

Employment of patients with multiple sclerosis: the influence of psychosocial–structural coping and context

Lavanya Vijayasingham^{1,2}
Fatima Fanna Mairami¹

¹Jeffrey Cheah School of Medicine, Monash University Malaysia, Bandar Sunway, Malaysia; ²Multiple Sclerosis Society of Malaysia, Petaling Jaya, Malaysia

Abstract: Patients with multiple sclerosis tend to report higher levels of work difficulties and negative outcomes, such as voluntary and involuntary work termination and reduced work participation. In this article, we discuss the complex interactions of disease, personal coping strategies, and social and structural factors that contribute to their work experiences and outcomes. An overview of the coping strategies and actions that leverage personal and context-level factors and dynamics is also provided to support the overall goal of continued work in patients with MS.

Keywords: work, psychological and psychosocial adjustment, structural coping and social determinants, vocational rehabilitation, quality of life

Introduction

Multiple sclerosis (MS) is usually diagnosed between the ages of 20 and 45, affecting most people during their employment years. Continued and long-term employment in MS patients is associated with higher quality of life, less welfare dependence, and better clinical and disease management.^{1–4} More broadly, employment provides economic resources such as monetary income, access to work benefits such as health insurance, a sense of personal and professional identity and fulfillment and social participation and interactions. As such, maintaining long-term employment in meaningful and engaging roles with minimal MS-related disruptions is a necessary target for holistic MS management at a policy and practice level.

However, many MS patients face challenging work lives, as portrayed through narratives of their work experiences and encounters, employment participation rates and trajectories. A higher proportion of individuals with MS report unemployment, part-time or reduced work participation and lower income from paid work, compared to the general population and other patient groups with chronic diseases such as arthritis, type-2 diabetes or depression.^{5–8} Work productivity losses are one of the largest drivers of economic costs in MS-related burden of illness studies.^{1,9} At or prior to diagnosis, a significant proportion of patients report positive work history and participation or full-time education across national contexts and time.^{10,11} However, work participation is found to reduce with increasing age, functional changes and disease severity.^{11,12} While increasing disease severity and impairments is one of the most widely attributed reasons for unemployment and negative work outcomes, the high levels of unemployment in MS patients is not adequately explained by levels of disability or impairment alone.¹¹

Correspondence: Lavanya Vijayasingham
Monash University Malaysia, Jalan Lagoon Selatan, 47500 Bandar Sunway, Selangor, Malaysia
Email lavanya.vijayasingham@monash.edu

The work outcomes and experiences of individuals with chronic illnesses are often a consequence of how patients holistically cope with MS, that is, how they navigate and respond to the joint psychological, social and structural influences to manage their lives, work and illness. Coping is an ongoing, time-related process, where individual coping trajectories are dynamic and are influenced by physical, behavioral, cognitive, emotional and social components, including personality attributes, gender, education, socioeconomic position, social resources and interpersonal support.¹³ Coping course and strategies influence individual perceptions, decision-making and behaviors in a patient's work environment and how they manage and meet task-oriented work demands.

The aim of this article is to provide an overview of the employment challenges of individuals with MS, with a focus on the interconnected domains and levels of influence, spanning individual, work context or organizational and sociostructural context. We integrate practical themes of knowledge¹⁴ from quantitative and qualitative studies, systematic and narrative reviews identified through PubMed, Scopus, PsychINFO and Google Scholar searches, to inform understanding and practice for a broad audience including MS patients, their family members, patient advocacy and support societies, employers of MS patients and multidisciplinary teams of health professionals. We first discuss some of the determinants and challenges of employment among MS patients across the multilevel person–environment context (disease, personal, psychological, social and structural). Next, we discuss MS coping, the styles and strategies and its influence on employment. We conclude with recommendations on coping strategies and behaviors that can support the goal of continued employment.

Challenges and determinants of employment in MS patients

Extant studies explore and find various rates and determinants of employment in MS patients. In a meta-analytic review of 33 cross-sectional studies that were predominantly from the Northern Hemisphere, employment participation ranged from 12% to 74%, with an average of 44% across all studies.¹⁵ In a 2015 global survey of 11,515 of individuals with MS, 39% of respondents reported being unemployed, with ~21% of this group becoming unemployed because of MS within 3 years of diagnosis and 34% within 10 years.¹⁶ The variations in these rates of employment are influenced by determinants and challenges that relate to disease status, types of neurologic manifestations, personal demographic positions and

resources, work context, social-structural environment and access to medical care and structural protection.¹²

Patients with less severe disease or less impairments are more likely to be employed.¹¹ Nevertheless, some patients report symptom-related work difficulties despite having little apparent disability⁴ and report higher levels of absenteeism or need for intermittent periods of moderate-to-long disability or sickness leave.¹⁷ Patients with milder and more episodic forms of MS also sometimes opt to make early decisions of work change, which are often motivated by health management, and work–life–illness balance pursuits.¹⁸ There is some evidence on the impact of stressful events on MS activity and progress,¹⁹ and so patients may sometimes strive to reduce their exposure to likely stress in individually appropriate and meaningful ways.¹⁸ The resultant employment decisions that are prompted by these perceptions and pursuits include reducing work hours or making work role transitions such as moving away from high-stress work profiles with challenging task or pace demands, and temporarily or permanently leaving the workforce.^{11,20–22}

Disease and personal demographic factors

A core theme in MS employment research is the strong influence of disease status and progress on employment participation. In a recent study of the burden and costs of MS across 16 European countries, disease severity or stage affected proportions of employed participants (below retirement age), where the proportion of employed participants with no MS-related impairments or disability was 81.9% and fell to 8.2% in the subgroup of those who were confined to bed and had the most significant impairments.⁹ Additionally, the experience and manifestations of specific symptoms such as mobility impairments, cognitive changes, weakness and fatigue also negatively influence employment status.^{12,16,23} In an longitudinal Australian study, inability to effectively manage MS disease-related factors or symptoms was found to be a stronger risk or predictive factor for work loss, in comparison to workplace dynamics such as discrimination.⁶ In many cases, invisible symptoms such as fatigue, anxiety, perceived attention and memory challenges that cause work issues can collectively contribute to a vicious cycle of disease experience, where insufficient recovery from each symptom can feed increased disease activity and progress.⁴ As a result, scholars and vocational rehabilitation experts advocate for more effective education and resources for MS patients to more effectively manage symptoms at work.

