

RESEARCH PAPER

Adding a subjective dimension to an ICF-based disability measure for people with multiple sclerosis: development and use of a measure for perception of disabilitiesKLASKE WYNIA^{1,2}, BERRIE MIDDEL^{1,3}, HAN DE RUITER⁴, JITSE P. VAN DIJK¹, WILLEM S. LOK¹, JACQUES H. A. DE KEYSER² & SIJMEN A. REIJNEVELD¹

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Abstract

Objective. The subjective dimension of disability, the perception of disability, is a dimension missing from the International Classification of Functioning, Disability and Health (ICF), and from health-related quality of life (HRQOL) instruments. However, it is a highly relevant dimension for clinical practice as perceived disability may identify care needs. We therefore developed a measure for this subjective dimension of disability in multiple sclerosis (MS) and examined the contribution of this dimension to QOL.

Method. A measure named the Multiple Sclerosis Impact Profile–Disability Perception (MSIP-DP) was developed to reflect a person's perception of disabilities reported using the original MSIP-disability (MSIP-D) items. MS patients ($n = 530$) completed both MSIP sections, the medical outcome study short form questionnaire (SF-36), the World Health Organisation Quality Of Life-BREF (WHOQOL-BREF) and questions concerning disease severity. The contribution of disability perception (DP) to QOL in MS was estimated using hierarchical multiple regression analyses after controlling for MS severity.

Results. Confirmative factor analysis confirmed the hypothesised disability perception domains that correspond with the related disability domains in the MSIP. DP scales yielded sufficient reliability. DP explained a unique and substantial part of the variance in QOL, particularly the perception of impairments in mental functions.

Discussion. Results indicated that the subjective dimension of functioning and health operationalised in the MSIP-DP is a relevant concept in explaining QOL in MS. In clinical practice psychological interventions addressing a patient's perception of disability, particularly of impairments in mental functioning, may contribute to QOL.

Keywords: *Disability perception, multiple sclerosis impact profile, health related quality of life, multiple sclerosis*

Introduction

The International Classification of Functioning, Disability and Health (ICF) [1] is the re-visited successor of the International Classification of Impairments, Disabilities and Health [2], that belongs to the 'family' of international classifications developed by the World Health Organisation (WHO) and was endorsed by the World Health Assembly in 2001. As a result of the rigorous revision

process ICF encompasses all aspects of human health and some health-related relevant components of well-being. As the ICF was endorsed by the World Health Assembly as a member of the WHO Family of International Classifications, it is likely to become the generally accepted classification to describe functioning and health, and in fact already become so.

Despite these positive and important qualities of ICF it also has an important shortcoming. The main

focus of the ICF is on the objective dimension of human function and disability and passes over the subjective dimension, the perception of these disabilities [3]. Particularly in chronic diseases a person's subjective perception of disease-related disabilities is an important contributing factor to better QOL.

Two separate cases provide examples. In the first case, during a period of rapid progression of the disease, a young man became permanently dependent on his wheelchair and had to give up his job. As a consequence he was depressive and not capable to accept the consequences and irreversibility of the situation. In the second case of another man with multiple sclerosis (MS) who had also a complete limitation in walking and was retired because of MS, the situation was much less negative. This person has found new satisfying goals in his life, and accepted his wheelchair as a helpful aid to keep independency. In these examples the functional limitations, that is the objective dimension of the situation, were the same. However, the perception of these limitations, that is the subjective dimension of the situation, differed.

The objective dimension (the disabilities) and the subjective dimension (the perception of these disabilities) are inter-related and interact, but also have a great relative independence from each other as illustrated in the example. Consequently, both dimensions should be integrated into a coherent whole of human functioning and disability [3].

It is a misunderstanding that health-related quality of life (HRQOL) measures enable the assessment of this missing subjective dimension of ICF. This is only partially true as these measures focus on both dimensions of human life and combine items focusing on either the objective dimension (e.g. items concerning functioning) or the subjective dimension (e.g. items concerning satisfaction with social life). Furthermore, QOL measures were developed for clinical purposes and had to be practical. As a consequence QOL constructs are not developed in a systematical way as ICF is [3]. Therefore, integration of ICF and QOL measurements reflecting both objective and subjective dimensions of human functioning, disability and health into one classification system would be a great step forward in understanding QOL. Several models were proposed to integrate both dimensions onto ICF [3,4].

