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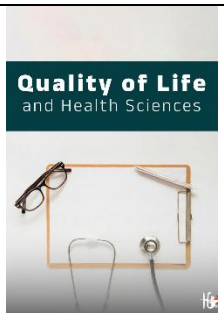

Experiences of Fatigue, Emotional Distress, and Daily Functioning Among Patients With Multiple Sclerosis: A Qualitative Study of Health-Related Quality of Life

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A B S T R A C T

Objective: This study aimed to explore the lived experiences of fatigue, emotional distress, and daily functioning among patients with multiple sclerosis in Canada and to understand how these experiences shape their health-related quality of life.

Methods and Materials: This qualitative phenomenological study was conducted among 26 adult patients with a confirmed diagnosis of multiple sclerosis who were recruited from neurology clinics, community-based multiple sclerosis organizations, and patient support groups in Toronto, Ontario, Canada. Participants were selected through purposeful sampling with maximum variation in age, gender, disease duration, disease type, occupational status, and functional limitation. Data were collected using a demographic and clinical information form, semi-structured individual interviews, audio recordings, and researcher field notes. Interviews focused on patients' experiences of fatigue, emotional distress, functional limitations, coping strategies, social participation, family and occupational roles, and perceived changes in health-related quality of life. Data collection continued until thematic saturation was achieved. Interviews were transcribed verbatim and analyzed using inductive thematic analysis. Credibility and trustworthiness were strengthened through peer debriefing, reflexive memo writing, comparison of coding decisions, an audit trail, and participant feedback on interpreted themes.

Findings: Thematic analysis revealed six major themes: fatigue as a dominant and unpredictable burden, emotional distress and psychological vulnerability, disruption of daily functioning and role performance, coping and reconstruction of normal life, social understanding and stigma, and health-related quality of life as a balance between limitation and control. Fatigue emerged as the most pervasive experience and affected physical activity, cognitive functioning, emotional regulation, employment, and social participation. Emotional distress was mainly associated with anxiety about progression, grief for the previous self, fear of dependency, irritability, and uncertainty about the future. Daily functioning was disrupted through limitations in work, household tasks, mobility, family roles, and social engagement. Protective factors included pacing, acceptance, social support, accessibility, and preservation of meaningful activities.

Conclusion: Health-related quality of life among patients with multiple sclerosis is shaped by the dynamic interaction of fatigue, emotional distress, functional limitation, coping capacity, and social context. Patient-centered care should address both visible and invisible symptoms and support autonomy, emotional balance, meaningful participation, and daily functioning.

Keywords: *Multiple sclerosis; fatigue; emotional distress; daily functioning; health-related quality of life; qualitative study; lived experience.*

1. Introduction

Multiple sclerosis is a chronic, immune-mediated, and potentially disabling neurological condition that affects the central nervous system and produces a wide range of sensory, motor, cognitive, emotional, and functional consequences. Although the disease is commonly described through clinical markers such as relapse activity, lesion burden, disability progression, and treatment response, the everyday burden of multiple sclerosis is often experienced most directly through fatigue, emotional distress, and disruption of daily functioning. These dimensions are central to health-related quality of life because they shape how patients move through ordinary routines, sustain relationships, maintain employment, participate socially, and preserve a coherent sense of identity. Recent research has increasingly emphasized that quality of life in multiple sclerosis cannot be understood only through neurological impairment, because patients' well-being is influenced by psychological symptoms, social support, stigma, coping resources, comorbid conditions, treatment experiences, and the degree to which the disease intrudes into daily life (Topcu et al., 2020; Văcăraș et al., 2020; Vissicchio et al., 2023).

Fatigue is among the most prevalent and disabling symptoms reported by people with multiple sclerosis, and it is often described as qualitatively different from ordinary tiredness. It may appear suddenly, persist despite rest, fluctuate across the day, and interfere with physical activity, concentration, emotional regulation, and social participation. The centrality of fatigue to health-related quality of life has been documented in recent studies showing that fatigue is strongly associated with diminished perceived health, reduced functional capacity, and lower quality of life outcomes among patients with multiple sclerosis (Al-Gamal et al., 2025). Interventional and rehabilitation-oriented studies have also treated fatigue as a major therapeutic target, reflecting its clinical importance and its impact on everyday functioning (Formica et al., 2025). However, quantitative evaluations alone may not fully capture how fatigue is interpreted, negotiated, hidden, justified, or managed by patients in the flow of daily life. A qualitative perspective is therefore needed to understand how patients experience fatigue not only as a symptom, but also as a force that reorganizes identity, planning, productivity, and social engagement.

The burden of fatigue in multiple sclerosis is also connected to broader questions about chronic disease adaptation. Studies in other long-term conditions indicate that fatigue trajectories and symptom persistence can substantially affect psychological adjustment and perceived quality of life, even when the underlying disease differs from multiple sclerosis (Klein et al., 2022). Research on electronic symptom monitoring in fibromyalgia has similarly shown the importance of capturing patients' daily symptom experiences in contexts where pain, fatigue, and functional limitations fluctuate and are difficult to observe externally (García et al., 2021). These findings are relevant to multiple sclerosis because many patients live with symptoms that are episodic, invisible, and difficult to explain to others. Fatigue may therefore produce not only physical limitation but also interpersonal misunderstanding, guilt, self-doubt, and pressure to appear well. In this sense, fatigue becomes both a physiological and psychosocial experience, requiring investigation through methods that allow patients to describe its meaning in their own words.

Emotional distress is another major dimension of living with multiple sclerosis. Depression, anxiety, irritability, fear of progression, grief over functional losses, and uncertainty about the future are frequently reported by patients and may intensify the burden of physical symptoms. Studies have shown that depression and anxiety are associated with neurological disability and quality of life in multiple sclerosis, suggesting that psychological symptoms are not secondary or peripheral concerns but integral components of the illness experience (Văcăraș et al., 2020). Recent predictive and comparative studies further indicate that anxiety, depression, and quality of life outcomes vary according to clinical, psychological, and treatment-related factors (Cuerda-Ballester et al., 2024; Özbek et al., 2025). These findings highlight the importance of examining emotional distress not merely as a comorbidity, but as part of the lived experience of multiple sclerosis, especially when patients confront uncertainty, limitations, stigma, and changes in self-perception.