Questions have been raised on whether depression is a risk factor for, or a consequence of, unemployment. The status of depression as a predictor of unemployment is equivocal, where results between studies provide disparate results.¹⁵ The authors of this review are cautious that these findings may be reflective of the use of different dimensions or evaluation questionnaires across studies. In a 13-year follow-up study on the influence of coping styles on long-term employment in MS patients, Grytten et al found that depression was independently associated with unemployment at baseline, but not at the follow-up point, which could suggest that depression may be a consequence rather than cause of unemployment.²³

Personal demographic status and positions such as age, education level and gender are also found to influence employment status.^{11,12,16} Younger age of diagnosis and shorter duration of illness are positive determinants of work,^{12,23} where these are also positive prognostic factors in milder disease course and presentation.²⁴ Patients with higher education at diagnosis are also found to be better protected against unemployment^{12,23} and have better success in finding new employment after periods of unemployment or after receiving vocational rehabilitation services.²⁵

Gender has been an ambiguous factor in the research of predictive or determinant factors of employment in MS patients. Grytten et al found that, being female was both associated with unemployment at study initiation and shorter time to unemployment in the employed cohort.²³ The authors note that unemployment in females could not be explained by their mother roles or the number of children. Similar findings have been reported by Simmons et al using data from 667 MS patients who were surveyed longitudinally over 4 years.⁶ Sweetland et al also present similar findings from a systematic review of 89 studies on MS work outcomes and suggest that women may tend to choose home-making roles in some circumstances.¹¹ Conversely, however, some studies, such as a systematic review of 42 papers on work-related difficulties and determinants by Raggi et al, found that being male was associated with having lower workforce participation than being female.¹² The authors reported that males had 4%–26% lower employment rate and up to 4.8 times higher odds of being unemployed than females.

Work and sociostructural context and resources

Work experiences and outcomes are also influenced by how symptoms, chronicity and the progressive nature of MS are responded to and managed within the work and social-structural context. Negative relational encounters such as

discrimination, stigma and resentment from colleagues, managers or supervisors and work organizations contribute to work transitions and termination, while positive support is linked to organizational embeddedness and work continuity.^{16,26,27}

In a systematic review of factors that contribute to unemployment in MS patients, Sweetland et al identified that activity limitations affect key competencies in the work context. The inability to endure work demands (i.e., physical, high stress, long work hours, and inflexible work arrangements) can contribute to work difficulties and reasons for unemployment. Additionally, conditions of the work context itself, such as hot rooms or open plan offices, can aggravate symptomatic presentations of illness in heat-sensitive patients and make concentration problematic, adding to the challenges of continued work.¹¹ Other studies similarly found that the nature, arrangements and environment of work, such as unpredictable workloads, lack of rest time and physical temperature or exposures, can impede work ability and productivity. Conversely, roles, conditions and arrangements that provide work flexibility and control are more supportive and conducive of continued work.^{12,16}

Presenteeism, that is, work attendance despite feeling ill or unwell, which may eventuate in reduced work output, is also another phenomenon reported by working MS patients. In a study on the work productivity of 377 employed MS patients, presenteeism was correlated with increasing disability or MS-related symptoms, fatigue, depression and anxiety and reduced quality of life.²⁸ Negative events such as increased absenteeism and presenteeism tend to precede decisions of voluntary or involuntary work termination, and it is likely that many patients do not seek help or interventions from health professionals or their work organizations until such negative events or crisis unfolds.^{8,11,21–24}

Structural support, such as timely access to disease-modifying treatment and health care, antidiscrimination legislative protection and comprehensive welfare provisions, buffers the impact of a chronic illness diagnosis by offering resources to be resilient in managing the chronic course of illness.³³ For instance, countries with more active and comprehensive welfare provisions have less unemployment rates in populations with chronic illness.³⁴ The distribution of these outcomes also differs among the welfare state models such as Scandinavian, Anglo-Saxon and Bismarckian, and there is highest employment rate in chronic illness groups in social democratic welfare states with active labor market policies, higher income equality and generous welfare benefits.³⁵

Vocational services are another example of protective structural provisions. In a retrospective study of 1920 case files of individuals with MS in the US Department of Education Rehabilitation Services Case Service Report Database, it was found that 924 or 48% of patients were employed after accessing vocational rehabilitation.²⁵ Access and uptake of a variety of vocational rehabilitation services significantly improves employment outcomes. Services such as counseling and guidance, job placement facilities, job support, maintenance services and assistive tech services were significant predictors of positive employment outcomes. At case closure, it was found that more unemployed patients were receiving disability-related medical or cash benefits than employed patients.

However, access, outreach and enforcement of structural provisions vary between and within countries. This is evident both among high-, low- and middle-income countries, and through gaps in policy and practice within individual countries.^{36–38} In the case of antidiscrimination laws, several national policy definitions categorize patients with MS as a person with a disability for antidiscrimination and equal employment purposes. In the UK, the Equality Act 2010 classes MS patients as disabled from the time of diagnosis because MS is a “progressive condition”. The Americans with Disability Act includes neurologic physiologic disorders or conditions as a physical impairment, and the Amendments Act 2008 extends to include episodic MS as disability. In contrast, the policy definitions on disability in Malaysia, an upper-middle income country, focus on long-term impairments, rather than a chronic illness status. Under these conditions of context, work organizations continue the practice of soliciting pre-employment medical testing from employees, which opens up the propensity for patients to be subject to “medical status discrimination” while applying for work or new positions.^{38–40}

