

Examining the impact of multiple sclerosis on health-related quality of life

Risma Fauziyah*

Editorial office, Journal of Neuroscience and Neuropharmacology, Belgium

Corresponding Author*

Risma Fauziyah,

Department of Neuroscience, Belgium,

Email: rismafauziyah77@gmail.com

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Abstract

Health-related quality of life (HR-QOL) is a crucial sign of health in MS patients since MS symptoms have an impact on many aspects of everyday living. Physicians may choose to concentrate on physical or cognitive changes in MS patients since these assessments involve physician- or psychologist-administered examinations rather than patient self-reporting. However, there are several approved techniques available for evaluating HR-QOL in clinical studies. These techniques have been used in several studies to evaluate how common disease-modifying therapies (DMTs), such as interferon and glatiramer acetate, affect MS patients' HR-QOL. Numerous of these studies discovered that DMTs enhanced different aspects of patients' HR-QOL; however, the results were difficult to interpret due to issues with research design, such as small patient populations or a lack of placebo control for comparison. The most recent DMT, natalizumab, was found to significantly enhance HR-QOL in individuals with relapse MS in two sizable, randomized, placebo-controlled trials. Furthermore, natalizumab's effects on HR-QOL were clear regardless of the characteristics of the disease. The natalizumab studies convincingly show that HR-QOL assessments may be pertinent in the context of clinical trials and support the idea that patient-reported outcomes, including HR-QOL measures, should be used in clinical trials to more thoroughly evaluate treatment efficacy.

Introduction

Multiple sclerosis (MS) is a chronic, degenerative neurological disorder that has a significant influence on the health-related quality of life of sufferers (HRQoL), encompasses broad disease effects in domains such as social and role functioning, and correlates with patient priorities more closely than traditional measures of disease severity. Identifying all factors influencing each domain of HRQoL and determining their relative importance has direct implications for individual care, service development, and the promotion of new psychological intervention strategies in MS patients.

A variety of variables have been identified as influencing HRQoL in MS patients. Physical impairment, increasing illness, exhaustion, pain, and cognitive, and psychological problems are examples of these. Recent research has used multivariate models to investigate the influence of a variety of components, however, in those that included all elements concurrently, only mental and physical component scores, rather than domain scores, were simulated. The impact of sickness perception in altering HRQoL in MS has received little attention. Disease perceptions are people's cognitive representations of their illness. They have been proven to predict adaptability in individuals with a variety of medical illnesses and are treatable. Schiaffino et al. discovered a link between disease perception and depression using the Implicit Models of Illness Questionnaire.

Vaughan et al. discovered a link between sickness perception, anxiety, and self-esteem. Two studies have demonstrated a link between perceived consequences, a component of sickness perception, and physical function, although neither used the Extended Impairment Status Scale (EDSS) to assess objective disability. This study demonstrates that disease perception can have an impact on HRQoL in MS patients, although it is unclear if this effect is independent of physical impairment, depression, tiredness, and pain. The purpose of this study, the first of its type in an Australian community, was to employ a large sample to assess the relative contribution of individual variables to each category of HRQoL, with a particular focus on the effect of sickness perception. Confirming an independent function for sickness perceptions might lead to novel approaches to psychological treatments in MS patients. Individual domain data may be employed in individual treatment and service development, and their significance is further confirmed by the discovery that persons with MS value some domains more than physical impairment, including social functioning, vitality, general health, and mental health. All factors previously identified as having a substantial influence on HRQoL in MS were put concurrently into the regression analyses in this study, whereas those previously proved not to have a strong effect on HRQoL, such as socio-demographic variables, were not. We hypothesized that: (a) illness perception would be a significant independent predictor of HRQoL in people with MS, particularly in the domains of the role and social function; (b) physical disability would have the greatest effect in the physical function domain but have a significant independent effect across a broader range of domains than previously described, and (c) depression would have the greatest impact in domains other than physical function and physical role function.

Quality of life measures related to health

There has been a substantial increase in interest in evaluating outcomes in MS during the past 20 years. The Expanded Disability Status Assessment (EDSS), a combined impairment/activity limits scale based on neurological examination of eight functional systems, including ambulation/mobility status, is the standardized tool that is used the most frequently. Despite serious flaws such as a bias toward locomotor function, variable sensitivity to change depending on scale score, and low inter-rater reliability, the EDSS is commonly used by academics and medical professionals since its results are simple to understand for everyone. Recent years have seen an increase in awareness of the value of MS outcome evaluation from the standpoint of the patient. The usage of MS-specific questionnaires and the number of publications on health-related quality of life (HRQOL) both progressively increased after 1992. While disease-specific instruments were created and validated, generic measures were utilized to evaluate MS. There are seven MS-specific HRQOL tests available, and they were all released between 1995 and 2001. There are two generic modules (SF-36 or FACT-G) and one MS-specific module. People with MS were often involved in their development. Except for the MS Quality of Life 54 (MSQOL-54), all surveys can only be accessed in their original versions. However, the Functional Assessment of MS (FAMS), which has been translated into a variety of languages, is also available in Portuguese. Four of the seven instruments looked at responsiveness in some detail, but overall, change sensitivity has received little study.

Clinical practice and health-related quality of life

The range of areas that the disease may affect as well as the effect of this impairment on coping mechanisms has drawn attention to HRQOL studies in MS. When compared to the general population, people with MS, particularly those with a progressive course, report worse physical functioning; they are also more likely to experience fatigue and depression, and they are also more likely to be unemployed.

Unexpectedly, it has been shown that MS patients and their neurologists' priorities about disability in several HRQOL categories differ considerably. The ultimate goal of HRQOL measurement is to provide a thorough assessment of patients' health conditions, to act as a baseline for the adaptation of interventions, whether pharmaceutical or non-pharmaceutical, and to gauge the effectiveness of those interventions, both in clinical trials and in routine care. HRQOL tools are anticipated to be particularly helpful in routine care, where they may enhance the detection of disease aspects that would otherwise go unnoticed, aid clinicians in understanding patient priorities, particularly in term of treat-

-ment goals, facilitate physician-patient communication, and encourage shared decision-making. Furthermore, HRQOL data from clinical studies can give doctors knowledge they can utilize to inform their patient conversations. HRQOL evaluations are not required as study objectives for MS research by the European Agency for the Evaluation of Medicinal Products. Even when HRQOL endpoints are taken into account, data collection and reporting are typical of low quality, which prevents cost-effectiveness issues from being investigated, such as sustained function, decreased work missed, and higher emotional well-being.