The relationship between emotional distress and functioning is complex and reciprocal. Psychological symptoms may reduce motivation, confidence, social participation, and treatment engagement, while functional decline may increase sadness, fear, and perceived loss of control. Recent research on temperament, psychological symptoms, and disability in persons with multiple sclerosis has emphasized the relevance of psychological characteristics in understanding functional disability and adaptation (Infortuna et al., 2025). Similarly, ongoing work investigating mood and cognition in people with multiple

sclerosis reflects the growing recognition that emotional and cognitive dimensions are closely related to disease burden and everyday functioning (Cooper et al., 2025). Case-based intervention research focused on emotional regulation and comorbidities also suggests that emotional adjustment is a clinically meaningful target in multiple sclerosis care (Martín et al., 2025). Therefore, studying emotional distress qualitatively can provide insight into how patients interpret psychological vulnerability, how they manage emotional fluctuations, and how emotional burden becomes embedded in daily decisions and social relationships.

Daily functioning represents the practical domain through which the effects of multiple sclerosis become visible in everyday life. Patients may experience difficulty with employment, household responsibilities, mobility, transportation, self-care, parenting, intimate relationships, social participation, and community engagement. These functional changes may not always correspond neatly to clinical disability scores because patients can experience substantial burden even when symptoms are intermittent or not externally obvious. Illness intrusiveness has been identified as a key concept in the relationship between cognition and mood in multiple sclerosis, indicating that the degree to which illness disrupts valued activities can shape emotional and quality of life outcomes (Vissicchio et al., 2023). Mental health and frailty have also been described as interrelated dimensions in people with multiple sclerosis, further showing that physical vulnerability, emotional health, and daily functioning must be understood together rather than in isolation (Worikat et al., 2024). These studies support a multidimensional approach to health-related quality of life that accounts for how patients experience the disease in relation to ordinary activities and valued roles.

Social relationships and support systems also have a substantial influence on the experience of multiple sclerosis. Perceived social support, mental health, and marital satisfaction have been shown to be meaningfully connected in patients with multiple sclerosis, suggesting that relational contexts can either buffer or intensify psychological distress (Özen et al., 2021). Dyadic coping research has similarly emphasized the importance of partner-level adjustment and coping congruence in the management of multiple sclerosis, particularly because the illness often affects both the patient and close family members (McGarragle, 2024). The importance of compassion in the care of people with multiple sclerosis has also been highlighted, indicating that supportive, validating, and patient-centered interactions may influence both emotional well-being and care experiences (Simpson et al., 2022). These findings suggest that health-related quality of life depends not only on symptom control, but also on whether patients feel understood, respected, and supported in the social environments in which daily life unfolds.

Stigma and identity disruption are increasingly recognized as important psychosocial concerns in multiple sclerosis. Patients may appear healthy while experiencing profound fatigue, cognitive strain, emotional distress, or functional limitation, creating tension between visible appearance and internal experience. Stigma may arise when symptoms are misunderstood, minimized, or interpreted as lack of effort, leading to withdrawal, concealment, and reduced willingness to seek support. Recent narrative review evidence has specifically emphasized the need to reduce stigma and enhance psychological well-being and identity in people with multiple sclerosis (Montesano et al., 2025). This perspective is particularly relevant to qualitative inquiry because stigma and identity are subjective, relational, and context-dependent phenomena that require detailed personal narratives. Understanding how patients describe changes in identity, autonomy, confidence, and social belonging can deepen knowledge of quality of life beyond standardized outcome scores.

Recent studies have also drawn attention to the influence of lifestyle, nutrition, and broader biopsychosocial factors on the psychological status of people with multiple sclerosis. For example, research examining dietary inflammatory index, MIND diet scores, serum parameters, depression, and nutritional status in women with multiple sclerosis reflects the growing interest in how biological, behavioral, and psychological factors intersect in disease experience (Eroğlu et al., 2025). Broader theoretical work has also proposed stress-based developmental frameworks for understanding disease processes in multiple sclerosis, suggesting that stress exposure, adaptation, and disease burden should be examined across time and context (Fauver et al., 2024). These perspectives support the view that multiple sclerosis is not experienced only as a neurological disorder, but as a condition shaped by the interaction of body, mind, environment, relationships, and life history.

The COVID-19 pandemic further highlighted the vulnerability of individuals living with chronic neurological conditions, including multiple sclerosis. Studies on people with multiple sclerosis and caregivers during the pandemic showed secondary impacts on fatigue, self-compassion, physical health, and mental health, emphasizing how external stressors can worsen existing illness burdens

(Giménez-Llort et al., 2021). Research involving Brazilian people with Parkinson's disease and multiple sclerosis also indicated that the pandemic influenced perceptions, emotional well-being, and daily life among people with neurological conditions (Simieli et al., 2022). Although the present study is not specifically about the pandemic, this body of evidence demonstrates that health-related quality of life among patients with neurological illness is sensitive to social disruption, isolation, uncertainty, and changes in access to care. Similar findings from qualitative work on nursing home workers during the COVID-19 pandemic show that lived experiences under prolonged stress can reveal dimensions of burden, adaptation, and resilience that are often missed by purely quantitative designs (Kunkle et al., 2024).

Patient-reported outcomes have become increasingly important in understanding quality of life, symptom burden, and treatment impact in chronic conditions. The psychometric validation of global health measures for people with multiple sclerosis reflects the need for reliable patient-centered assessment of perceived health and functioning (Chan et al., 2025). Broader reviews of patient-reported outcome measures in childhood cancer and survivorship challenges in lung cancer similarly show that patient-centered outcomes are essential for capturing the burden of disease beyond biomedical indicators (Ha et al., 2025; Horan et al., 2022). Umbrella review evidence on digital health interventions for patients with cancer and caregivers also illustrates the growing emphasis on supportive care, self-management, and patient experience across chronic and serious illnesses (Fournier et al., 2023). Although these conditions differ from multiple sclerosis, they share the need to understand how patients evaluate their own health, functioning, distress, and quality of life in the context of long-term illness.

Digital care, self-management, and psychological interventions have also become increasingly relevant in multiple sclerosis. Study protocols for multidisciplinary care and self-management through MSmonitor-plus and video calling care demonstrate the movement toward more accessible, continuous, and patient-centered models of care (Hoving et al., 2022). Technology-supported mindfulness programs have also been explored as feasible approaches to supporting people with multiple sclerosis at home (Motolese et al., 2023). Online single-session cognitive behavioral therapy for depression and anxiety associated with multiple sclerosis has similarly been investigated as a potentially accessible intervention model (Schenk et al., 2024). In addition, schema therapy and mindfulness techniques have been compared in relation to existential anxiety among individuals with multiple sclerosis, highlighting the importance of meaning, acceptance, and psychological flexibility in adjustment to chronic neurological illness (Parast et al., 2024). These intervention-oriented studies suggest that patients' narratives about fatigue, emotional distress, and functioning may help clinicians design more responsive supportive care strategies.