On another note, though many countries have discrimination laws that are meant to protect patients against discriminating employment practices, covert and indirect encounters are still reported by MS patients within countries with these legislative structures.^{29,30,32} In a hermeneutic phenomenology study conducted in Australia on why individuals with MS terminate their employment, Vickers discusses the concept of “Clayton’s choice”—“the choice you have when you do not really have a choice”. This study highlights the relational influences within a workplace and identifies that individual choices to leave work where accumulated negative experiences, such as being alienated, involuntary downgrading of duties, perceived negative attitudes or resentment from

colleagues who were rostered to work more frequently as a consequence of their requested accommodation, prompt an “ugly passage out” or “being counseled out” by organizational members.²⁶

Similar reports come from US-based surveys on the types of employment discrimination encountered by MS patients. In a survey of 200 respondents, 29% reported at least one encounter of perceived discrimination.⁴¹ These included failure of employer to provide reasonable accommodation on the job, denial or delay of promotion, different or harsher standards of performance, assignment to inappropriate jobs or tasks, restriction to a certain type of job, receiving excessive supervision, denied hire due to MS, unfair compensation and wages and forced retirement. A large majority of respondents who encountered perceived discrimination either did nothing to address the situation or eventually retired, quit or applied for security or disability benefits. Only a small number pursued and filed formal grievances through internal process, union representation, US Equal Employment Opportunity Commission or lawsuits, and of these, only a handful successfully received favorable outcomes.⁴¹

Though expensive, the use of disease-modifying therapeutics (DMTs) has been instrumental in producing overall better clinical and quality of life outcomes in the management of MS, including work productivity and retention.^{9,42} Some countries, such as Australia, report reduced difference in unemployment between MS and general populations.⁴³ The researchers on this longitudinal survey series attribute these improved outcomes to timely access to DMTs through the highly subsidized public Pharmaceutical Benefits Scheme and governmental support in encouraging work organizations to offer work accommodations.⁴³ However, not all countries have similar systems of public or universal access to DMTs. Access to medicines in many low- and middle-income countries is provided and financed through multiple public and private institutions. In Malaysia, narratives from working patients with MS provide insights on how power asymmetries and fragmented systems of access prevent timely and continued access and also jeopardize continued employability in some cases.⁴⁴

Coping styles and strategies in managing MS

MS management also involves personal proactivity and self-determination to effectively respond to the encounters, experiences and dynamics that patients face or will face in the future, so that they may navigate the long course of work with greater degrees of choice and agency. In this section,

we discuss MS-related personal coping styles and strategies and their influence on employment outcomes.

Various points in the MS course, such as diagnosis, relapses and increasing impairments, introduce and remind patients of the embodied, personal and social changes that the illness represents and brings into their lives. These include changes imminent to future life, limitations to goal achievements, shifts in self-identity, body image and self-efficacy and ability to access resources such as economic income and health care.⁴⁵ Newly diagnosed MS patients often describe states of depression and anxiety and reduction in perceived self-efficacy, quality of life and perceived health status, which were not related to concomitant neurologic symptoms or disabilities.^{46,47} For these reasons, MS, like many other chronic illnesses, is often perceived as a life disturbance, disruption, disadvantage and disorder.⁴⁸ At diagnosis, many patients are informed by their clinicians and other health professionals, or through educational literature, that MS is a life-long condition and that their condition may develop in severity and limit them either temporarily for short periods of time or more permanently as the disease progresses. Patients diagnosed at younger ages or at less-severe stages of MS must confront the potential of future impairments, while older and more progressed patients must physically and psychologically reconcile with the actual changes.⁴⁹ Likewise, a relapse often serves as a reminder, a call to confront their MS and uncertain futures and revisit their current life roles, behavioral and lifestyle choices, treatment and health care option.³⁷ The uncertainty of the illness course, deteriorating health, changing relationships and increased support needs stimulate a need to constantly appraise and evaluate the situation.

The physical and psychological course of processing this information and the consequent mental, attitudinal or behavioral changes are referred to as coping. Psychological responses to MS diagnosis may vary according to individual predispositions, circumstance and context, but can include a spectrum of emotional states or behaviors such as shock, anxiety, denial, depression, hostility, bitterness, guilt and closedness.^{50,51} Various and changing reactions and responses are observed in studies, clinical and therapy practice, which are influenced by an individual's subjective physical, psychosocial, economic and environmental context and circumstance.^{51,52} It is important to note that depression, anxiety, emotional and cognitive processing and other mental health-related issues can be seen as both neuropsychological symptoms of MS that result from disease pathology and also psychosocial responses to MS as a stressful life event

or new life dynamic that represents change. In this article, we focus on the latter.

Positive and volitional coping, adjustment or normalization can be achieved through the "ability to adapt and self-manage".⁵³ For the purpose of clarification, the term coping is used interchangeably with other near-synonymous concepts in this area of scholarship such as adjustment, self-management and other volitional attitudinal and behavioral strategies that address the lived perception, experience and embodiment of MS. These concepts, though distinct, are found to overlap and provide important lessons for practice.⁵⁴ The practice of positive psychology, such as actively choosing to focus on positive aspects, positive cognitive reframing, emotional awareness and management, spirituality, confronting fears, being hardy, acceptance, previous exposure and management of mild stressful events and social support are positive influences or predictors of physical and psychological well-being.⁵⁵

Coping styles, strategies and context

Much of MS-specific coping scholarship draws from Lazarus and Folkman's seminal work on the stress-coping model, which conceptualizes coping as "constantly changing cognitive and behavioral effort to manage specific external or internal demands that are appraised as taxing".⁵⁹ This model focuses on coping as an ongoing and fluid evaluation-response process that is embedded within the person-environment context, where the dynamic interaction between cognition and emotion prompts behavioral responses. Main components of their model include the cognitive and emotional evaluation, strategic response or action/behavioral orientation and access to resources available to individuals, which support or influence the former two aspects.⁵¹