In this study, an attempt is made to integrate both dimensions of functioning and health into one measure for people with MS. MS is a chronic, demyelinating, neurodegenerative disorder of the central nervous system. Its onset is usually in early adulthood and the course of the disease is often progressive and debilitating [5]. As a consequence,

MS-related disabilities have a profound impact on all aspects of QOL. Therefore, receiving insight into both, a person's disabilities and his or her perception of these disabilities, is a relevant issue in QOL research and in health care for people with MS.

In summary, the objectives of this study were (1) to develop a measure reflecting the subjective dimension of functioning and health, the perception of MS-specific disabilities; and (2) to examine the unique contribution of this subjective dimension of MS-related disabilities to QOL, as we hypothesised that, apart from the disabilities, the perception of disabilities explains a relevant and statistically significant part of QOL in MS. We controlled for disease severity (as an estimate for disability) in analysing the impact of disability perception (DP) on QOL.

Method

Samples and procedures

We applied a postal survey in two samples of MS patients (see Table I): members of the MS Patient Association (PA sample) in the northern parts of the Netherlands, and patients from the Groningen MS centre, which is part of the Neurology Department of the University Hospital (UH sample). Respondents could not participate in both samples.

Of the 172 questionnaires sent out in the PA sample, 153 questionnaires (89% response rate) were returned and used for analyses. Of the 562 patients in the UH sample, 377 patients (67% response rate) completed the questionnaires. Non-responders in both samples did not differ in age and gender from participating patients. Respondents in both samples completed the Multiple Sclerosis Impact Profile (MSIP) [7] with the linked DP questions, the World Health Organisation Quality of Life (abbreviation version) (WHOQOL-BREF) [8] and demographic and disease severity questions. In addition, respondents in the PA sample also completed the Medical Outcome Study Short Form Questionnaire (SF-36) [9]. Data for the test-retest analysis on the DP scales was obtained from a UH sub-sample. Of the 279 patients who agreed to fill out the items twice, at a 2 month interval, 251 returned the questionnaire (90% response rate). Non-respondents in the test-retest sample did not differ in age or gender from participating patients.

The local University Hospital Medical Ethics Committee approved the study protocols of both studies. Written informed consent from respondents in both samples was obtained.

Table I. Patient characteristics from total sample and test-retest sample.

Variable	PA sample	UH sample	Differences PA and UH samples	Total sample	Test-retest sample	Differences UH and test-retest samples
<i>N</i>	153	377		530	251	
Gender <i>N</i> (%)						
Female	114 (75)	261 (69)	0.24*	375 (71)	182 (73)	0.04*
Male	39 (25)	116 (31)		155 (29)	69 (27)	
Age						
Mean (SD)	49 (9)	49 (12)	0.06 [†]	50 (12)	51 (11)	0.13 [‡]
Range	32–75	23–85		23–85	23–85	
Years since MS diagnosis						
Mean (SD)	11 (7)	14 (8)	0.00 [†]	13 (8)	13 (8)	0.82 [‡]
Range	2–30	1–53		1–53	2–42	
Marital status <i>N</i> (%)						
Married/in partnership	117 (80)	297 (80)	1.00*	414 (80)	203 (82)	0.76*
No partnership	31 (20)	75 (20)		106 (20)	46 (18)	
Educational level (highest) <i>N</i> (%)						
Primary school/vocational training	42 (28)	112 (30)	–10.3 to 6.5 [‡]	154 (29)	74 (30)	–7.1 to 7.4 [‡]
Secondary school/vocational training	59 (40)	151 (40)	–10.4 to 7.8 [‡]	210 (40)	95 (38)	–5.6 to 9.9 [‡]
High school/vocational training	41 (28)	90 (24)	–4.9 to 11.5 [‡]	131 (25)	64 (26)	–8.6 to 5.1 [‡]
University	7 (5)	20 (5)	–4.3 to 4.2 [‡]	27 (5)	16 (6)	–5.2 to 2.6 [‡]
Employment status <i>N</i> (%)						
In training or studying	4 (3)	15 (4)	–4.3 to 2.8 [‡]	21 (4)	10 (4)	–3.6 to 3.1 [‡]
Employed	30 (20)	82 (22)	–9.2 to 5.9 [‡]	112 (21)	55 (22)	–6.9 to 6.3 [‡]
Voluntary work	15 (10)	18 (5)	4.0 to 11.0 [‡]	33 (6)	14 (6)	(4.8 to 2.7 [‡])
Partially/totally retired due to MS	95 (62)	232 (62)	–8.7 to 9.4 [‡]	327 (62)	149 (59)	–5.6 to 10.0 [‡]
Housewife/househusband	51 (33)	113 (30)	–4.5 to 13.0 [‡]	164 (31)	83 (33)	–5.4 to 9.6 [‡]
Retired due to age	9 (6)	33 (9)	–2.6 to 7.2 [‡]	42 (8)	23 (9)	–5.3 to 4.0 [‡]