Mindfulness and compassion-focused perspectives are also relevant to neurological care and chronic illness adaptation. Reviews of meditative and mindfulness-focused interventions in neurology have described the potential role of these approaches in supporting emotional regulation, coping, and symptom management among selected patients (Kraemer et al., 2022). In multiple sclerosis, compassion has been discussed not only as a personal coping resource but also as a quality of clinical care that may affect patient experience and outcomes (Simpson et al., 2022). These perspectives are important because many patients with multiple sclerosis face a continuous need to regulate expectations, accept fluctuating capacity, respond to uncertainty, and negotiate help from others. Understanding how patients make sense of these processes can enrich clinical practice by moving beyond symptom reduction toward dignity, autonomy, and meaningful participation.

Qualitative inquiry is especially appropriate for examining the lived experience of fatigue, emotional distress, and daily functioning because these phenomena are subjective, context-dependent, and deeply embedded in personal and social life. Previous qualitative research on urinary dysfunction consequences among women with multiple sclerosis has shown that specific symptoms can have broad effects on self-image, daily routines, social participation, and emotional well-being (Roshdi et al., 2020). Evidence from other chronic and complex conditions, such as hypermobility spectrum disorders, also demonstrates that a biopsychosocial perspective is necessary when symptoms affect identity, relationships, activity, and quality of life (Clark et al., 2023). In pediatric multiple sclerosis, parental experience research has similarly shown that the disease affects family systems and caregiving concerns, reinforcing the need to understand illness beyond the individual biomedical level (Tarantino et al., 2024). Taken together, these studies justify a qualitative approach that allows participants to describe how multiple sclerosis reshapes daily existence through fatigue, emotional

vulnerability, functional limitation, coping, and social interaction.

Despite the growing number of studies on fatigue, psychological symptoms, disability, and patient-reported outcomes in multiple sclerosis, there remains a need for integrated qualitative evidence that explores how patients themselves connect fatigue, emotional distress, and daily functioning within their broader experience of health-related quality of life. Much of the existing literature examines these domains separately or through standardized measures, while patients often experience them as overlapping and mutually reinforcing dimensions of one illness trajectory. A qualitative study can therefore contribute by clarifying how fatigue influences emotional well-being, how emotional distress shapes daily functioning, how functional limitations affect identity and social participation, and how protective factors such as support, coping strategies, accessibility, and acceptance help patients preserve quality of life. Such knowledge is important for developing patient-centered interventions, improving communication between patients and healthcare providers, and designing services that respond to lived needs rather than only clinical indicators.

The aim of this study was to explore the lived experiences of fatigue, emotional distress, and daily functioning among patients with multiple sclerosis in Canada and to understand how these experiences shape their health-related quality of life.

2. Methods and Materials

2.1. Study Design and Participants

This study was conducted using a qualitative phenomenological design to explore the lived experiences of fatigue, emotional distress, and daily functioning among patients with multiple sclerosis in relation to health-related quality of life. The phenomenological approach was selected because the purpose of the study was not to measure predetermined outcomes, but to obtain an in-depth understanding of how patients interpret, describe, and manage the physical, emotional, and social consequences of multiple sclerosis in everyday life. The study population consisted of adult patients with a confirmed diagnosis of multiple sclerosis who were receiving outpatient neurological care or were members of multiple sclerosis support and rehabilitation networks in Canada. Participants were recruited from neurology clinics, community-based multiple sclerosis organizations, and patient support groups in Toronto, Ontario, Canada. Purposeful sampling with maximum variation was used to include participants with different ages, disease durations, employment statuses, marital statuses, and levels of functional limitation. The final sample included 26 patients with multiple sclerosis. Participants were eligible for inclusion if they were 18 years of age or older, had received a definite medical diagnosis of multiple sclerosis from a neurologist, had lived with the disease for at least six months, were able to communicate in English, and were willing to describe their personal experiences in an interview. Patients were excluded if they had severe cognitive impairment, an acute relapse at the time of data collection, a severe psychiatric condition that prevented participation in an interview, or any other neurological disorder that could substantially affect fatigue, emotional functioning, or daily activities. Recruitment continued until data saturation was achieved, meaning that no substantially new concepts or themes emerged from the final interviews. Before participation, all individuals received verbal and written information about the aims and procedures of the study, and written informed consent was obtained. Participants were assured that participation was voluntary, that they could withdraw at any stage without consequences for their care or support services, and that all identifying information would remain confidential.

2.2. Measures

Data were collected using a demographic and clinical information form, a semi-structured interview guide, audio-recorded individual interviews, and researcher field notes. The demographic and clinical information form was developed to obtain contextual information about each participant, including age, gender, marital status, educational level, employment status, type of multiple sclerosis, disease duration, current treatment status, history of relapse, perceived level of disability, and use of rehabilitation or psychological support services. This information was used to describe the study sample and to support interpretation of participants' narratives within their clinical and social contexts. The main data collection tool was a semi-structured interview guide designed specifically for this study based on the concept of health-related quality of life and the core domains of living with multiple sclerosis. The interview guide included open-ended questions about experiences of fatigue, emotional distress, daily functioning, social participation, family and occupational roles, coping strategies, treatment-related concerns, and perceived changes in quality of life after diagnosis. Examples of

guiding questions included asking participants to describe how fatigue affected their daily routine, how multiple sclerosis influenced their emotional well-being, what activities had become difficult or limited, how they managed uncertainty and symptom fluctuation, and what forms of support were most helpful in maintaining daily functioning. Follow-up probes were used to encourage clarification, depth, and concrete examples. The interview guide was reviewed by experts in neurology, health psychology, qualitative research, and rehabilitation nursing to ensure relevance, clarity, and sensitivity. Two pilot interviews were conducted to refine the wording and sequence of questions; these pilot interviews were not included in the final analysis. All interviews were conducted individually in a private setting or through a secure online platform according to participant preference and accessibility needs. Interviews lasted approximately 45 to 75 minutes and were audio-recorded with permission. Field notes were written immediately after each interview to document nonverbal cues, emotional tone, contextual details, and preliminary analytic reflections.

