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Health-related quality of life in patients with longstanding ‘benign multiple sclerosis’



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Abstract

Background: We explored health-related quality of life (HRQoL) and psychosocial aspects in a cohort of patients with a history of longstanding benign MS (BMS).

Methods: Patients with BMS (EDSS ≤ 3 after 20 years disease duration) were re-assessed 25-30 years post-MS symptom onset for: EDSS, HRQoL (MSQoL-54), depression (Beck Depression Inventory-II), and fatigue (Modified Fatigue Impact Scale). Associations between these measures and patient characteristics (age, disease duration, ‘benign status’ [remained benign (EDSS ≤ 3) vs no longer benign (EDSS > 3)]) were examined.

Results: Of the 61 patients included, 36 (49%) remained benign and 25 (41%) progressed (EDSS > 3). Overall, physical and mental HRQoL scores were positively associated with each other ($r=0.63$; $p<0.0001$) and both negatively correlated with fatigue ($r=-0.76$ and -0.44 , respectively; $p<0.0005$) and depression ($r=-0.55$ and -0.77 ; $p<0.0001$). Patients who remained benign reported better physical HRQoL vs those no longer benign (mean (SD) = 67.3 ± 18.1 vs 50.7 ± 19.9 , $p=0.001$), but not mental health (mean (SD) = 67.4 ± 19.3 vs 65.0 ± 20.6 , $p=0.639$). Generally, neither age nor disease duration was strongly associated with HRQoL ($r<0.35$).

Conclusion: Lower self-reported physical or mental HRQoL was associated with worsening fatigue and depression. However, EDSS progression was associated with the physical, but not mental aspects of HRQoL. Patient-reported HRQoL in ‘benign MS’ provides insight on the impact of MS beyond EDSS alone.

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1. Introduction

Health-related quality of life (HRQoL) is adversely affected by multiple sclerosis (MS) (Janardhan and Bakshi, 2002; Vickrey et al., 1995). However, this chronic, neurological disease exhibits a high degree of clinical heterogeneity. How this clinical heterogeneity impacts HRQoL is not well understood.

One extreme clinical presentation of MS is so called ‘benign MS’ (BMS) characterized primarily by minimal physical disability maintained over a prolonged period of time, with disability often measured by the Expanded Disability Status Scale (EDSS). While many aspects of BMS have been investigated (Ramsaransing and De Keyser, 2006), particularly at the clinical level, less is known about the broader psycho-social aspects of the disease, and how these patients perceive their own HRQoL, especially in the context of an extended disease duration.

We set out to describe HRQoL and related psychosocial aspects in a cohort of MS patients after 25–30 years of disease; all of whom had a documented history of long-standing benign MS (lasting at least two decades) in British Columbia, Canada. We also examined the relationship between HRQoL and patient characteristics.

2. Methods

This study was nested within a prospective investigation of a previously reported benign MS cohort (Sayao et al., 2007, 2011). The current analysis focused on a battery of health-related quality of life (HRQoL) and related psychosocial measures—depression, fatigue, and employment status—administered to patients after 25 years of disease. Ethical approval to conduct this study was obtained from the University of British Columbia’s Clinical Research Ethics Board.

2.1. Subjects

Briefly, the original cohort (Sayao et al., 2007) (see Fig. 1) was first selected from the British Columbia (BC) MS Clinic Database over a decade ago, based on the following criteria: definite MS (Poser Criteria) (Poser et al., 1983), presence of benign MS, defined as EDSS ≤ 3 at 10 years from onset, and alive and attending a BC MS Clinic with onset symptoms between 1978 and 1984. Patients from this original cohort ($n=200$) who ‘remained benign’ after 20 ± 2 years disease duration (i.e. remained at or below EDSS 3 at follow-up during the original study) were eligible to participate ($n=88$). Efforts were also made to re-contact the 31/200 patients who were considered lost to follow up in the original study (Sayao et al., 2007). Exclusion criteria included those: who were no longer benign when followed-up in the original study (i.e. EDSS > 3 at 20 years disease duration, $n=81$); unwilling to complete the required study assessments (outlined below); experiencing an acute MS relapse; with a major co-morbid illness considered largely unrelated to their MS, but that might potentially confound testing (e.g. cancer); or who were no longer alive (see Fig. 1).

Letters were mailed to patients in 2008 (after 25–30 years disease duration) inviting them to participate in a study on psychosocial and cognitive evaluation. This was followed by 2 reminder letters and follow-up phone calls, where needed. Patients unable to return to the MS clinic were given the option of completing questionnaires at home and by telephone. There was no payment for participation, other than reimbursement of parking when attending the MS clinic.

2.2. Measures

Where possible, scales were selected both for their application to clinical practice and validation for use in MS.

Physical ability was measured after at least 25 years of disease duration using the Expanded Disability Status Scale (EDSS) or the validated North American Research Consortium on MS (NARCOMS) Performance Status (PS) scale (Marrie and Goldman, 2007; Schwartz et al., 1999) for those unable to attend clinic. An EDSS or PS ≤ 3 was considered as ‘remaining benign’ (BMS); an EDSS or PS > 3.0 was considered ‘no longer benign’ (NLB).

HRQoL was captured via the self-administered MS Quality of Life-54 Instrument (MSQoL-54) (Vickrey et al., 1995) which is comprised of a generic core (the Short Form Health Survey 36, SF-36) with 18 additional MS-specific questions. Results were expressed as 12 separate scale scores (physical function, role limitations due to physical problems, role limitations due to emotional problems, pain, emotional well-being, energy, health perceptions, social function, cognitive function, health distress, overall quality of life and sexual function), two single item scores (change in health and satisfaction with sexual function) as well as two summary scores—the physical health composite (PHC) and mental health composite (MHC) scores (derived from a weighted combination of the 12 scale scores). All scores (i.e. scale, single item and summary scores) were expressed linearly from 0 to 100, with a higher score indicating a better quality of life.

Depression was assessed using the 21-item Beck Depression Inventory-II (Beck et al., 1996b); total scores can range from 0 to 63 indicating minimal to severe depression (Beck et al., 1996a, 1996b). Fatigue was measured using the 21-item Modified Fatigue Impact Scale (MFIS) (Ritvo et al., 1997). The score on each of the 21 items is added to yield a possible total score from 0 to 84 with a higher score indicating a greater (detrimental) impact of fatigue on patients’ activities (Ritvo et al., 1997).

Employment status and related information were collected via a questionnaire developed specifically for this study (see Appendix).

2.3. Statistical analyses

HRQoL was described for the entire cohort and also compared between those who remained benign vs those who progressed at this 25–30 year follow-up using the *t*-test for the multi-item scales scores and composite scores and the Mann-Whitney test for single items.

The association of other patient characteristics (current age, age at onset and disease duration, and measures of

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