*Mann Whitney-Wilcoxon Rank sum test.

[†]Fisher exact test.[‡]Difference of proportions test (95% CI) [6].

Measures

Disability perception measure

We wanted to evaluate the subjective dimension or perception of disabilities of each individual patient for each separate MS-related disability. We therefore used the validated MSIP [7,10] that reflects the prevalence and severity of MS-related disabilities, and linked a DP question to each ‘disability’ (D) question. We developed a new measure with these items and named this section of the MSIP the MSIP-Disability Perception (MSIP-DP) section, whereas the original section of the measure is denoted as MSIP-Disability section (MSIP-D).

The MSIP-D section consists of 36 items with seven scales covering the ICF domains for body functions, activities, participation and environmental factors, and four single impairment items. DP questions were directly linked to each MSIP-D question. MSIP-D questions were phrased (for example) ‘Do you face impairments in ...’ Next, the DP question for each disability was: ‘Do you perceive this disability as problematic?’ Response options were (0 = No, Never; 1 = Yes, Sometimes; 2 = Yes, Frequently; and 3 = Yes, Always. Only

when a disability was reported, the patient was asked to answer the linked DP question on the degree to which that specific disability was perceived as a problem (see Addendum). When a patient reported having no disability, the DP question was skipped.

Before scale construction, ‘missing’ values to the perception questions resulting from reporting ‘no disability’, were recoded with a ‘zero’ score. Summed scores for the hypothesised MSIP-DP domains indicate the extent to which patients perceive the reported disabilities as problematic. A lower DP score means that a reported disability is perceived as less problematic.

Measures of disease severity

Disease severity was measured through self-report questions on (1) disease duration; (2) extent of limitations due to MS; and (3) disease progression. Disease duration was measured by the period of time that had elapsed since definite diagnosis was made by a neurologist. To assess the extent of limitations, respondents were asked: ‘To what extent are you limited due to MS?’ on a 10-point scale with a score ranging from 1 (not limited at all) to 10 (severely

limited). To assess disease progression, respondents were asked to choose the best suitable response option out of five briefly described disease courses to identify whether patients had a stable (with or without relapses), slowly progressive (with or without relapses) or rapidly progressive disease course during the preceding 6 months [11]. Because the MS progression subgroups are based on self-reports, they are similar but not equal to distinctions in disease progression made by neurologists.

QOL measures

QOL was assessed by two generic HRQOL measures, the SF-36 and the WHOQOL-BREF.

SF-36 consists of eight scales and two separate questions covering physical, psychological and social aspects of health [9]. For each dimension, item scores are coded, summed and transformed to a scale with a range from 0 (worst health) to 100 (best health). In a previous Dutch study among MS patients [12], the SF-36 showed satisfactory levels of internal consistency: Cronbach's α ranged between 0.74 and 0.96.

The WHOQOL-BREF [8] was the second QOL measure applied in this study. The WHOQOL-BREF consists of 26 items divided into four domains covering physical, psychological, social and environmental aspects and has two single item questions. For each scale, item scores were coded, summed and transformed to a scale with a range from 0 (worst health) to 20 (best health). In a previous Dutch study [13], the WHOQOL-BREF showed satisfying levels of internal consistency: Cronbach's α ranged between 0.66 and 0.80. In our study, Cronbach's α ranged between 0.63 and 0.81.