The two most popular dimensions of coping studied and explored in MS coping research are problem- and emotion-focused coping.^{26,42,43} Problem-focused coping is the use of active strategies to directly address the source of stress, challenge or problem faced.^{59,60} In the case of MS, examples include benefit finding or cognitive reframing and goal setting, seeking out reputable sources of information and targeted resources to solve or mitigate the impact of symptoms or issues faced, engaging in healthy behavioral strategies such as regular physical activity, smoking cessation, use of disease-modifying or symptomatic treatment and lifestyle pacing to integrate regular time for rest and fatigue recovery.^{51,61,62} Emotion-focused coping involves addressing or managing the emotional responses to the evaluations of the problems or issues faced. Examples of this coping style include avoidance,

wishful thinking, denial or escapism, which can behaviorally translate into alcohol or substance use.⁶³ Further examples can be drawn from the study of personality traits on quality of life in MS patients, where correlations have been found with traits such as extraversion and neuroticism.⁶⁴ Avoidant personality traits are negatively correlated with employment and quality of life,⁶⁵ while persistence is positively correlated.⁶⁶ Levels of perceived stress and emotion-focused coping were found to be related to worse coping to MS.⁶⁷

Literature on coping styles has typically signaled the benefits of problem-focused coping over emotion-focussed coping.⁶⁸ Normalization and positive or successful coping, usually with some duration of experience in living with MS, is more associated with problem-focused coping styles and approaches.^{52,68} However, it is important to note that both styles of coping have positive and negative consequences, as it is possible that a strategy is positive in one context and negative in another.⁶⁹ The effectiveness of a coping strategy depends on the continuous appraisal in relation to the dynamics of the illness course.⁵²

Coping is also dependent on and is embedded within social and structural context. The lived experience and course of disease is contingent on the multilevel influences on an individual's circumstances in their lived sociostructural context.³³ These include variances and inequalities in access to medicines, protective legislation and welfare provisions that mitigate the negative causes and consequences of disease progression. Additionally, literature is replete with studies that demonstrate the positive effect of social support as a resource that decreases psychological distress and encourages psychological adjustments to difficult and taxing situation.^{70–72} Social support through interpersonal relations and resources mediates positive coping by encouraging positive healthy behaviors and diminishing physiological reactivity to stress.^{13,71}

Levels of disability, employment status and coping types also were predictive and correlated with the levels of depression and anxiety.⁴⁷ In a 5-year comparative and follow-up study, MS patients, in comparison to healthy controls, indicated a lower overall coping score at study initiation or baseline, and even lower scores at a 5-year follow-up, with disabled pensioners showing more tendencies of using social support, venting emotional frustrations and behavioral disengagement.⁵⁶ A study also found that coping styles changed over time and with levels of impairment.⁵⁷ The Expanded Disability Severity Score (EDSS) is a scale that categorizes the level of mobility, functional change and the need for assistive technology or aids in MS patients. Those categorized

between EDSS 3 and 6 engaged more intensively and actively with disease self-management, but were also more prone to depression with increasing disease severity. The authors suggest that successful coping at the EDSS stage of 3–6 is crucial for longer course of disease coping, management and psychological well-being.⁵⁷

Influence of psychological factors and coping styles on employment

Employed patients with positive coping tend to report more positive relational dynamics at work and a better sense of job security.⁷⁴ There is overall consensus from a broad range of studies that problem-focused coping styles and strategies provide more success in work retention and continuation.^{15,67} Denial, avoidant or emotion-focused coping was broadly related to behavioral disengagement maladaptive and unfavorable coping outcomes^{15,23,74} and is often found to be predictive or associated with unemployment or shorter time to unemployment.²³

Problem-focused strategies allow a greater sense of perceived control over issues and thereby greater drive to tackle the issue. Dorstyn et al conducted a meta-analysis of 33 studies with a combined sample of 22,864 participants on the influence of psychological factors and mental health on the employment status of patients with MS. Their overall analysis highlights that employed patients scored higher on quality of life and mood-related scales, tended to report fewer work- and illness-related challenges and adopted more problem-focused coping strategies.¹⁵

This conclusion, however, does not negate the fact that coping strategies change with time and the fluctuations of the illness. The ongoing course of MS includes fluctuating psychological states, intraindividual change and subjectivity across time. In a study of the association between psychological factors and the work instability of 208 MS patients, intrapersonal changes in psychological states such as optimistic and pessimistic outlooks were observed in 8-month duration.⁵⁸ One-third of the participants indicated a change from optimistic to pessimistic outlooks, and only a few of them (2.5%) indicated a change from pessimistic to optimistic.⁵⁸ Hence, positive coping is not synonymous with the absence of distress, and unbalanced attention to positive coping can build toward unrealistic expectations of consistent strength and perpetual positive or successful coping.¹³

Maladaptive coping mechanisms, such as behavioral disengagement, that is, the reduction of efforts to manage stressors, and abandoning care or concern over the future

course of outcomes, which will emerge from their (lack) of efforts, can contribute to negative work encounters and dynamics and, ultimately, negative work outcomes such as work termination.^{22,74} Denial as a strategy can be considered a maladaptive coping mechanism if it causes more psychological distress and discourages one from pursuing active coping efforts and is connected with behavioral disengagement.²³ On the other hand, denial in the short term can be positive, offering one time to adjust to and manage the stressor, a form of stop-gap measure.⁷⁵ Emotion-focused strategies may also be beneficial for a short period of time when issues are perceived to be beyond the control of the individual and can help by alleviating stress and anxiety.⁷³

Related to denial or emotion-focussed coping behavior is the tendency for employed patients to “mask” or conceal their true feelings, concerns or grievances and work difficulties, often citing impression management or self-preservation goals in the workplace.^{22,76,77} Vickers writes about the phenomenon of masking, even in working patients who had disclosed their illness status to employers. She suggests that this behavior is not helpful, but that the alternative may not be as well. Several other qualitative studies also highlight evasive and denial-based work behaviors in the workplace, including downplaying illness status to prevent being perceived as a burden, working harder to meet performance expectations and passive acceptance of perceived discrimination.^{76,78} In many cases, patients make decisions to disclose or seek help only when a negative event or illness-related crisis, such as increasing impairments or formal need for accommodations, occurs.^{4,10,20–23,79} Often, the timing of these decisions and actions does not fully address or rectify their concerns or difficulties and leads to negative events such as work termination.

