audio recorded and professionally transcribed. Transcripts were analyzed by our team using established standards of qualitative research.²⁰⁻²³ An initial coding scheme was developed to reflect the interview guide, and new codes were iteratively added to account for new and unexpected responses.

Four team members individually coded each transcript. Meetings were held to reconcile codes, refine the coding scheme, and discuss preliminary themes. Team decisions were kept in an audit trail, which tracked the team's developing analysis.^{21,24-27}

Our data were coded and organized via the qualitative software package NVivo. After identifying our themes, we returned to the community center and "member checked" our findings to ensure that data accurately reflected participants' experiences and were complete.²¹

RESULTS

Of the 46 who participated, 75.6% were female. Nineteen participants reported years since diagnosis, which ranged from 2 to 39 years, with an average of 17.2 years. A wide range of fluctuating disease severity was represented: one had difficulty with speaking, and two with writing. Only one reported maintaining full-time employment. Some participants required wheelchairs, some used canes, walkers, or other assistive devices, and some needed no mobile assistance. Participants described a range in assistance with daily living, including some who did not require services.

We elicited the following themes described below. Additional quotes representing these themes are found in **Table 1**, see appendix.

Theme 1. Participants described how MS symptoms complicate daily life by causing physical and financial insecurity.

MS symptoms were reported to cause hardship by making work and daily tasks progressively difficult. Although each participant described a unique set of symptoms, they emphasized that MS had decreased their energy level and mobility, negatively impacting their ability to care for themselves and family members. Low energy and mobility appeared especially pronounced during hot weather, accompanied by extreme fatigue that made it hard to move their limbs. Common struggles included dressing, meal preparation, and household chores that caused them to ask family or friends for assistance or pay others to carry out tasks. Participants also noted that MS caused secondary and sometimes unpredictable problems such as, depression, anxiety, gastroparesis, irritable bowel syndrome, further increasing burden and disability. While participants reported receiving subspecialty care for these issues, many voiced concerns around inter-departmental coordination and communication related to their medical care.

As their disease worsens, participants said they would rely more on health professionals, friends, and family for support. However, they said their health providers were not always adequately informed or attentively listening, as detailed below.

Theme 2. Individuals reported that health professionals need to be more active learners and listeners.

From participants' perspectives, the heterogeneity of their symptoms baffled healthcare providers. Participants recounted initially receiving an incorrect diagnosis based on their symptoms. One shared, "For years, I kept being told that my urine problem was, 'You're overweight. Lose weight and you'll be able to hold your bladder more.'" Participants said that diagnosing MS subtypes was guesswork. One man explained: "[The doctor] said, 'worst case scenario is you have to try them all...I'll tell you what might help and you can try that.'"

Participants suggested how health professionals could improve their care. One recommended MS-specific classes for general practitioners, while group members agreed with another who emphasized the importance of providing affirmative care: "If doctors understood that worry is one of the worst additives to the condition, and to help us to relax as we go through this, that would be good."

Like health professionals, friends and family were also said to be perplexed about their struggles, as seen below.

Theme 3. Participants noted their relationships were strained due to lack of shared MS experience.

While participants said social networks helped alleviate burden, they also described strained relationships. A popular sentiment was, "You don't really get it unless you have it." Since symptoms fluctuate, are unpredictable and not always outwardly visible, participants said loved ones struggled to understand why they could no longer keep up. As a result, some loved ones reportedly refused to help when asked. One man described, "You don't look like you have a problem. And they almost, like, they think you're faking, [multiple participants agree]."

Unlike reports of feeling doubted and misunderstood, which were pervasive, only female participants reported feeling stigmatized and abandoned because of their diagnosis. However, individuals were not all explicitly asked to comment. One woman revealed: "I have lost my entire family, four years ago, when I was diagnosed, they flat out told me they don't, uh, they do not believe me." Another woman, agreed: "I've become a pariah to the majority of people that I knew before."

Participants unanimously valued social engagement to cope with the disease. While health professionals and loved ones were said to not always offer support, individuals said they found assistance and friendship at MS support groups in contrast.

Theme 4. Individuals described collaboration and understanding as benefits to forming friendships within the MS community.

New ties within the MS community were described as highly beneficial. Participants reported liking the collaboration and support they received and appreciated learning tools for adapting to life with MS from each other. Their closeness was reflected by one man: "It's a community; we've all become family; you know, I like to say that MS is the worst best thing that's ever happened to me because I've met the best people through coming here." Another credited the group with saving her life through its support and resources.

Others noted improvements in their physical condition and social lives since attending the MS center. Despite these uplifting accounts, participants also confessed their fears for the future.

Theme 5. Anticipating increased disability over time, participants said they worried about future physical and financial insecurity.

Despite currently receiving treatment from neurologists and having health insurance, participants acknowledged the future would be difficult as symptoms increased. In valuing their independence, they worried that advancing disability would threaten it. Fears of reduced mobility included losing the ability to drive, traveling with loved ones, or walking children down the aisle.

Some were distressed that they did not have nearby relatives to help with their care. One woman commented: *“In terms of dressing myself, cooking meals and things like that, I do that myself. My big concern is what happens when I can no longer do that because I don’t have family local.”*

Anticipating worsening symptoms and inflating MS-related healthcare costs, they expressed fears about financial insecurity. Living with MS had already drained savings, as most lost the ability to hold full-time employment. One single mother shared: *“While I was waiting to get on disability, it took a long time. So, what did my daughter and I live on, my savings. So, things have been depleted, bankruptcies have been filed, I mean, what is going to happen to me?”*

Others considered more fortunate said they worried that challenges to employment and health insurance could lead to financial turmoil. Participants acknowledged that they could be fired, thereby losing insurance through their employers. They also feared periodic changes in coverage that may no longer cover their expensive treatments. Due to their young age, many participants failed to qualify for Medicare, which amplified these financial concerns. Those who could reported saving money: *“Right now, I’m comfortable, but ...I got to keep saving, saving, saving, in anticipation of possibly needing help at home.”*

The reports above illuminate just a few of the daily problems those with MS face.