Analyses

Scale construction

For further development of the MSIP-DP scales, we conducted a Confirmatory Factor Analysis (CFA), using the Linear Structural Relations (LISREL) programme, to confirm the hypothesised MSIP-DP domains that correspond with the MSIP-D domains. Two models were tested. These were the three-factor model for the ICF-Body Functions items and a two-factor model for the ICF-activity component. These models corresponded with the MSIP-D domain constructs for body functions and activities. Application of CFA to the ICF-Participation and the ICF Environmental Factors components items was not relevant because of these domains' one-factor solution in the MSIP-D.

Model fit was assessed using multiple criteria as suggested by Schermelleh-Engel et al. [14] – (1) a non-significant χ^2 statistic indicating that a non-significant amount of variance remains unexplained; (2) a measure for overall fit, the root mean square error of approximation ≤ 0.08 with confidence interval; (3) descriptive measures – the Normed Fit Index ≥ 0.90 , the Non-normed Fit Index ≥ 0.95 and the Comparative Fit Index ≥ 0.95 .

Reliability

For confirmation of the factor solutions, we examined internal consistency with Cronbach's α for each domain [15,16] and mean inter-item correlation coefficient (MICC) among the items [17]. A Cronbach's α was considered sufficient if ≥ 0.70 [15]. MICCs should preferably fall in an optimal range between 0.20 and 0.50, but should not be less than 0.15 [7,18,19].

Test-retest reliability or stability was examined using descriptive statistics, paired-samples *t*-tests with related *p*-values and one-way random Intra-class correlation coefficients (ICCs) [16]. An ICC was considered sufficient if ≥ 0.80 [15].

Interrelation between MSIP-DP and MSIP-D domains

Dependency of MSIP-DP and the linked MSIP-D scales was examined with Pearson's correlation coefficient (two sided). Moderate correlation coefficients ($r=0.30-0.70$) and explained variance (R^2) values below 0.50 were considered sufficient to indicate that distinct concepts were being measured [20].

Regression analyses

To test the hypothesis that DP explains a statistically significant part of QOL in MS when controlling for disease severity, a series hierarchical regression analyses was conducted with each of the QOL scale variables as dependent variables. On the basis of statistically significant correlations of the most important background variables (age, gender, marital status and educational level) with the QOL dependent variables, age was included as co-variate for five QOL variables, and educational level as co-variate for two QOL variables. Before entering variables into the analysis, dummy-variables were generated for the categorical variables (MS progression and educational level). Relevant co-variables and the disease severity variables were entered in the regression model in the first step and the MSIP-DP variables (all in one) in the second step to determine whether

they explained a significant percentage of the variance in QOL. The expected direction of standardised β weights is negative meaning that perceiving disabilities as less problematic attributes to better QOL.

Results

The PA and UH samples were similar for most background characteristics (see Table I) but differed for the number of years since receiving the MS diagnosis: in the PA sample this was 11 years (SD = 7) and in the UH-sample this was 14 years (SD = 8). Furthermore, patients of the PA sample were more likely to be in voluntary work. Patients from the UH sample who participated in the test-retest procedure only differed from the overall UH sample insofar as there was a statistically significant higher proportion for women.

Confirmatory Factor Analysis

Results of the CFA (see Table II) indicated a good-model-fit on the three factor solution for the ICF-Body functions domains indicated by all five model fit criteria. For the two factor solution for the ICF-activities domains, model fit was acceptable

considering the good fit results for four out of five criteria for model fit.

Reliability

The internal consistency of five MSIP-DP scales was good (Table III). For the 'mental functions' and 'environmental factors' scales α was acceptable, given the small number of items and good MICC. The final version of the MSIP-DP consists of seven scales and 36 items, including the four single impairment items. Test-retest analysis demonstrated no statistically significant change over time for six MSIP scales, indicating stability between both measurement moments (Table III). Although the paired t -test results for the 'muscle and movement functions' scale showed a statistically significant change, this change was, according to Cohen's thresholds, trivial in magnitude, as evidenced by the effect sizes (ES = 0.12). Six MSIP-DP scales showed good ICCs, affirming sufficient stability. ICC for the 'environmental factors' scale was moderate.

Interrelation between MSIP-DP and MSIP-D domains

Scale scores for the linked MSIP-D and MSIP-DP scales (Table III) were moderately correlated (0.49–

Table II. Confirmatory factor analysis for MSIP-DP domains.