2.3. Data Analysis

Data analysis was performed using thematic analysis with an inductive approach. All interviews were transcribed verbatim, and transcripts were checked against the audio recordings to ensure accuracy. The analysis began with repeated reading of the transcripts to achieve immersion in the data and to gain a holistic understanding of participants' experiences. Initial codes were generated line by line by identifying meaningful units related to fatigue, emotional distress, daily functioning, coping, relationships, work, uncertainty, and perceived quality of life. Coding was conducted without imposing predetermined categories so that themes could emerge from participants' own descriptions. To enhance analytic rigor, two researchers independently coded several initial transcripts and then compared their coding decisions to refine the coding framework. Disagreements were discussed until consensus was reached, and the revised coding framework was applied to the remaining transcripts while allowing new codes to be added when necessary. Related codes were then grouped into subthemes and broader themes that reflected recurring patterns across the interviews. The themes were reviewed in relation to the coded extracts and the entire data set to ensure that they accurately represented participants' narratives. Analytic memos were used throughout the process to document interpretive decisions, researcher reflections, and emerging conceptual links between fatigue, emotional distress, functional limitation, and health-related quality of life. Data organization and coding were supported by qualitative data management software. Trustworthiness was strengthened through prolonged engagement with the data, peer debriefing among the research team, maintenance of an audit trail, reflexive memo writing, and the use of direct participant quotations in the findings section. Credibility was further supported by returning brief summaries of the interpreted themes to a subset of participants for feedback on whether the analysis reflected their experiences. Transferability was addressed by providing detailed descriptions of the study setting, participant characteristics, sampling strategy, and data collection procedures. The analysis continued until thematic saturation was achieved and the final themes provided a coherent account of how patients with multiple sclerosis experienced fatigue, emotional distress, and disruptions in daily functioning as central components of health-related quality of life.

3. Findings and Results

The findings were derived from in-depth semi-structured interviews with 26 patients with multiple sclerosis in Canada. The participants included 18 women and 8 men, and their ages ranged from 24 to 67 years, with a mean age of 43.8 years. The duration of illness ranged from 1 to 22 years, indicating that the sample included both recently diagnosed patients and individuals who had lived with multiple sclerosis for a prolonged period. In terms of disease type, 14 participants reported relapsing-remitting multiple sclerosis, 7 reported secondary progressive multiple sclerosis, and 5 reported primary progressive multiple sclerosis. Regarding marital status, 15 participants were married or living with a partner, 7 were single, and 4 were divorced or widowed. Educational levels varied from high school diploma to postgraduate education, and participants represented a broad range of occupational situations, including full-time employment, part-time employment, medical leave, unemployment, retirement, and disability-related work withdrawal. At the time of the interviews, 16 participants were receiving disease-modifying treatment, 6 were receiving symptomatic pharmacological treatment without active disease-modifying therapy, and 4 reported no current medication use due to previous side effects, treatment discontinuation, or personal preference. Most participants described their health condition as unpredictable and

fluctuating, with periods of relative stability interrupted by fatigue, pain, weakness, cognitive problems, emotional strain, or relapse-related limitations. The demographic and clinical diversity of the participants allowed the study to capture different patterns of living with multiple sclerosis and to examine how fatigue, emotional distress, and impaired daily functioning shaped health-related quality of life across different stages of the disease.

Table 1

Thematic Structure of Experiences Related to Health-Related Quality of Life Among Patients With Multiple Sclerosis

Main Theme	Subthemes	Core Meaning	Number of Participants Referring to the Theme
Fatigue as a dominant and unpredictable burden	Persistent tiredness, sudden energy loss, cognitive fatigue, post-activity exhaustion, invisibility of fatigue	Fatigue was experienced as the most disruptive and least understood symptom, limiting physical activity, concentration, planning, and social participation.	25
Emotional distress and psychological vulnerability	Anxiety about progression, sadness and grief, irritability, fear of dependency, uncertainty about the future, loss of confidence	Emotional distress emerged from the uncertainty of the illness, the perceived loss of previous identity, and fear of future decline.	23
Disruption of daily functioning and role performance	Work limitations, household difficulties, reduced mobility, disrupted routines, dependence on others, reduced social involvement	Participants described multiple sclerosis as a condition that gradually reorganized daily life and forced them to modify personal, family, and occupational roles.	24
Coping, adaptation, and reconstruction of normal life	Pacing, rest planning, acceptance, seeking support, lifestyle adjustment, prioritizing meaningful activities	Patients attempted to protect quality of life by redefining normality, managing energy, accepting limitations, and developing practical coping strategies.	21
Social understanding, support, and stigma	Misunderstanding by others, hidden symptoms, family support, workplace accommodation, social withdrawal	The quality of social responses strongly affected patients' emotional well-being and ability to participate in daily life.	20
Health-related quality of life as a balance between limitation and control	Maintaining autonomy, preserving identity, symptom management, emotional stability, meaningful participation	Quality of life was described not as the absence of symptoms, but as the ability to maintain control, dignity, purpose, and participation despite illness-related limitations.	26

Table 1 presents the overall thematic structure that emerged from the interviews. The analysis showed that health-related quality of life among patients with multiple sclerosis was shaped by a continuous interaction between physical symptoms, emotional reactions, functional limitations, coping strategies, and social context. Fatigue was the most frequently reported experience and was described by almost all participants as more disabling than pain, weakness, or sensory symptoms because it affected every aspect of everyday life. Emotional distress was also highly prominent and was closely connected to uncertainty, fear of disease progression, and the psychological burden of living with a chronic neurological condition. Daily functioning was disrupted through limitations in work, family responsibilities, household tasks, social participation, and personal independence. However, participants did not describe themselves only as passive recipients of illness-related restrictions. Many emphasized the development of coping strategies, such as pacing, planning, accepting help, adjusting expectations, and prioritizing important activities. The findings also showed that the social environment played a central role in either protecting or weakening quality of life. When family members, employers, and friends understood the hidden and fluctuating nature of multiple sclerosis, participants felt more secure and capable of maintaining daily participation. In contrast, misunderstanding, stigma, and lack of accommodation increased emotional distress and social withdrawal. Overall, quality of life was constructed by participants as a dynamic balance between limitation and control, in which the preservation of autonomy, identity, meaningful activity, and emotional stability was more important than complete physical recovery.

Table 2

Experiences of Fatigue Among Patients With Multiple Sclerosis

Subtheme	Description of Experience	Consequences for Health-Related Quality of Life	Illustrative Quotation
Persistent physical tiredness	Participants described fatigue as a constant heaviness in the body that was not relieved completely by sleep or ordinary rest.	Reduced ability to complete daily activities, increased dependence on others, and loss of confidence in physical capacity.	"It is not just being tired. It feels like my body has been switched off, even when I have not done anything."
Sudden and unpredictable energy loss	Fatigue often appeared unexpectedly and forced participants to stop activities without warning.	Difficulty planning the day, cancelling social activities, and feeling unreliable in family or work roles.	"I can feel fine in the morning and then suddenly I have no energy at all. It makes planning almost impossible."
Post-activity exhaustion	Even simple tasks such as shopping, cooking, walking, or attending appointments could lead to prolonged exhaustion.	Participants avoided activities they previously enjoyed and restricted their daily routines to preserve energy.	"If I go grocery shopping, that may be the only thing I can do that day. Everything has a cost."
Cognitive fatigue	Participants reported difficulty concentrating, remembering information, following conversations, or making decisions when fatigued.	Lower work productivity, reduced communication quality, embarrassment, and frustration.	"My brain gets tired before my body sometimes. I know what I want to say, but I cannot organize it."
Invisible nature of fatigue	Many participants felt that others did not understand fatigue because they appeared physically well.	Feelings of invalidation, guilt, social misunderstanding, and pressure to justify limitations.	"People say I look good, but they do not see what it takes just to get through the day."
Need for pacing and rest planning	Participants learned to divide tasks, schedule rest periods, and avoid overexertion.	Improved sense of control, but also reduced spontaneity and increased awareness of illness.	"I have to plan rest the same way other people plan meetings. If I do not, I pay for it later."

