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Patient perception of bodily functions in multiple sclerosis: gait and visual function are the most valuable

C Heesen¹, J Böhm¹, C Reich², J Kasper³, M Goebel¹ and SM Gold⁴

Multiple sclerosis is a heterogeneous disease with varying clinical picture. There have been substantial efforts to develop outcome measurements for therapeutic interventions but very few studies have addressed the value of bodily functions from the patient perspective. In a randomly selected cohort of early (<5 years, n = 84) and longer lasting disease courses (>15 years, n = 82) patients we asked for a weighting of 13 bodily functions and compared results with actual disability as measured by the United Kingdom Disability Scale. Lower limb function was given the highest priority in both patient groups followed by visual functioning and cognition especially in longer lasting MS. Actual disability did not correlate with the given priorities indicating that experienced deficits do not influence the subjective ratings of bodily functions. These results underline that ambulation-focused scales in MS represent a key dimension from the patient perspective. Visual functioning should be taken more into account. *Multiple Sclerosis* 2008; 14: 988–991. <http://msj.sagepub.com>

Key words: multiple sclerosis; outcome scale; perception of bodily functions; United Kingdom Disability Scale

Introduction

Multiple sclerosis (MS) has been called the disease of ‘thousand images’ owing to the wide range of disabilities affecting many bodily functions. Therefore, it is very difficult to rate disease impact with any summary scale. Analyses from studies on immunomodulatory treatment of MS have revealed psychometric shortcomings of conventional disability rating scales such as the Expanded Disability Status Scale (EDSS) [1,2]. One major problem of the EDSS is that it is heavily based on ambulation as the scale scores between 4.0 and 7.5 are just determined by walking distances. Numerous efforts have been made to develop patient based outcome instruments either by deductively scoring each possible impairment dimensions or by inductively collecting and condensing items from patient interviews [2].

However, no single instrument has yet been adopted as a gold standard [3]. The contribution of each symptom to overall distress has rarely been studied [4]. One small study in 50 MS patients has postulated that physicians and patients do not agree which domains are most important for overall well-being [5]. Physicians seem to overestimate physical well-being while patients stress mental well-being and cognitive function. To our knowledge no study has yet addressed the question which bodily dimensions are considered the most valuable in different disease stages in MS. Therefore, we performed a survey among recently and long-time diagnosed MS patients assuming that with disease progression and the coping process of the disease values might change. We hypothesized that physical functions might be more relevant in earlier stages while in advanced stages mental functioning might become more relevant.

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Methods

Based on the study hypothesis we recruited patients with MS based on Poser criteria [6] with disease courses less than 5 years and longer than 15 years. 100 patients in each group were randomly selected from the database of the Institute of Neuroimmunology and Clinical MS-Research (INIMS) containing the data of 846 patients. Questionnaires were sent out with a stamped return envelope. All patients received a cover letter delineating the background and funding of the study and clarifying anonymous data protection policy. After 4 weeks patients who did not respond were contacted by telephone and a second copy was mailed if requested. 14 patients could not be contacted and 20 refused participation. Therefore, data of 166 patients were obtained.

Questionnaire on values of bodily function

Patients had to rate functions according to their importance for them. Thirteen bodily functions, i.e. upper and lower limb function, sensibility, lack of pain, bladder control, bowel control, visual function, wakefulness/alertness, cognition, speech, mood, swallowing and others had to be weighted. Numbers from 1 to 13 should be distributed in the sequence of declining value and relevance. Patients were instructed to rate these functions regardless from their actual disabilities, i.e. not to indicate disabilities. The questionnaire format has been used and proven feasible in a study on information needs [7].

United Kingdom Disability Scale (UNDS)

The UNDS was used as a measure of the functional state [8]. The UNDS overall score varies from 0 to 60 (maximal disability) and results from the following 13 items: cognition, mood, vision, speech and communication, swallowing, upper limb, lower limb, bladder, bowel, sexuality, fatigue, sensory symptoms and 'other disabilities'. Scores are obtained on each of these dimensions ranging from 0 (no disability) to 5 (maximal disability). A German version has recently been validated [9].

Statistical analysis

Descriptive statistics were used with means, ranges and standard deviations (SD). Student's *t*-tests were used to compare ratings in both groups and different genders. Spearman rank correlation coefficients were used to correlate UNDS and questionnaire results on a scale/item level.