	χ^2 (p -value)	df	RMSEA (CI)	NFI	NNFI	CFI	n
ICF-Body function component*	31.51 (0.41)	30	0.013 (0.00 to 0.045)	0.99	1.00	1.00	319
ICF-activities component†	68.17 (0.00)	39	0.039 (0.023 to 0.054)	1.00	1.00	1.00	488

*Three-factor model domains: Muscle and movement functions, excretion and reproductive functions and mental functions.

†Two-factor model domains: Basic movement activities, Activities of daily living.

RMSEA: Root Mean Square Error of Approximation; CI: Confidence Interval; NFI: Normed fit Index; NNFI: Non-normed fit Index; CFI: Comparative fit Index.

Table III. Descriptive statistics and reliabilities for MSIP-DP scales.

			Reliability			Test-retest		MSIP-disability R/R^2
	K	n	Mean (SD)	α	MICC	t -value (p -value)	ICC	
MSIP-disability perception*								
Muscle and movement functions	4	515	4.4 (3.2)	0.88	0.64	2.92 (0.004)†	0.89	0.69/0.48
Excretion and reproductive functions	3	433	3.1 (2.5)	0.74	0.49	1.61 (0.109)	0.91	0.59/0.35
Mental functions	3	424	2.5 (2.1)	0.65	0.39	1.27 (0.205)	0.91	0.53/0.28
Basic movement activities	5	538	4.1 (4.4)	0.91	0.66	0.48 (0.629)	0.93	0.61/0.37
Activities of daily living	8	546	6.4 (6.7)	0.93	0.62	1.78 (0.077)	0.96	0.49/0.24
Participation in life situations	5	492	2.7 (3.3)	0.79	0.43	1.95 (0.053)	0.90	0.54/0.29
Environmental factors	4	451	0.5 (0.0)	0.50	0.20	1.19 (0.235)	0.54	0.63/0.40

K : Number of items; n : Number of respondents; SD: standard deviation; α : Cronbach's α MICC: Mean inter-item correlation coefficient; ICC: Intra-class correlation (one-way random); R : Pearson's correlation coefficient (two sided); R^2 : explained variance.

*Higher scores = more problem perception.

†Effect size = 0.12.

0.69) and explained variance was below 0.50 indicating that the linked scales measured related but distinct constructs.

Impact of the perception of disabilities on the SF-36 variables

Table IV shows the results of the regression analysis designed to ascertain the role of DP in the prediction of QOL measured on the eight SF-36 scales. DP variables explained a statistically relevant and unique segment of the variance in all SF-36 variables, particularly for the social functioning, mental health and bodily pain variables, but with the exception of the role physical variable. Most statistically significant β weights were in the expected negative direction. Beta weights showed that the perception of impairments in mental function is the most significant predictor for five SF-36 variables, meaning that patients who perceived their impairments in mental functions (cognitive, emotional and sleep functions) as less problematic reported a better QOL. The perception of restrictions in life situations (mobility, personal care, informal social relationships, employment and

re-creation) was an important predictor of the quality of social functioning. Concerning the single MSIP-DP items, perception of pain was a statistically significant predictor in the bodily pain QOL domain, whereas perception of impairment in seeing functions was a significant predictor of the quality of general health. Fatigue was a statistically significant predictor of vitality. Unexpected were the positive betas for (1) the perception of impairments in muscle and movement functions in predicting the SF-36 general health domain, (2) the perception of limitations in basic movement activities in the mental health QOL domain and (3) the perception of fatigue in the quality of physical functioning domain.

Impact of the perception of disabilities on the WHOQOL-BREF variables

The results of the regression analysis to determine the effect of DP on QOL, measured by the four WHOQOL-BREF domains, are presented in Table V. The DP variables explain a unique segment of the variance in all four QOL domains. The most statistically significant β weights were in the expected

Table IV. Hierarchical multiple regression of MSIP-DP dimensions and perception of impairment items on the SF-36 scales.