Table 2 shows that fatigue was not experienced as a simple symptom but as a complex, multidimensional condition that affected the body, mind, emotions, and social life. Participants repeatedly distinguished multiple sclerosis-related fatigue from ordinary tiredness, emphasizing that it was deeper, more disabling, less predictable, and less responsive to rest. The unpredictability of fatigue was one of its most distressing features because it interfered with planning and created uncertainty in daily life. Participants reported that they often had to cancel commitments, reduce social activities, or avoid making promises because they could not predict their energy level. Post-activity exhaustion also shaped daily decision-making, as patients described having to calculate the physical and emotional cost of each task. Activities that were previously routine, such as cooking, cleaning, driving, shopping, or attending a family gathering, became energy-consuming events requiring preparation and recovery. Cognitive fatigue added another layer of difficulty by affecting concentration, communication, memory, and work performance. Several participants reported feeling embarrassed when they lost track of conversations or forgot simple information, especially in social and occupational settings. The invisibility of fatigue contributed to psychological burden because participants often felt that they had to prove the legitimacy of their symptoms to others. As a result, fatigue reduced health-related quality of life not only by limiting activity, but also by weakening autonomy, spontaneity, self-confidence, and social participation. Nevertheless, pacing and rest planning emerged as important adaptive strategies. Although these strategies helped participants maintain control and reduce symptom exacerbation, they also required continuous self-monitoring and reduced the sense of living freely.

Table 3

Experiences of Emotional Distress Among Patients With Multiple Sclerosis

Subtheme	Description of Experience	Consequences for Health-Related Quality of Life	Illustrative Quotation
Anxiety about disease progression	Participants feared future disability, relapse, mobility loss, and increased dependence.	Increased worry, sleep disturbance, difficulty making long-term plans, and reduced sense of security.	"The hardest part is not knowing what I will be able to do next year or even next month."
Grief for the previous self	Participants described mourning the loss of their former energy, independence, appearance, work capacity, and social identity.	Reduced self-esteem, sadness, identity disruption, and comparison with life before diagnosis.	"I miss the person I was before MS. I still look like myself, but I do not feel like that person anymore."

Fear of becoming dependent	Many participants worried about needing help with mobility, household tasks, finances, or personal care.	Feelings of vulnerability, guilt toward family members, and fear of burdening others.	"I am afraid of the day when I cannot do basic things by myself."
Irritability and emotional sensitivity	Participants reported becoming more easily frustrated, overwhelmed, or emotionally reactive, especially during fatigue or symptom flare-ups.	Tension in family relationships, guilt after emotional reactions, and increased need for emotional regulation.	"When I am exhausted, I get irritated quickly, and then I feel bad because my family is only trying to help."
Depression and hopelessness	Some participants described periods of low mood, loss of motivation, and reduced interest in previously meaningful activities.	Reduced engagement in self-care, social withdrawal, and lower perceived quality of life.	"There are days when I feel like my life is getting smaller and smaller."
Emotional relief through support and understanding	Participants felt emotionally stronger when they received validation, practical help, and nonjudgmental support.	Improved resilience, greater willingness to communicate needs, and stronger sense of belonging.	"When someone understands without making me explain everything, it makes a huge difference."

Table 3 indicates that emotional distress was deeply embedded in the experience of living with multiple sclerosis. Participants did not describe emotional distress as a separate psychological reaction occurring after physical symptoms; rather, it was interwoven with uncertainty, fatigue, changes in identity, fear of dependency, and the social consequences of illness. Anxiety about disease progression was one of the most frequent emotional concerns. Participants described the future as uncertain and difficult to imagine because the course of multiple sclerosis could not be fully predicted. This uncertainty affected not only health-related concerns but also decisions about employment, relationships, parenthood, finances, and long-term independence. Grief for the previous self was also prominent. Participants frequently compared their current abilities with their pre-diagnosis identity and described sadness related to the loss of physical confidence, professional productivity, social spontaneity, and independence. For many patients, the emotional burden was intensified by the fact that they still appeared healthy to others, creating a discrepancy between external appearance and internal suffering. Fear of dependency was another major source of distress, particularly among participants with progressive symptoms or those who had already experienced mobility limitations. Some participants expressed guilt about relying on spouses, children, parents, or friends, even when support was willingly provided. Irritability and emotional sensitivity often emerged in relation to fatigue and symptom exacerbation, suggesting that emotional regulation became more difficult when physical resources were depleted. Depression and hopelessness were described by some participants as periods in which life felt increasingly restricted. However, the findings also showed that emotional distress could be buffered by meaningful support. Participants who felt understood and validated reported greater psychological stability, better coping, and a stronger sense of belonging. Therefore, emotional well-being was a central component of health-related quality of life and was strongly influenced by both disease-related uncertainty and the quality of interpersonal support.

Table 4

Experiences of Daily Functioning and Social Participation Among Patients With Multiple Sclerosis

Subtheme	Description of Experience	Consequences for Health-Related Quality of Life	Illustrative Quotation
Work and productivity limitations	Participants described reduced concentration, physical stamina, punctuality, and ability to manage full-time work demands.	Financial stress, reduced professional identity, fear of disclosure, and need for workplace accommodations.	"I want to work, but I cannot always keep up with the pace I used to handle."
Household and family role disruption	Daily tasks such as cleaning, cooking, childcare, shopping, and organizing the home became more difficult.	Guilt, dependence on family members, role changes within the household, and reduced sense of competence.	"I used to take care of everything at home. Now I have to ask for help with things that once felt simple."
Mobility and accessibility challenges	Participants reported difficulty walking long distances, climbing stairs, driving, using public transportation, or attending appointments.	Reduced independence, avoidance of unfamiliar places, and increased planning before leaving home.	"Before I go anywhere, I think about parking, stairs, bathrooms, distance, and whether I can get back safely."
Social withdrawal and reduced participation	Fatigue, embarrassment, fear of symptoms, and lack of understanding led some participants to reduce social contact.	Loneliness, reduced enjoyment, loss of friendship networks, and lower emotional well-being.	"Sometimes I say no to invitations because I do not want people to see me struggling."
Adaptation of routines	Participants modified daily routines by prioritizing essential tasks, resting between activities, using assistive devices, or simplifying responsibilities.	Greater control and symptom management, but also reduced spontaneity and a sense of restricted living.	"I can still do many things, but everything has to be organized around my energy."
Preservation of meaningful activities	Participants attempted to maintain selected activities that gave them purpose, identity, or pleasure.	Improved motivation, emotional resilience, and sense of continuity despite illness.	"I cannot do everything I used to do, but I try to keep the things that make me feel like myself."