Negative encounters or work events such as formal communication on productivity, verbal criticism, declines in productivity levels and need for work accommodation or aid usually precede work loss or termination.^{29–32} In a questionnaire-based study on the association between the encounter of negative work experiences and the use of various coping strategies, reports of negative events were associated with higher use of emotion-focused coping and absenteeism.³⁰ The researchers attribute the higher frequency of negative work events to individuals’ focus on managing the emotions that accompany the issue, rather than the work or task-related issue itself.³⁰ The study also assessed the levels of physical, psychological and cognitive functioning, but the researchers suggest that coping styles may be more influential in managing workplace dynamics and encounters, more so

than self-reported cognition, physical abilities, fatigue and depression.

Recommended strategies to support continued employment at personal, work and structural levels of context

We have discussed some of the known individual, work-based and structural factors that positively and negatively influence continuous employment in individuals with MS. On the basis of the above discussion, we provide some strategies that can facilitate the overall aim of continued and meaningful work.

Employment can be challenging and a source of distress when continued without a sense of engagement and control.¹⁵ At a personal level, patients need to proactively and efficiently navigate the dynamics of work and identify and pursue strategies that are subjectively meaningful and sustainable over time and the unpredictable course of MS. Ideally, strategies should engage a variety of situation-appropriate coping strategies – both problem and emotion focused – and uniquely draw from individual subjectivities and creativities in combined physical, behavioral, cognitive, emotional and social domains.^{13,80,81}

Necessary personal-level coping strategies should include goal-setting and problem-solving skills, positive cognitive reframing and engagement in a continuous process of evaluating and addressing circumstances in real time. Active coping or behavioral engagement, as opposed to over-reliance on denial-based, evasion or behavioral disengagement, is necessary to address or mitigate the occurrence and impact of negative work events.³⁰ Placing a focus on the individual’s work ability rather than disability, inculcating personal persistence and higher levels of social extroversion are examples of practices that can have a positive influence on employment.⁶⁶

At a work context level, patients also need effective resources and skills to manage the interpersonal and relational dynamics within their employment contexts. Workplace dynamics influences a patient’s emotional states, career development and work-related self-efficacy beliefs.⁸² Positive support from employment organizations and colleagues offers an opportunity and platform to empower, realign and acquire mastery over illness and its disruptions. However, the same can also be the context for negative psychosocial encounters and experiences at organizational and interpersonal levels.⁷¹ Patients encounter a spectrum of dynamics from employers, such as being overinvolved in micromanaging, checking in too often or being oversolicitous; being indifferent and underinvolved, which may be

perceived by the patient as being inconsiderate;⁸² and more negatively, being stigmatic, overcritical and malicious toward the patient. Employed individuals with a sense of job and psychological security at work tend to report positive work dynamics and relationships.⁷⁴ These dynamics are likely outcomes of balanced and positive relational dynamics with members of work organizations. Kirk-Brown and Van Dijk⁸² and Kirk-Brown and Dijk⁸³ discuss the outcomes and benefits of psychological safety in the workplace and the level of comfort achieved in order to take interpersonal risks to discuss personal issues with trust and respect. The authors conceptually relate encounters of discrimination, stigma and paternalism or solicitude to low psychological safety, in turn, low work-self efficacy and, consequently, increased turnovers and restrictions in professional growth. Drawing from their research, patients could derive beneficial outcomes from strategizing and striving to create conditions and relations that support personal psychological safety.

Utilizing and engaging supportive structural features are a vital component that contributes to continued work. Depending on the national or state settings, patients have various levels of access to supportive and protective structural resources. These include welfare provisions, legal protection against discrimination and allocated paid sick or disability leave, vocational rehabilitation, affordable universal health care and risk-pooled health financing that reduces the need for out-of-pocket health expenditure. Cumulatively, these resources help diminish the cumulative health and economic and social challenges by providing patients the resources and capabilities to be resilient toward risk and detriment.³³ In national settings with existing supportive structures, health professionals, patient societies and even employers should encourage uptake of these provisions. Nevertheless, as highlighted in the earlier sections, not all countries provide sufficient and cohesive levels of structural resources and protection. In countries with gaps in structural support, stronger patient-targeted protection, educational programs and national policy advocacy are required to address these gaps in policy and practice.

Conclusion

In this article, we discussed the employment of individuals with MS, with a focus on the influence and interactions between disease and the psychological, social and structural factors that contribute to their work experiences and outcomes. To achieve better work outcomes in MS patients, there is a need to equip them with early assessment, advice and resources to manage their work futures. Health care providers should consider the benefits of encouraging

continued employment and the psychological impact of nonemployment.¹⁵ We present some strategic suggestions based on literature that can help patients to actively pursue positive work relations and arrangements and subjectively meaningful goals.

Nevertheless, work challenges and issues are not always solved by personal-level action or effort. Conditions and dynamics within the work and sociostructural context play an integral role in shaping their work experiences, decisions and outcomes. Patients should explore how to leverage relational dynamics within the work context, but should simultaneously be aware that not all conditions and dynamics are necessarily amenable to the achievement of continued work. For this, greater multisectoral effort, particularly from employers of MS patients, is required to facilitate continued work and mitigate work challenges.

The aim of structural protection is to buffer the effect of any negative dynamics that contributes to their position of disadvantage. Where available, patients should be made aware of, and encouraged to utilize, structural protections that may enable them to address their illness–work challenges. There is also a necessity to expand research and policy focus to include considerations of resource-limited structural settings, such as in many low- and-middle-income countries, where differences in conditions of context can play a role in individual employment and employability.