Results

Demographic data

Questionnaires of 166 patients (response rate 83%) were returned and 162 could be analyzed. Age and MS duration did not differ in non-responders (*t*-test). Most UNDS scores were significantly higher in patients with longer disease duration (*t*-test). The strongest differences could be detected in the dimensions lower limb function and bladder disturbances, followed by bowel, upper limb function and cognition, sexuality and visual function (*t*-tests, all significant). No differences could be detected in the dimensions mood and fatigue, speech, swallowing and pain. (See Table 1)

Perceived values of bodily functions

Gait function followed by visual functioning were most frequently rated as the most important domain (see Figure 1). In early MS lack of pain and in long-standing MS thinking and memory followed on position three of first ranks. By analyzing mean ranks (Figure 2) where low values indicate higher priorities, data indicate that in earlier MS walking, visual function and speech have the highest priorities while in long-term MS visual function, followed by gait and speech, are given the highest relevance. Nevertheless these differences were not statistically significant (*t*-test).

We found no statistical significant differences between the ratings of bodily functions in both groups. The dimension cognition showed the largest difference (rank 6.5 versus 5.3, $p = 0.051$; *t*-test), indicating that patients with advanced MS rate cognition as being more important. Controlling for age, however, eliminated the statistical trend.

Table 1 Demographic data

	n	Age (range)	Years MS (range)	UNDS (mean)
Cohort	162	43.7 (18–66)	12.7 (1–44)	14.5 (1.12)
MS <5 years	82	38.7 (18–66)	3.5 (1–5)	11.6 (7.72)
MS >15 years	80	49.0 (31–66)	22.5 (15–44)	17.5 (8.34)
Non-responder	20	42.8	13 (2–31)	No data

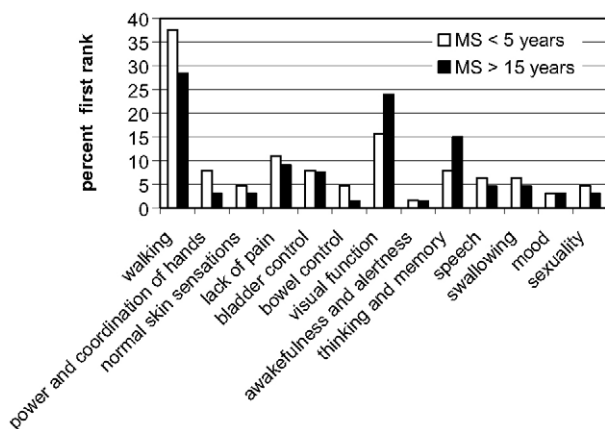


Figure 1 First rank dimensions in early and late MS.

Women and men showed minor differences in response patterns. The only significant finding was a minor relevance of walking in men ($p < 0.05$) which might have been a random finding owing to multiple tests.

Perceived values in relation to disabilities

We furthermore studied the correlation between UNDS subscores and the rated priorities. We hypothesized that a close correlation of theoretical priorities and experienced deficits would lead to low values in a certain priority scale dimension and high values in the corresponding UNDS subscale and vice versa. We found only weak, albeit significant, correlations in the dimensions bowel function and lack of pain ($r = -0.21$, $p = 0.014$ and -0.17 , $p = 0.047$). Therefore, patients seem to separate

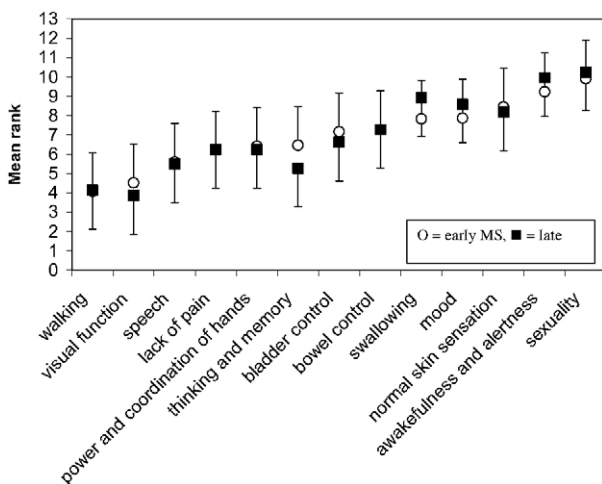


Figure 2 Priorities (mean ranks and SD) of bodily functions (O = early MS, ■ = late MS).

experienced disability and theoretical weighting of bodily functions.