SF-36	Physical functioning (β)	Role physical (β)	Bodily pain (β)	General health (β)	Vitality (β)	Social functioning (β)	Role emotional (β)	Mental health (β)
MSIP-disability perception								
<i>Perception of impairments in ...</i>								
Muscle and movement functions	-0.18	-0.09	-0.14	0.52** (-0.13)	-0.04	-0.07	-0.13	-0.17
Excretion and reproductive functions	-0.08	-0.04	-0.02	-0.21	-0.18	0.05	0.27	-0.03
Mental functions	0.10	-0.18	-0.33**	-0.15	-0.24*	-0.33**	-0.31*	-0.50***
<i>Perception of limitations in ...</i>								
Basic movement activities	-0.09	0.18	0.21	-0.37	-0.08	0.27	0.03	0.55* (-0.20*)
Activities of daily living	-0.24	-0.10	-0.06	0.14	0.06	-0.36	-0.31	-0.32
<i>Perception of restrictions in ...</i>								
Participation in life situations	-0.10	-0.16	0.07	-0.03	-0.05	-0.30*	-0.17	-0.24
<i>Perception of lack of support from ...</i>								
Environmental factors	-0.12	0.07	0.09	-0.05	-0.04	0.13	-0.08	-0.07
<i>Perception of impairments</i>								
Fatigue	0.36*** (0.02)	-0.10	0.09	-0.19	-0.21*	0.02	-0.01	-0.01
Pain	-0.08	-0.17	-0.56***	-0.09	0.12	-0.09	0.04	-0.04
Perception of impairment in speech functions	0.02	0.08	-0.05	-0.01	0.01	-0.08	0.02	0.08
Perception of impairment in seeing functions	-0.03	-0.12	-0.09	-0.25*	-0.10	-0.14	0.02	-0.09
Adjusted R ²	0.67	0.44	0.61	0.45	0.58	0.54	0.29	0.41
R ² change	0.29	0.17	0.54	0.28	0.17	0.45	0.24	0.39
F	9.49***	4.19***	8.07***	4.77***	7.41***	6.48***	2.90**	4.25***
F change	5.38***	1.84	8.58***	3.22**	2.50*	6.16***	2.15*	4.15***

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

In bold: statistically significant β values and R² change values. Between brackets: β value when analysed as a single explaining variable.

Table V. Hierarchical multiple regression of MSIP-DP dimensions and perception of impairment items on the WHOQOL-BREF scales.

	Physical health (β)	Psychological health (β)	Social relationships (β)	Environment (β)
WHOQOL-BREF				
MSIP-disability perception				
<i>Perception of impairments in . . .</i>				
Muscle and movement functions	-0.07	0.06	-0.03	-0.06
Excretion and reproductive functions	0.03	-0.15*	-0.33***	-0.01
Mental functions	-0.34***	-0.42***	-0.13	-0.24**
<i>Perception of limitations in . . .</i>				
Basic movement activities	-0.12	-0.05	0.02	0.04
Activities of daily living	-0.20	-0.03	0.12	0.04
<i>Perception of restrictions in . . .</i>				
Participation in life situations	-0.04	-0.09	-0.09	-0.28**
<i>Perception of lack of support from . . .</i>				
Environmental factors	-0.07	-0.10	-0.07	-0.23***
<i>Perception of impairments</i>				
Fatigue	-0.02	0.07	0.21** (-0.09)	0.13* (-0.12*)
Pain	-0.19***	-0.03	-0.04	-0.09
Perception of impairment in speech functions	-0.02	-0.03	-0.03	0.11
Perception of impairment in seeing functions	0.04	0.06	-0.06	0.04
<i>Adjusted R²</i>	<i>0.63</i>	<i>0.41</i>	<i>0.22</i>	<i>0.32</i>
<i>R² change</i>	0.35	0.28	0.19	0.24
<i>F</i>	21.90***	11.02***	4.71***	6.90***
<i>F change</i>	18.02***	9.38***	4.59***	6.70***

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

In bold: statistically significant β values and R^2 change values. Between brackets: β value when analysed as a single explaining variable.

negative direction. Standardised betas showed that the perception of impairments in mental functions was a significant predictor for all QOL variables, except for social relationships, and was even the most significant contributing predictor for physical health and psychological health, meaning that patients who perceived their impairments in mental functions as less problematic reported better QOL. The perception of impairments in excretion and reproductive functions was a significant predictor of psychological health and even the most significant predictor for the social relationships QOL variable – patients who perceived these impairments as less problematic reported better QOL for social relationships. The perception of restrictions in participation in life situations was the strongest predictor for the environment QOL variable – patients who perceived fewer restrictions in participation in, for example, mobility, relationships, recreation or employment reported higher QOL with regard to their environment. Perception of lack of support from environmental factors (family, professionals, social security and health services) also contributed to a statistically significant proportion of the explanation of the environment QOL domain. Finally, the perception of pain explained a statistically significant proportion of QOL concerning physical health. Unexpected were the positive betas for the perception of fatigue in the social relationships and environment QOL domains.