Acknowledgments

We thank the three anonymous reviewers for their constructive feedback and suggestions. This review is dedicated to the committee and members of the Multiple Sclerosis Society of Malaysia.

Author contributions

All authors contributed toward data analysis, drafting and revising the paper and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

References

1. Ernstsson O, Gyllenstein H, Alexanderson K, Tinghög P, Friberg E, Norlund A. Cost of illness of multiple sclerosis - a systematic review. *PLoS One*. 2016;11(7):e0159129.
2. Patti F, Pozzilli C, Montanari E, et al. Effects of education level and employment status on HRQoL in early relapsing-remitting multiple sclerosis. *Mult Scler*. 2007;13(6):783–791.
3. Yamout B, Issa Z, Herlopian A, et al. Predictors of quality of life among multiple sclerosis patients: a comprehensive analysis. *Eur J Neurol*. 2013;20(5):756–764.

4. Playford E. Work status in MS: a proxy measure for comprehensive MS management. *Mult Scler J*. 2016;22(14):1766–1767.
5. Australian Institute of Health and Welfare. Chronic disease and participation in work [webpage on the Internet]. Cat. no. PHE 109. Canberra: AIHW; 2009. Available from: <http://www.aihw.gov.au/publication-detail?id=6442468211>. Accessed May 15, 2014.
6. Simmons RD, Tribe KL, McDonald EA. Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management. *J Neurol*. 2010;257(6):926–936.
7. Jennum P, Wanscher B, Frederiksen J, Kjellberg J. The socioeconomic consequences of multiple sclerosis: a controlled national study. *Eur Neuropsychopharmacol*. 2012;22(1):36–43.
8. Julian LJ, Vella L, Vollmer T, Hadjimichael O, Mohr DC. Employment in multiple sclerosis: exiting and re-entering the work force. *J Neurol*. 2008;255(9):1354–1360.
9. Kobelt G, Thompson A, Berg J, Gannedahl M, Eriksson J; MSCOI Study Group; European Multiple Sclerosis Platform. New insights into the burden and costs of multiple sclerosis in Europe. *Mult Scler*. 2017;23(8):1123–1136.
10. O'Connor RJ, Cano SJ, Ramió i Torrentà L, Thompson AJ, Playford ED. Factors influencing work retention for people with multiple sclerosis: cross-sectional studies using qualitative and quantitative methods. *J Neurol*. 2005;252(8):892–896.
11. Sweetland J, Howse E, Playford ED. A systematic review of research undertaken in vocational rehabilitation for people with multiple sclerosis. *Disabil Rehabil*. 2012;34(24):2031–2038.
12. Raggi A, Covelli V, Schiavolin S, Scaratti C, Leonardi M, Willems M. Work-related problems in multiple sclerosis: a literature review on its associates and determinants. *Disabil Rehabil*. 2016;38(10):936–44.
13. Stanton AL, Revenson TA, Tennen H. Health psychology: psychological adjustment to chronic disease. *Annu Rev Psychol*. 2007;58(1):565–592.
14. Cornish F, Gillespie A. A pragmatist approach to the problem of knowledge in health psychology. *J Health Psychol*. 2009;14(6):800–809.
15. Dorstyn DS, Roberts RM, Murphy G, Haub R. Employment and multiple sclerosis: a meta-analytic review of psychological correlates. *J Health Psychol*. 2017;1359105317691587.
16. Multiple Sclerosis International Federation. Global MS Employment Report 2016 [webpage on the Internet]. MS International Federation. Available from: <https://www.msif.org/about-us/advocacy/employment-and-ms/>. Published May 2016. Accessed June 3, 2016.
17. Ivanova JI, Birnbaum HG, Samuels S, Davis M, Phillips AL, Meletiche D. The cost of disability and medically related absenteeism among employees with multiple sclerosis in the US. *Pharmacoeconomics*. 2009;27(8):681–691.
18. Vijayasingham L, Jogulu U, Allotey P. Work change in multiple sclerosis as motivated by the pursuit of illness-work-life balance: a qualitative study. *Mult Scler Int*. 2017;2017:8010912.
19. D'hooghe M, Nagels G, Bissay V, De Keyser J. Modifiable factors influencing relapses and disability in multiple sclerosis. *Mult Scler*. 2010;16(7):773–785.
20. Kirk-Brown AK, Dijk PV, Simmons RD, Bourne MP, Cooper BK. Disclosure of diagnosis of multiple sclerosis in the workplace positively affects employment status and job tenure. *Mult Scler J*. 2014;20(7):871–876.
21. Moore P, Harding KE, Clarkson H, Pickersgill TP, Wardle M, Robertson NP. Demographic and clinical factors associated with changes in employment in multiple sclerosis. *Mult Scler J*. 2013;19(12):1647–1654.
22. Vijayasingham L. Work right to right work: an automythology of chronic illness and work. *Chronic Illn*. 2018;14(1):42–53.
