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Cognitive and behavioural correlates of different domains of psychological adjustment in early-stage multiple sclerosis

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Abstract

Objective: This study investigated a cognitive–behavioural model of adjustment to multiple sclerosis (MS). It aimed to determine the contribution of cognitions and behaviours to the explanation of two distinct adjustment outcomes above and beyond measures of MS severity. Illness-related functional impairment was anticipated to be most strongly related to unhelpful thoughts and behaviours that were specific for MS and the experience of symptoms. Psychological distress was hypothesised to be most strongly related to more general unhelpful cognitions about the self and emotions. **Methods:** Ninety-four people with MS completed questionnaires. Correlations and hierarchical multiple regressions determined the relative contribution of illness severity, cognitions, and behaviours to the prediction of psychological distress and functional impairment. **Results:** Illness-related functional impairment was related to disease severity, progressive versus relapsing–remitting disease, and unhelpful illness perceptions and cognitive and behavioural responses to symptoms. Illness severity factors accounted for a significant 23.7% of the variance in functional impairment ($P<.001$). Cognitive and behavioural variables explained a further 22.6% of the variance ($P<.001$), with behavioural responses to symptoms emerging as the strongest predictor. The correlates of distress were unhelpful beliefs about the self, unhelpful beliefs about emotions, acceptance, and unhelpful cognitive responses to symptoms and illness perceptions. Illness severity factors explained only 2.2% of the variance in distress ($P>.05$), while cognitive and behavioural variables accounted for 37.1% ($P<.001$). Unhelpful beliefs about the self were the strongest predictor. **Conclusion:** Longitudinal and experimental research is required to investigate potential causal relationships. However, the cognitions and behaviours identified as important for adjustment are potentially modifiable and thus may be useful to address within interventions for adjustment to MS.

Keywords: Multiple sclerosis; Adjustment; Distress; Impairment; Cognitive; Behavioural

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Introduction

Multiple sclerosis (MS) is a neurological disease that is thought to affect more than 2.5 million people worldwide [1]. MS symptoms vary enormously among people with MS (PwMS), but can include spasticity; disturbances in strength, balance, sensation, and vision; bowel and bladder disturbances; sexual dysfunction; cognitive impairment; pain; and fatigue. Around 85% of patients present with a relapsing–remitting form of MS. However, for the majority, the disease progresses over time, and impairment increases [2]. Although there is no cure for MS, available disease-modifying drugs are somewhat successful in reducing the severity and frequency of relapses and disease progression [3,4].

Individuals with MS are faced with uncertainty about the future, unpleasant and unpredictable symptoms, difficult treatment regimes, and drug side effects. MS can have profound consequences, including disruption of life goals,

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employment, income, relationships, social and leisure activities, and activities of daily living. This may be particularly significant because for the majority of PwMS, the disease begins in young adulthood, a period that is often important for career development and starting families. Therefore, it is not surprising that many patients encounter difficulties with psychosocial adjustment. Research demonstrates elevated levels of depression and psychological distress [5,6], anxiety [7], relationship and social dysfunction [8,9], and reduced quality of life [6,10] in PwMS.

Illness-related factors can influence levels of adjustment (e.g., Chwastiak et al. [11] and McIvor et al. [12]). Such factors include MS type, length of illness, and remission status. MS severity also appears to be important; this is most commonly measured by the Expanded Disability Status Scale (EDSS [13]), which assesses gait disturbance and other symptoms including cognitive impairment, visual disturbances, and bladder dysfunction. However, illness-related factors are not consistently associated with adjustment outcomes and only predict modest amounts of the variance. In a recent systematic review of the psychological literature in MS, we showed that a range of cognitive and behavioural factors are important in predicting and explaining individual differences in adjustment [14]. Importantly, it may be possible to address these factors in psychological interventions in order to improve adjustment in PwMS. As a result of the review, we suggested a cognitive–behavioural model of adjustment to MS. According to the model, MS development, diagnosis, and progression are conceptualised as critical events that disrupt emotional equilibrium and quality of life, at least in the short term [13]. Whether a person continues to be distressed and to perceive one's quality of life as poor in the longer term is influenced by a range of variables. These include the individual's cognitive and behavioural responses to the critical event, as well as social and environmental factors. Our review identified factors for which existing research had clearly established links to adjustment (e.g., coping strategies, perceived social support). However, we also suggested a number of cognitive and behavioural variables that warrant further investigation [14].

Our review suggested that variables derived from health psychology frameworks, such as illness representations [15] and how people interpret and respond to symptoms [16], may be important for adjustment. There have, however, been few studies of these factors thus far. The role of acceptance in MS also requires more research. Only two studies identified in the review examined acceptance. Both explored its relationship to marital adjustment, and the findings were inconsistent [17,18]. The paucity of research into acceptance is surprising, given the enduring belief held by many patients and health professionals that developing an acceptance of the disease is critical for adjustment [19].

The review also indicated that variables derived from cognitive models of psychopathology may be important for understanding and predicting depression in PwMS. These include cognitive biases towards negative information, and attributions and unhelpful or negative beliefs about oneself, the world, and the future. However, only a handful of studies have been conducted so far [20–24], and these factors have not been studied in relation to broader adjustment outcomes such as social and role functioning and quality of life. Another variable deemed worthy of exploration is people's beliefs about experiencing and expressing negative emotions. Although no existing quantitative studies have explored this area, our recent qualitative study suggested that beliefs about emotions are important [25]. Our participants described how strong negative emotions are almost inevitable in response to MS-related challenges such as diagnosis and relapse. Participants also expressed feeling that ongoing negative emotions should not be tolerated and that demonstrating positivity and "putting on a brave face" is desirable. Such beliefs about the unacceptability of negative emotions have been noted in populations with other mental and physical health problems [26–29] and are thought to play a role in the development and maintenance of clinical problems [30].

The current study sought to extend the promising areas of research highlighted above. We aimed to understand the types of variables that are related to adjustment in order to pinpoint factors that could be targeted by interventions seeking to improve adjustment outcomes for PwMS. Adjustment is multifaceted, comprising various outcomes such as psychological distress, functional impairment, and quality of life. Therefore, this study explored how different factors might contribute to different forms of adjustment. We examined functional impairment (the impact of MS on the ability to perform key roles such as work and social activities) and psychological distress. These outcomes capture two key aspects of adjustment; although potentially related, these are, in fact, distinct dimensions.

This study also addressed some important methodological limitations of previous studies. Most existing studies fail to measure or account for the influence of illness-related factors such as MS type and disability status. They cannot therefore conclude that the psychological factors that explain variance in adjustment outcomes are not simply a response to more severe and advanced disease. This study examined the influence of cognitive and behavioural variables over and above MS type and severity factors. It also addressed sampling problems inherent in existing research. Many studies do not distinguish between patients at different points in their disease trajectories, where adjustment issues may differ. Very few studies have examined adjustment in people relatively early on in their disease course despite research suggesting that distress is apparent early on and that patients desire psychological support at this stage [6,25]. We therefore specifically sampled patients early on in their disease trajectory. Furthermore, previous studies have typically drawn participants from voluntary patient organisations who represent only a percentage of all PwMS. Those who join support groups may have different ways of dealing with the illness than those who do not join such groups. For a