Table 4 demonstrates that daily functioning was one of the main pathways through which multiple sclerosis affected health-related quality of life. Participants described the illness as a condition that reorganized daily life by changing how they worked, managed the home, participated in family roles, moved through public spaces, and maintained social relationships. Work-related limitations were particularly important because employment was connected not only to income but also to identity, independence, and self-worth. Participants who remained employed often described the need to conceal symptoms, negotiate accommodations, reduce working hours, or manage fatigue privately. Those who had reduced employment or left work due to the disease described financial stress and a sense of loss related to professional identity. Household and family functioning were also strongly affected. Tasks that had previously been automatic became physically and cognitively demanding, and some participants felt guilt when responsibilities shifted to partners, children, or other family members. Mobility limitations created another layer of restriction by making participants more cautious about leaving home and more dependent on accessible environments. Even when participants were physically able to attend appointments or social gatherings, the need to consider distance, stairs, transportation, temperature, rest opportunities, and bathroom access reduced spontaneity and increased psychological burden. Social withdrawal was often described as a protective response to fatigue, embarrassment, or fear of being misunderstood. However, reduced participation also increased loneliness and weakened emotional well-being. Despite these difficulties, many participants actively adapted their routines to maintain a degree of independence and continuity. They described learning to prioritize essential tasks, use assistive strategies, accept support, and preserve activities that remained personally meaningful. These findings suggest that daily functioning in multiple sclerosis should not be understood only in terms of physical ability, but also in relation to identity, autonomy, social participation, environmental accessibility, and the capacity to sustain meaningful roles.

Figure 1

Conceptual Model of the Relationship Between Fatigue, Emotional Distress, Daily Functioning, and Health-Related Quality of Life Among Patients With Multiple Sclerosis

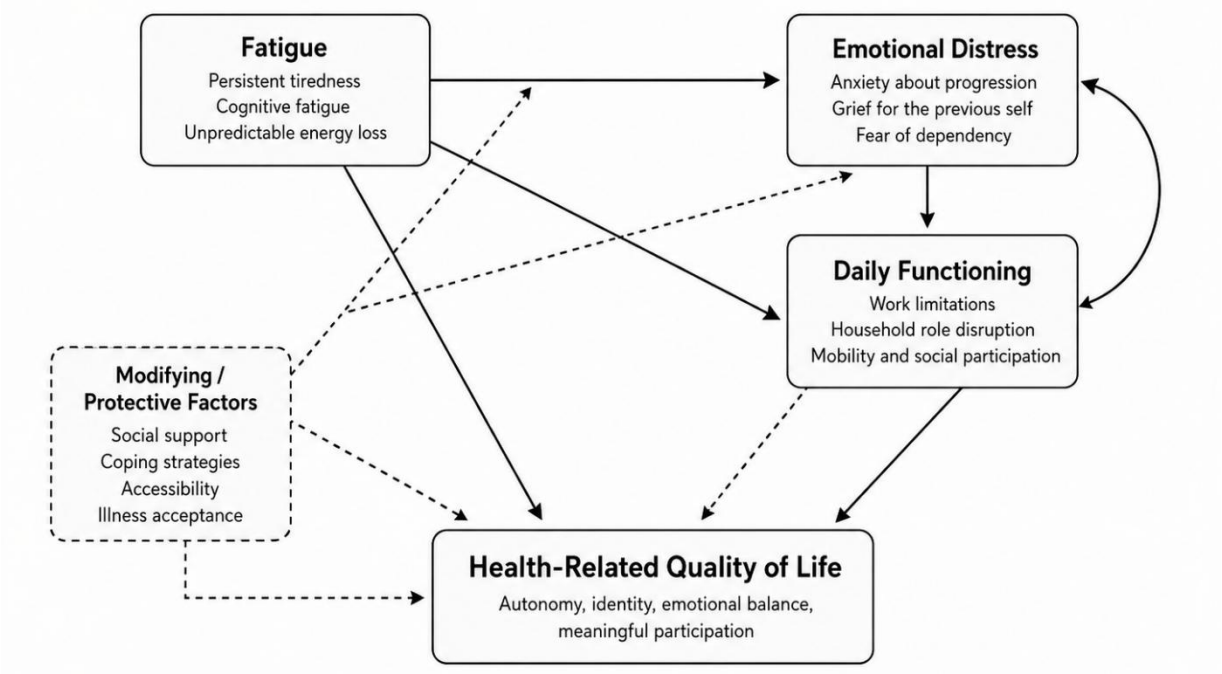

Figure 1 illustrates the interpretive model developed from the qualitative findings. The model shows that fatigue, emotional distress, and daily functioning were not isolated domains but mutually reinforcing dimensions of health-related quality of life. Fatigue directly restricted daily activities by reducing physical stamina, cognitive capacity, and the ability to maintain social or occupational routines. At the same time, fatigue intensified emotional distress by increasing frustration, anxiety, helplessness, and feelings of inadequacy. Emotional distress, in turn, affected daily

functioning by reducing motivation, confidence, and willingness to participate in social or work-related activities. Daily functional limitations also fed back into emotional distress by creating experiences of dependency, role loss, uncertainty, and social isolation. Within this cycle, social support, coping strategies, accessibility, and illness acceptance acted as modifying factors. When participants had supportive relationships, flexible environments, effective pacing strategies, and a sense of acceptance, they were better able to maintain autonomy and protect quality of life. Conversely, lack of understanding, inaccessible environments, poor symptom control, and fear of disease progression intensified the negative effects of multiple sclerosis on quality of life. The model therefore suggests that health-related quality of life among patients with multiple sclerosis is best understood as a dynamic process in which physical symptoms, emotional responses, functional capacity, and social context continuously influence one another.