23. Grytten N, Skåar AB, Aarseth JH, et al. The influence of coping styles on long-term employment in multiple sclerosis: a prospective study. *Mult Scler J*. 2017;23(7):1008–1017.
24. Runmarker B, Andersen O. Prognostic factors in a multiple sclerosis incidence cohort with twenty-five years of follow-up. *Brain*. 1993;116(1):117–134.
25. Chiu C-Y, Chan F, Bishop M, da Silva Cardoso E, O'Neill J. State vocational rehabilitation services and employment in multiple sclerosis. *Mult Scler J*. 2013;19(12):1655–1664.
26. Vickers M. Why People with MS are really leaving work: from a Clayton's choice to an ugly passage – a phenomenological study [webpage on the Internet]. *Rev Disabil Stud Int J*. 2014;4(4):43–45. Available from: <http://www.rds.hawaii.edu/ojs/index.php/journal/article/view/245>. Accessed October 1, 2015.
27. Vickers MH. “For the crime of being different...”: multiple sclerosis, teams, and stigmatisation at work—lessons from a case study. *Empl Responsib Rights J*. 2011;24(3):177–195.
28. Glanz BI, Dégano IR, Rintell DJ, Chitnis T, Weiner HL, Healy BC. Work productivity in relapsing multiple sclerosis: associations with disability, depression, fatigue, anxiety, cognition, and health-related quality of life. *Value Health*. 2012;15(8):1029–1035.
29. Benedict RH, Rodgers JD, Emmert N, Kininger R, Weinstock-Guttman B. Negative work events and accommodations in employed multiple sclerosis patients. *Mult Scler J*. 2014;20(1):116–119.
30. van der Hiele K, van Gorp DAM, Benedict RHB, et al. Coping strategies in relation to negative work events and accommodations in employed multiple sclerosis patients. *Mult Scler J Exp Transl Clin*. 2016;2:2055217316680638.
31. Frndak SE, Kordovski VM, Cookfair D, Rodgers JD, Weinstock-Guttman B, Benedict RH. Disclosure of disease status among employed multiple sclerosis patients: association with negative work events and accommodations. *Mult Scler J*. 2015;21(2):225–234.
32. Kordovski VM, Frndak SE, Fisher CS, Rodgers J, Weinstock-Guttman B, Benedict RHB. Identifying employed multiple sclerosis patients at-risk for job loss: when do negative work events pose a threat? *Mult Scler Relat Disord*. 2015;4(5):409–413.
33. Vijayasingham L, Allotey P. Reframing non-communicable diseases. *Lancet Glob Health*. 2017;5(11):e1070.
34. Burström, B, Whitehead M, Lindholm C, Diderichsen F. Inequality in the social consequences of illness: how well do people with long-term illness fare in the British and Swedish labor markets? *Int J Health Serv*. 2000;30(3):435–451.
35. van der Wel KA, Dahl E, Thielen K. Social inequalities in “sickness”: does welfare state regime type make a difference? A multilevel analysis of men and women in 26 European countries. *Int J Health Serv Plan Adm Eval*. 2012;42(2):235–255.
36. Browne P, Chandraratna D, Angood C, et al. Atlas of multiple sclerosis 2013: a growing global problem with widespread inequity. *Neurology*. 2014;83(11):1022–1024.
37. Hickey D, Leatham O, Macaulay R. Inequalities in access to treatment for multiple sclerosis in England continue despite service improvement initiatives and policy reforms. *Value Health*. 2015;18(7):A764.
38. Vijayasingham L. Closing the gap on employment rates: success stories pave the way for policy works-in-progress [webpage on the Internet]. March 2017. Available from: <http://journals.sagepub.com/eprint/cNSK7rSVA7kEItfS7gN/full>. Accessed March 16, 2017.
39. Vijayasingham L, Jogulu U. Is mild episodic chronic illness a disability? A reflexive exploration in a middle income country. *Acad Manag Proc*. 2017;2017(1):13308.
40. Vijayasingham L, Jogulu UD. Organizational meanings of chronic illness in a middle income country. *Acad Manag Proc*. 2016;2016(1):15658.
41. Roessler RT, Neath J, McMahon BT, Rumrill PD. Workplace discrimination outcomes and their predictive factors for adults with multiple sclerosis. *Rehabil Couns Bull*. 2007;50(3):139–152.
42. Messmer Uccelli M, Specchia C, Battaglia MA, Miller DM. Factors that influence the employment status of people with multiple sclerosis: a multi-national study. *J Neurol*. 2009;256(12):1989–1996.
43. Dijk PAV, Kirk-Brown AK, Taylor B, Mei I van der. Closing the gap: longitudinal changes in employment for Australians with multiple sclerosis. *Mult Scler J*. 2017;23(10):1415–1423.
44. Vijayasingham L, Jogulu U, Allotey P. Challenges for accessing and financing high-cost medicines in multipayer systems: case studies of multiple sclerosis in Malaysia. *Crit Public Health*. 2017;1–10.
45. Charmaz K. Measuring pursuits, marking self: meaning construction in chronic illness. *Int J Qual Stud Health Well-Being*. 2006;1(1):27–37.