In subgroup analysis patients with higher cognitive disability scores in the UNDS (>3 , $n = 51$) gave gait, bladder function and vision the highest priorities while patients with higher mood disability scores (>3 , $n = 24$) gave gait, vision and cognition the highest priority. While patients with higher disability scores (UNDS > 20 , $n = 59$) gave cognition the third priority after gait and vision, the most advanced cases in our cohort (UNDS > 30 , $n = 12$) gave hand function the third priority after gait and vision.

Discussion

The increasing amount of therapeutic interventions in MS has elicited a discussion which functional status measure might be the most valid and relevant in this clinically heterogeneous disease. Different dimensions are relevant in different MS patient groups. We aimed to clarify which bodily functions are considered the most valuable and if there is a difference between minor and more severely disabled patients.

Assuming that physician-based outcome instruments rely too much on physical functioning and especially walking abilities we have now demonstrated that early and late MS patients gave lower limb function the highest values underlying that ambulation-focused instruments such as the EDSS are not as weak as discussed [1,3] from the perspective of patient values. On the other hand visual functioning was given a similarly high importance by the patients, especially in late MS. In contrast, very few outcome instruments assess the visual system. Even the MS functional composite [10] does not include an objective measure on this dimension. In more advanced cases cognition was considered the clear third priority, a dimension that has been underrepresented in older MS rating instruments. The rating pattern especially in more advanced MS patients may indicate that cognitive deficits must have been experienced before they might be rated important. On the other hand we found no correlation of the UNDS self-report score in this dimension and the score on the priority scale. Furthermore, the relevance of cognition seemed to decline in most advanced cases. We think that these response patterns could be best explained partially by the experience of deficits as well as by the presence of other deficits being more relevant for self-care.

We could not prove the concept that patients rate mental functioning higher than physical functions as Rothwell, *et al.* [5] have postulated. We hypothesize that the aim of social functioning for

which gait, vision and speech are major prerequisites might at least partially explain this consistent response pattern.

Interestingly the weighting of bodily functions did not vary significantly across patients with <5 or >15 years of disease duration in our cohort. We conclude that scoring instruments in early and more advanced MS should cover similar dimensions.

As our data show, patients separated the value of bodily functions and their actual disabilities. We suggest that throughout the disease course therapeutic efforts should focus on these functions. Any scale measuring functioning in the dimensions of the top three or five of our priority scale (i.e. walking, visual function, cognition, lack of pain, bladder control) will cover the most relevant aspects of the disease from the patient perspective.

Finally, we have shown that gender influenced the weighting of bodily functions only marginally. The one differing item might have been a random effect. The random selection of patients out of the database and the high response rate account for the representativeness of our findings.

As a limitation we did not obtain objective disability measures. However, our UNDS validation study has shown that subscores are highly correlated with health-professional-based scales [9]. Furthermore, our advanced MS cohort with a disease duration over 15 years only showed moderate disability (mean UNDS 17.5). In the study of Hoogervorst, *et al.* [11], mean baseline EDSS of 4.0 (range 2.5–6.0) referred to a mean UNDS score of 13 (range 8–19). In our German validation study [9] the subgroup of EDSS 4–6 referred to mean UNDS values of 12.6. Therefore, we think patients with relevant disabilities have been included. Nevertheless, conclusions on severely disabled patients should be drawn cautiously.

Taken together our data demonstrate that walking and visual function followed by cognition are given the highest priorities out of 13 dimensions of bodily functions among early and advanced MS patients. Outcome measurements for therapeutic interventions should strongly consider the mentioned bodily functions. In parallel, further studies should clarify whether the findings are valid through different MS cohorts in different cultures and look for possible moderating factors such as the aim of social functioning. Recently, it has been shown that patient-based outcome instruments might be more sensitive than physician-based or even objective MS rating scales [12]. Therefore, we think that patient-centered scales tailored to the value of bodily functions should be major outcome

instruments in any therapeutic intervention in MS. We furthermore suggest that this approach might be valuable in any chronic disease helping to establish relevant outcome instruments from the patient perspective.

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