DISCUSSION

We conducted focus groups to better understand the daily challenges faced by those with MS. The five resulting themes are largely consistent with previous research. Participants described the negative impact of MS on daily function,^{4,5,11} health providers’ shortcomings,^{5,11} altered relationships with friends and family,^{14,16} numerous benefits of attending an MS support organization (e.g., social support, learned coping skills, reduced anxiety, improved quality of life),^{16,28} and fear of an uncertain future as symptoms progress (e.g., psychosocial symptoms, social abandonment).^{4,5,9,10,16}

However, our research differed from previous findings in nuanced ways. In our sample, males and females expressed equal frustration by their inability to perform housework and hold employment.¹¹ There were fewer reports of disrespect

and insensitive remarks by healthcare workers.^{5,11} Participants said they minimized their requests to avoid burdening loved ones and reported that they preferred accomplishing tasks themselves, as opposed to other research where individuals accentuated their disability to increase assistance.¹⁰ Our participants did not describe concealing MS status to avoid stigma,^{2,14} but this topic was not explicitly asked during our focus groups. Participants indicated they focused on obtaining needed services and were less concerned with avoiding wheelchairs and other supports that could reveal their illness to others, unlike prior research.² Instead, participants freely discussed their use of mobility supports. Lastly, in addition to concerns around worsening disability, our participants were equally concerned that disease progression would divert their savings to healthcare and home services, leaving them with little for living expenses.

Participants’ accounts highlight the clinical importance of supportive social networks and informed healthcare providers. For instance, current efforts to link MS clients to needed healthcare and home services are considered inadequate. Therefore, social workers ought to be included in health care teams to help identify and match community and social services and resources with MS clients. Increasing involvement from friends or family members would likely foster increased understanding and empathy. More support organizations should be constructed that help social workers link clients to pertinent resources. Lastly, social workers should utilize cognitive behavioral therapy (CBT) to improve interpersonal communication with care team members,²⁹ and mindfulness-based cognitive therapy (MBCT) to treat the psychosocial needs of those with MS.^{30,31}

Strengths of this study include the robust sample size by qualitative research standards, the inclusion of men and a variety of MS subtypes, and the use of focus groups. By including various MS subtypes and males, who account for 26% of all cases and are usually diagnosed later in life with more severe symptoms than females,^{3,8,14,32} we were able to capture a wide range of disability and dependency. The focus group format allowed participants to relate to one another, and elicit varied viewpoints, opinions, and feelings, including estimating the amount of consensus and the range of opinion among them.

Certain limitations must also be noted. Results may not be generalizable to other MS populations. Since the focus groups took place at a support center, those with greater mobility impairment may have been excluded. Participants were linked to neurological (and other specialty) care and frequented the same MS support organization. Therefore, quality of health may have been overestimated and stress and burden may have been underestimated, as they were socially engaged and informed about MS services. Since participants knew each other, sharing may have been facilitated as well as inhibited. While group leaders perceived

that participants expressed opinions candidly, participants may have felt disinclined to raise new or offer discrepant opinions from those of the group. Also, since focus groups took place in Rhode Island, findings reflect healthcare and support services that may not be generalizable to other locations. Since the focus groups took place prior to the COVID-19 pandemic (when video conferencing became ubiquitous), future research should examine how online support groups can advance camaraderie and assistance.

Qualitative research such as this provides an essential look into individual frustration and loneliness of life with MS and the importance of social support. Our sample was unique in that everyone had access to an MS support center for resources and socialization. These facilities are out of reach for many with MS. Social workers and healthcare providers can keep these individuals from having to navigate painful symptoms and mounting bills by themselves. Stigmatizing those with chronic disease compounds their burden and discourages them from seeking needed treatment and services. Health professionals, friends, and family must, therefore, work together to create an encouraging environment by active listening to learn their specific needs and to ensure these needs are met.

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Authors

Kayla K. Haubrick, MPH, Brown University, Center for Gerontology and Healthcare Research.

Emily A. Gadbois, PhD, Brown University, Center for Gerontology and Healthcare Research.

Susan E. Campbell, MA, Brown University, Center for Gerontology and Healthcare Research.

Jessica Young, MSW, Rhode Island Hospital, Multiple Sclerosis Center.

Tingting Zhang, MD, PhD, Brown University, Center for Gerontology and Healthcare Research.

Syed A. Rizvi, MD, Rhode Island Hospital, Multiple Sclerosis Center & Brown University Warren Alpert Medical School, Neurology.

Theresa I. Shireman, PhD, Brown University, Center for Gerontology and Healthcare Research.

Renee R. Shield, PhD, Brown University, Center for Gerontology and Healthcare Research.

Disclosures

The authors report no conflicts of interest.

Correspondence

Kayla K. Haubrick

Rhode Island Hospital, Department of Psychiatry

167 Point Street, Suite 161

Providence RI, 02903, USA

401-793-8815

Fax 401-793-8851

kayla_haubrick@alumni.brown.edu; khaubrick@lifespan.org