46. Possa MF, Minacapelli E, Canale S, Comi G, Martinelli V, Falautano M. The first year after diagnosis: psychological impact on people with multiple sclerosis. *Psychol Health Med*. 2017;22(9):1063–1071.
47. Tan-Kristanto S, Kiropoulos LA. Resilience, self-efficacy, coping styles and depressive and anxiety symptoms in those newly diagnosed with multiple sclerosis. *Psychol Health Med*. 2015;20(6):635–645.
48. Bury M. Sociological theory and chronic illness: current perspectives and debates. *Österr Z Für Soziol*. 2002;27(4):7–22.
49. Kalb R. The emotional and psychological impact of multiple sclerosis relapses. *J Neurol Sci*. 2007;256:S29–S33.
50. Livneh H, Antonak RF. Psychosocial adaptation to chronic illness and disability: a primer for counselors. *J Couns Dev*. 2005;83(1):12–20.
51. McNulty K. Coping with multiple sclerosis: considerations and interventions. In: Martz E, Livneh H, editors. *Coping with Chronic Illness and Disability*. USA: Springer US; 2007:289–311. Available from: http://link.springer.com/chapter/10.1007/978-0-387-48670-3_14. Accessed August 24, 2015.
52. Bianchi V, Pozzilli C. Coping and multiple sclerosis. In: Brochet B, editor. *Neuropsychiatric Symptoms of Inflammatory Demyelinating Diseases*. Cham: Springer International Publishing; 2015:121–137.
53. Huber M, Knottnerus JA, Green L, et al. How should we define health? *BMJ*. 2011;343:d4163–d4163.
54. Auduly Å, Packer T, Hutchinson S, Roger KS, Kephart G. Coping, adapting or self-managing-what is the difference? A concept review based on the neurological literature. *J Adv Nurs*. 2016;72(11):2629–2643.
55. Foley FW. Psychology of multiple sclerosis. In: Brochet B, editor. *Neuropsychiatric Symptoms of Inflammatory Demyelinating Diseases*. Cham, Switzerland: Springer International Publishing; 2015:107–119.
56. Lode K, Bru E, Klevan G, Myhr KM, Nyland H, Larsen JP. Coping with multiple sclerosis: a 5-year follow-up study. *Acta Neurol Scand*. 2010;122(5):336–342.
57. Rommer PS, Sühnel A, König N, Zettl U-K. Coping with multiple sclerosis-the role of social support. *Acta Neurol Scand*. 2017;136(1):11–16.
58. Wicks C, Ward K, Stroud A, Tennant A, Ford H. Multiple sclerosis and employment: associations of psychological factors and work instability. *J Rehabil Med*. 2016;48(9):799–805.
59. Lazarus RS, Folkman S. Transactional theory and research on emotions and coping. *Eur J Personal*. 1987;1(3):141–169.
60. Folkman S, Lazarus RS. The relationship between coping and emotion: implications for theory and research. *Soc Sci Med*. 1988;26(3):309–317.
61. Pakenham KI, Cox S. The dimensional structure of benefit finding in multiple sclerosis and relations with positive and negative adjustment: a longitudinal study. *Psychol Health*. 2009;24(4):373–393.
62. Hedström A, Olsson T, Alfredsson L. Smoking is a major preventable risk factor for multiple sclerosis. *Mult Scler J*. 2016;22(8):1021–1026.
63. Radnitz CL, Tiersky L. Psychodynamic and cognitive theories of coping. In: Martz E, Livneh H, editors. *Coping with Chronic Illness and Disability*. USA: Springer US; 2007:29–48. Available from: http://link.springer.com/chapter/10.1007/978-0-387-48670-3_2. Accessed August 24, 2015.
64. Zarbo IR, Minacapelli E, Falautano M, Demontis S, Carpentras G, Pugliatti M. Personality traits predict perceived health-related quality of life in persons with multiple sclerosis. *Mult Scler J*. 2016;22(4):551–558.
65. Mohamadi A, Davoodi-Makinejad M, Azimi A, Nafissi S. Personality characteristics in MS patients: the role of avoidant personality. *Clin Neurol Neurosurg*. 2016;144:23–27.
66. Strober LB, Christodoulou C, Benedict RH, et al. Unemployment in multiple sclerosis: the contribution of personality and disease. *Mult Scler J*. 2012;18(5):647–653.
67. Dennison L, Moss-Morris R, Chalder T. A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clin Psychol Rev*. 2009;29(2):141–153.
68. Pakenham KI. Adjustment to multiple sclerosis: application of a stress and coping model. *Health Psychol*. 1999;18(4):383–392.
69. Mikula P, Nagyova I, Krokavcova M, et al. Coping and its importance for quality of life in patients with multiple sclerosis. *Disabil Rehabil*. 2014;36(9):732–736.
70. Hatchett L, Friend R, Symister P, Wadhwa N. Interpersonal expectations, social support, and adjustment to chronic illness. *J Pers Soc Psychol*. 1997;73(3):560–573.
71. Kosciulek JF. The social context of coping. In: Martz E, Livneh H, editors. *Coping with Chronic Illness and Disability*. USA: Springer US; 2007:73–88. Available from: http://link.springer.com/chapter/10.1007/978-0-387-48670-3_4. Accessed August 24, 2015.
72. King G. Social support processes and the adaptation of individuals with chronic disabilities. *Qual Health Res*. 2006;16(7):902–925.
73. Carver CS, Vargas S. Stress, coping, and health. In: *The Oxford Handbook of Health Psychology*. Oxford University Press; 2012. August 2011.
74. Strober LB, Arnett PA. Unemployment among women with multiple sclerosis: the role of coping and perceived stress and support in the workplace. *Psychol Health Med*. 2016;21(4):496–504.
75. Suls J, Fletcher B. The relative efficacy of avoidant and nonavoidant coping strategies: a meta-analysis. *Health Psychol*. 1985;4(3):249–288.
76. Grytten N, Måseide P. “What is expressed is not always what is felt”: coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. *Chronic Illn*. 2005;1(3):231–243.
77. Vickers MH. Dark secrets and impression management: workplace masks of people with multiple sclerosis (MS). *Empl Responsib Rights J*. 2017;29(4):175–195.
78. Mak AKY, Chaidaroon S, Fan G, Thalib F. Unintended consequences: the social context of cancer survivors and work. *J Cancer Surviv*. 2014;8(2):269–281.
79. Munir F, Leka S, Griffiths A. Dealing with self-management of chronic illness at work: predictors for self-disclosure. *Soc Sci Med*. 2005;60(6):1397–1407.
80. Carel H. *Illness: The Cry of the Flesh*. UK: Routledge; 2016.
81. Sanderson T, Calnan M, Morris M, Richards P, Hewlett S. Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Sociol Health Illn*. 2011;33(4):618–633.
82. Kirk-Brown AK, Van Dijk PA. An empowerment model of workplace support following disclosure, for people with MS. *Mult Scler J*. 2014;20(12):1624–1632.
83. Kirk-Brown A, Dijk PV. An examination of the role of psychological safety in the relationship between job resources, affective commitment and turnover intentions of Australian employees with chronic illness. *Int J Hum Resour Manag*. 2016;27(14):1626–1641.

Degenerative Neurological and Neuromuscular Disease

Publish your work in this journal

Degenerative Neurological and Neuromuscular Disease is an international, peer-reviewed, open access journal focusing on research into degenerative neurological and neuromuscular disease, identification of therapeutic targets and the optimal use of preventative and integrated treatment interventions to achieve improved outcomes, enhanced

survival and quality of life for the patient. The manuscript management system is completely online and includes a very quick and fair peer-review system. Visit <http://www.dovepress.com/testimonials.php> to read real quotes from published authors.

Submit your manuscript here: <https://www.dovepress.com/degenerative-neurological-and-neuromuscular-disease-journal>

Dovepress