The overall findings revealed that patients with multiple sclerosis experienced health-related quality of life as a fragile and constantly negotiated state. Participants did not define quality of life only by symptom severity or medical status; instead, they emphasized the ability to preserve independence, participate in meaningful activities, maintain emotional balance, and feel understood by others. Fatigue was the most dominant symptom and was repeatedly described as the central factor shaping daily limitations. Emotional distress emerged from uncertainty, identity disruption, fear of dependency, and the effort required to adapt to an unpredictable illness. Daily functioning was affected through limitations in work, household tasks, mobility, social participation, and family roles. However, the findings also showed that participants were actively engaged in reconstructing their lives around the illness. Through pacing, prioritization, support-seeking, acceptance, and preservation of meaningful roles, many participants developed practical ways to maintain a sense of control. The interaction among fatigue, emotional distress, and daily functioning suggests that interventions aimed at improving quality of life in multiple sclerosis should address not only physical symptoms but also emotional adjustment, social understanding, accessibility, and the patient's ability to sustain valued daily activities.

4. Discussion

The present study explored the lived experiences of fatigue, emotional distress, and daily functioning among patients with multiple sclerosis and examined how these experiences shaped health-related quality of life. The findings showed that health-related quality of life was not perceived by participants as a single clinical outcome or as a direct reflection of neurological impairment. Instead, it emerged as a dynamic and negotiated state shaped by the interaction of symptom burden, emotional vulnerability, functional restriction, social understanding, and coping resources. Participants described fatigue as the most dominant and disruptive experience, emotional distress as a persistent response to uncertainty and identity disruption, and daily functioning as the practical field in which the disease affected work, family roles, mobility, and social participation. These findings are consistent with previous research indicating that health-related quality of life in multiple sclerosis is strongly influenced by fatigue, depression, anxiety, disability, social support, stigma, and illness intrusiveness rather than by biomedical disease indicators alone (Al-Gamal et al., 2025; Topcu et al., 2020; Văcăraș et al., 2020; Vissicchio et al., 2023).

One of the central findings of this study was that fatigue was experienced as a pervasive and unpredictable burden that affected nearly all aspects of life. Participants distinguished multiple sclerosis-related fatigue from ordinary tiredness and described it as a profound reduction in physical and cognitive energy that could not be fully resolved through rest. This finding aligns with Al-Gamal et al., who emphasized the significant association between fatigue and reduced health-related quality of life in patients with multiple sclerosis (Al-Gamal et al., 2025). The present findings extend this evidence by showing how fatigue is experienced subjectively as an invisible, socially misunderstood, and functionally limiting phenomenon. Participants reported that fatigue reduced their ability to work, participate socially, manage household responsibilities, concentrate, and maintain predictable routines. This is also compatible with intervention-oriented studies that have targeted fatigue as a clinically meaningful outcome in multiple sclerosis, including research on rehabilitation approaches designed to reduce fatigue and improve function (Formica et al., 2025). However, the qualitative findings of the present study suggest that fatigue management should not be limited to symptom reduction; it

should also address energy planning, role adjustment, patient validation, and social communication.

The findings also showed that fatigue and emotional distress were closely connected. Participants reported that fatigue intensified irritability, sadness, frustration, anxiety, and feelings of inadequacy. In some cases, patients described emotional distress as emerging directly from the inability to rely on their own bodies or to plan daily life with confidence. This finding is supported by studies showing that depression and anxiety are common and clinically important in multiple sclerosis and may influence neurological disability, quality of life, and perceived health status (Cuerda-Ballester et al., 2024; Özbek et al., 2025; Văcăraș et al., 2020). The present study adds depth to these findings by illustrating that emotional distress was not only a comorbid psychological condition, but also a lived response to uncertainty, fatigue, role loss, social misunderstanding, and fear of progression. Recent studies on mood, cognition, temperament traits, psychological symptoms, and functional disability similarly support the view that emotional and cognitive domains are inseparable from the everyday burden of multiple sclerosis (Cooper et al., 2025; Infortuna et al., 2025). Therefore, the emotional experience of multiple sclerosis should be understood as part of the illness trajectory rather than as a secondary reaction occurring outside the disease process.

Another important finding was the experience of grief for the previous self. Participants often compared their current lives with their pre-diagnosis identity and described a sense of loss related to energy, independence, social spontaneity, productivity, and self-confidence. This finding is consistent with literature emphasizing psychosocial adjustment to multiple sclerosis diagnosis and the identity-related challenges that accompany chronic neurological illness (Topcu et al., 2020). It also aligns with recent work on stigma, psychological well-being, and identity in multiple sclerosis, which suggests that patients may struggle to preserve a stable sense of self when symptoms are invisible, fluctuating, or misunderstood by others (Montesano et al., 2025). The present findings show that identity disruption was not limited to severe disability; even participants with relatively preserved physical appearance described internal losses that were difficult to communicate. This discrepancy between looking well and feeling impaired contributed to emotional distress, guilt, and the need to justify limitations. Similar concerns have been reported in qualitative work on symptom consequences in multiple sclerosis, where specific symptoms such as urinary dysfunction affected self-image, participation, and daily confidence (Roshdi et al., 2020).

Daily functioning was another major domain through which multiple sclerosis shaped quality of life. Participants described difficulties with work, household responsibilities, mobility, transportation, social participation, and family roles. These findings align with research identifying illness intrusiveness as an important factor in the cognition-mood relationship among people with multiple sclerosis (Vissicchio et al., 2023). In the present study, illness intrusiveness was visible in the way participants reorganized daily life around fatigue, mobility limitations, rest periods, symptom unpredictability, and accessibility concerns. Functional difficulties were not limited to physical disability; they also included cognitive fatigue, reduced concentration, emotional exhaustion, and fear of symptom exacerbation. This supports research showing a complex relationship between mental health, frailty, functional vulnerability, and multiple sclerosis outcomes (Worikat et al., 2024). The findings also echo broader biopsychosocial perspectives from chronic illness research, which emphasize that functional limitation affects social participation, identity, emotional well-being, and quality of life across conditions (Clark et al., 2023).

Work and productivity emerged as particularly meaningful aspects of daily functioning. Participants who remained employed often described the need to manage fatigue privately, reduce hours, request accommodations, or conceal symptoms because of fear of judgment. Those who had left work or reduced employment described financial stress and loss of professional identity. This finding is consistent with the broader patient-reported outcome literature, which emphasizes the importance of measuring global health, functional capacity, and subjective well-being from the patient perspective (Chan et al., 2025). Standardized tools are essential for evaluating health-related quality of life, yet the present findings suggest that qualitative accounts are needed to understand how work limitations affect dignity, independence, self-worth, and social identity. Similar arguments have been made in patient-reported outcome research in other chronic and serious illnesses, where quality of life cannot be fully understood without considering the patient's own interpretation of functional and emotional burden (Ha et al., 2025; Horan et al., 2022).