Discussion

This study had two objectives. The first was to develop a measure reflecting the subjective dimension of functioning and health, the perception of MS-specific disabilities. We succeeded in applying a subjective dimension to the objective MSIP-Disability measure that reflects the perception of reported disabilities. We named this new section of the MSIP as MSIP-DP. Both sections generated different results indicating that both sections reflected distinct, though related, dimensions of functioning and health. CFA demonstrated a good fit for the hypothesised MSIP-DP model, and the MSIP-DP section turned out to be a reliable measure.

The second objective was to examine the unique contribution of this subjective dimension of MS-related disabilities to QOL, as we hypothesised that apart from the disabilities, the perception of disabilities explains a relevant and statistically significant segment of QOL in MS. We controlled for disease severity as an estimate of disability in analysing the impact of DP on QOL. Results in this study support our hypothesis: the perception of disabilities explained a substantial and significant proportion of the variance in QOL in MS, even when the effects of disease severity were taken into account.

The perception of impairments in mental functions (cognitive, emotional and sleep functions)

appeared to be the most important factor in explaining QOL – it was an important contributing factor in eight out of twelve QOL variables. The perception of impairments in excretion and reproductive functions was a significant explanatory factor in two QOL aspects – social relationships (WHOQOL-BREF) and psychological health (WHOQOL-BREF), which underlines the potentially significant psychosocial impact of impairments in urination, defecation and sexual functions. The perception of restrictions in participation in life situations was the most important explanatory factor for quality of the environment (WHOQOL-BREF) and important to the quality of social functioning (SF-36). These results underline the relationship between environmental aspects as operationalised by the WHOQOL-BREF, such as financial resources, home environment, transportation, accessibility of health and social care, and transportation and the perception of participation in life situations.

Surprisingly, we found some statistically significant positive betas (i.e. perceiving a disability as more problematic = better QOL) where negative betas were expected. A possible explanation could be the inter-item correlation between the MSIP-DP variables. As we entered MSIP-DP variables ‘all in one’ in the model, these correlations could explain the positive betas as being a matter of confusion of correlations between the MSIP variables. We therefore also introduced the MSIP-DP variables with positive betas as a single explaining variable into the regression model. The direction of all five betas changed from positive to the expected negative, and three betas became no longer statistically significant – perception of fatigue in social relationships (WHOQOL-BREF), physical functioning (SF-36) and perception of impairments in muscle and movement functions in general health (SF-36). The perception of limitations in basic movement activities remained a significant predictor in the quality of mental health (SF-36), whereas perception of fatigue was a significant predictor in quality of the environment (WHOQOL-BREF).

When considering our findings concerning the impact of the perception of MS-related disabilities on QOL, three factors influencing the results should be borne in mind. Firstly, the results differed for both generic HRQOL measures applied, which underlines the fact that the QOL ‘moving’ concept is still under development. Secondly, a further limitation of these measures is that they reflect HRQOL, which is a limited view of the broader concept of wellbeing. Finally, these QOL measures are probably limited as they blend objective and subjective items and dimensions in the measures, and therefore are not clear in what they reflect – functional status or the perception of functional status.

Strengths and limitations

We considered the possibility of applying the MSIP-D scales in the regression analysis as measures of disability. Despite the fact that the MSIP-D and the MSIP-DP scales assessed distinct constructs, we rejected this option since the perception questions were dependent on the responses to the disability questions with a risk of auto-correlation in regression analysis. Therefore, we applied three generic disease-severity items that proved to be good indicators for overall disease severity.

Some minor issues may limit the validity of our findings on disease severity. Disease duration based on self-reported time since diagnosis probably slightly underestimates the actual duration of MS because it may take some time before the definite diagnosis is established. Results for the extent of limitation variable, as a single item for perceived disease severity, might have been affected by the known limited stability of a single-item measure [21]. However, this question, with a 10-point response option, turned out to be a strong item in discriminating between patient subgroups [10].

Finally, a minor issue concerning our sample may limit the representativeness of our findings – the number of patients (5%) who reported a rapidly progressive disease course, as is typical for primary progressive MS, was limited. Although it is known that a minority of patients (prevalence about 15%) have primary progressive MS [22], this subsample probably does not fully reflect the status of the patients with a primary progressive disease course.