The social context of multiple sclerosis was also prominent in the findings. Participants reported that support, understanding, and validation helped them cope with fatigue and emotional distress, while misunderstanding, stigma, and lack of accommodation intensified isolation and reduced

participation. This finding is supported by evidence showing that perceived social support is associated with mental health and marital satisfaction among patients with multiple sclerosis (Özen et al., 2021). Research on dyadic coping further indicates that adjustment to multiple sclerosis often occurs within close relationships and that congruence between patient and partner coping may influence well-being (McGarragle, 2024). The present study confirms that the burden of multiple sclerosis is not experienced in isolation. Family members, partners, employers, colleagues, friends, and healthcare professionals can either reduce or increase the patient's burden depending on the extent to which they recognize the invisible and fluctuating nature of symptoms. The importance of compassion in the care of people with multiple sclerosis further supports this interpretation, as compassionate interactions may help patients feel validated, respected, and less alone in the management of their illness (Simpson et al., 2022).

Another key finding was that participants actively attempted to reconstruct normal life through pacing, planning, acceptance, help-seeking, and prioritization of meaningful activities. This adaptive process is consistent with psychological and supportive care research in multiple sclerosis, including studies on mindfulness, cognitive behavioral therapy, schema therapy, and emotion regulation interventions (Kraemer et al., 2022; Martín et al., 2025; Parast et al., 2024; Schenk et al., 2024). Participants did not describe coping as a simple acceptance of illness; rather, coping involved continuous negotiation between what they wanted to do, what their bodies allowed, what others expected, and what was necessary to preserve quality of life. At-home technology-supported mindfulness programs and digital self-management approaches have also been proposed as potentially useful for people with multiple sclerosis, especially when fatigue, mobility limitations, or access barriers make traditional care difficult (Hoving et al., 2022; Motolese et al., 2023). The present findings suggest that such interventions may be most helpful when they address the integrated reality of fatigue, emotional distress, functional limitations, and social support rather than focusing on a single symptom.

The findings also support the need to understand multiple sclerosis within a broader biopsychosocial and developmental framework. Participants' experiences were shaped by disease duration, symptom unpredictability, stress exposure, social support, employment status, and expectations about the future. This aligns with the developmental model of stress as applied to multiple sclerosis, which emphasizes that stress and disease interact across time and may influence adaptation and vulnerability (Fauver et al., 2024). The relevance of lifestyle and biological factors is also reflected in research examining diet, inflammatory markers, nutritional status, and depression in women with multiple sclerosis (Eroğlu et al., 2025). Although the present study did not directly investigate nutrition or biomarkers, participants' narratives confirmed that quality of life is shaped by multiple interacting systems, including physical symptoms, emotional regulation, lifestyle routines, environmental accessibility, and social resources. This interpretation is also supported by evidence from the COVID-19 period, which showed that external stressors can worsen fatigue, mental health, and self-compassion among people with multiple sclerosis and caregivers (Giménez-Llort et al., 2021; Simieli et al., 2022). Such findings indicate that quality of life is highly sensitive to contextual disruption and cannot be understood independently of social and environmental conditions.

5. Conclusion

Overall, the present study contributes to the literature by showing that fatigue, emotional distress, and daily functioning form an interconnected experiential system in multiple sclerosis. Fatigue restricted daily functioning and intensified emotional distress; emotional distress reduced confidence, motivation, and social engagement; and functional limitations reinforced fear, grief, and uncertainty. Protective factors such as social support, coping strategies, accessibility, and illness acceptance helped participants maintain autonomy and meaningful participation. This integrated interpretation is consistent with existing studies across multiple sclerosis and other chronic conditions showing that patient experience, supportive care, digital tools, family systems, stigma reduction, and psychosocial adaptation are central to quality of life (Fournier et al., 2023; Kunkle et al., 2024; Maristany et al., 2024; Tarantino et al., 2024). The findings therefore suggest that clinical care for multiple sclerosis should move beyond disease monitoring alone and should include systematic attention to fatigue, emotional well-being, functional participation, relational support, and the patient's own definition of quality of life.

6. Limitations & Suggestions

The present study has several limitations. First, the study was conducted with a qualitative design and a relatively

small sample of patients with multiple sclerosis in Canada; therefore, the findings are not intended to be statistically generalizable to all patients with multiple sclerosis. Second, participants were recruited through clinical and community-based networks, which may have resulted in greater participation by individuals who were more willing or able to discuss their experiences. Third, the data were based on self-report interviews, and participants' accounts may have been influenced by memory, current emotional state, disease stage, or recent symptom fluctuations. Fourth, although maximum variation sampling was used, the sample may not fully represent the experiences of patients with severe cognitive impairment, advanced disability, limited access to care, or diverse linguistic and cultural backgrounds. Finally, because the study was cross-sectional, it captured experiences at one point in time and could not examine how fatigue, emotional distress, and daily functioning change across disease progression, relapse, remission, or treatment transitions.

Future research should expand the current findings through longitudinal qualitative and mixed-methods designs that follow patients over time and examine how fatigue, emotional distress, and daily functioning evolve across different stages of multiple sclerosis. Studies with larger and more diverse samples are needed to compare experiences across disease types, gender, age groups, employment status, cultural backgrounds, and levels of disability. Future research should also include family members, caregivers, and healthcare professionals to better understand the relational and systemic dimensions of quality of life. In addition, future studies may examine how digital health tools, psychological interventions, rehabilitation programs, workplace accommodations, and peer-support models influence the lived experience of fatigue and emotional adjustment. Greater attention should also be given to underrepresented groups, including patients with progressive multiple sclerosis, patients living in rural or underserved areas, and individuals who face barriers related to language, income, disability, or limited access to specialized care.

In practice, the findings suggest that healthcare providers should assess fatigue, emotional distress, and daily functioning as interconnected dimensions of health-related quality of life rather than as separate clinical problems. Patients should be given opportunities to describe how symptoms affect their work, family roles, relationships, mobility, self-care, and identity. Care plans should include fatigue management education, emotional support, referral to psychological services when needed, rehabilitation planning, occupational accommodations, and practical strategies for pacing and energy conservation. Clinicians should also pay attention to invisible symptoms and validate patients' experiences even when disability is not externally apparent. Family education and workplace awareness may help reduce misunderstanding and stigma, while accessible environments and flexible care delivery can support autonomy and participation. A patient-centered approach should focus not only on controlling disease activity, but also on helping individuals preserve dignity, independence, meaningful roles, and emotional balance in everyday life.

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Declaration of Interest

The authors of this article declared no conflict of interest.

Ethical Considerations

The study protocol adhered to the principles outlined in the Helsinki Declaration, which provides guidelines for ethical research involving human participants.

Transparency of Data

In accordance with the principles of transparency and open research, we declare that all data and materials used in this study are available upon request.

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Authors' Contributions

All authors equally contributed to this article.

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