Implications

As this is the first study that has made an attempt to apply a subjective dimension to the objective dimension of the ICF, further exploration of possibilities concerning this issue should be undertaken. We recommend exploration of the relationships between the objective dimension of ICF, a subjective dimension of the ICF and QOL concepts. Furthermore, it is of interest to explore the role or place of the concept of DP in the processes of adaptation and adjustment to a chronic disease.

In this study, we examined the construct validity with CFA, the internal consistency and test-retest reliability of the MSIP-DP scales with satisfactory results. Therefore, the MSIP-DP, in combination with the MSIP-D version, can be used as an outcome measure to assess the present disability and DP. However, further research should examine the treatment-related sensitivity to change (responsiveness) of the MSIP-DP.

The results of DP measurement may have important consequences in clinical practice. This easy to apply, self-report measure for DP is designed to detect individual patients' problems in the perception of disabilities, and as such it provides a basis for shared clinical decision-making between the patient and the health professional, in identifying patient priorities in treatment and care and in facilitating the setting of realistic treatment goals. In our clinical practice, for example, both versions of the MSIP (D and DP) are used to develop an integrated and patient-centred care plan. The procedure is as follows – patients prepare themselves for a consultation [with a nurse specialist (NS)] by filling out the MSIP, which they receive by mail about 2 weeks before the consultation. The NS prepares her- or himself for the consultation by studying the completed questionnaire, which is sent back by the patient before the consultation. During the consultation, the MSIP is used as a tool to bring up the most important issues and to stimulate a good consultation with a full assessment. We tested the MSIP feasibility in a pilot study with seven NSs and 62 MS-patients during three consultations for each patient. As a result, the MSIP seemed to have added value in the enhancement of the role and influence of MS-patients during a consultation: patients seemed to be better prepared and NSs reported gaining better insight into patient health problems.

To improve a patient's perceived QOL; health professionals should not only focus on the interventions aimed at disabilities but also on a patient's perception of these disabilities. Psychological interventions, for example, to prevent depression or to improve autonomy, may support the perception of disabilities as being less problematic and improve QOL.

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Addendum

Examples of MSIP-disability and MSIP-disability perception questions

MSIP-Disability Questions

MSIP-Disability Perception Questions

Do you face impairment in your **urination functions**?* (e.g. frequency of urination, incontinence, difficulties with urination) (b620)

0 = no, not at all.

1 = yes, I have a slight impairment.

2 = yes, I have a moderate impairment.

3 = yes, I have a severe impairment.

4 = yes, I have a complete impairment.

If 'yes', do you perceive this impairment as problematic?

0 = no, never.

1 = yes, sometimes.

2 = yes, frequently.

3 = yes, always.

Do you face limitations in **preparing meals**?† (a630)

0 = No

1 = Yes, but assistance devices and/or adaptations are not necessary

2 = Yes, and assistance devices and/or adaptations are necessary

3 = Yes, and assistance devices and/or adaptations and another person's help are necessary.

If 'yes', do you perceive this limitation as problematic?

0 = no, never.

1 = yes, sometimes.

2 = yes, frequently.

3 = yes, always.

Are there **obstacles in your environment** that complicate your participation in **community, recreation and leisure**?‡ (e.g. accessibility of clubs or associations) (p910/p920)

0 = no

1 = Yes, as a consequence I have some trouble with ...

2 = Yes, as a consequence I have trouble with ...

3 = Yes, as a consequence I have a lot of trouble with ...

4 = Yes, as a consequence ... is (nearly) impossible.

If 'yes', do you perceive this obstacle as problematic?

0 = no, never.

1 = yes, sometimes.

2 = yes, frequently.

3 = yes, always.

Is your relationship with your **immediate family** supportive to you?§ (e.g. partner, children, parents, brothers, sisters) (e310)

0 = Yes, (very) supportive.

2 = Yes, somewhat supportive.

4 = No, not supportive.

If 'no', do you perceive this lack of support as problematic?

0 = no, never.

1 = yes, sometimes.

2 = yes, frequently.

3 = yes, always.

*Body function impairment question.

†Activity limitation question.

‡Participation obstacle question.

§Environmental support question.