The impact of self-perceived limitations, stigma and sense of coherence on quality of life in multiple sclerosis patients: results of a cross-sectional study

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Abstract

Objective: To examine the impact of perceived limitations, stigma and sense of coherence on quality of life in multiple sclerosis patients.

Design: Cross-sectional survey.

Setting: Department of Neurology, University Medical Center Groningen, the Netherlands.

Subjects: Multiple sclerosis patients.

Main measures: World Health Organization Quality of Life – abbreviated version, Stigma Scale for Chronic Illness, Sense of Coherence Scale, background and disease-related questions.

Results: In total, 185 patients (61% response rate) participated in the study with moderate to severe limitations. Stigma was highly prevalent but low in severity. Patients with a higher sense of coherence experienced a lower level of limitations ($B = -0.063$, $P < 0.01$) and less stigma (enacted stigma $B = -0.030$, $P < 0.01$; self-stigma $B = -0.037$, $P < 0.01$). Patients with a higher level of limitations experienced more stigma (enacted stigma $B = 0.044$, $P < 0.05$; self-stigma $B = 0.063$, $P < 0.01$). Patients with a higher sense of coherence experienced better quality of life (physical health $B = 0.059$, $P < 0.01$; psychological health $B = 0.062$, $P < 0.01$; social relationships $B = 0.052$, $P < 0.01$; environmental aspects $B = 0.030$, $P < 0.01$). Patients with a higher level of limitations experienced poorer quality of life (physical health $B = -0.364$, $P < 0.01$; psychological health $B = -0.089$, $P < 0.05$) and patients with more stigma also experienced poorer quality of life (self-stigma: physical health $B = -0.073$, $P < 0.01$; psychological health $B = -0.089$, $P < 0.01$; social relationships $B = -0.124$, $P < 0.01$; environmental aspects $B = -0.052$, $P < 0.01$, and enacted stigma: physical health $B = -0.085$, $P < 0.10$).

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Conclusion: Patients with less perceived limitations and stigma and a higher level of sense of coherence experienced better quality of life. Patients with a higher sense of coherence experienced a lower level of limitations and less stigma.

Introduction

The relationship between perceived limitations, a feeling of stigmatization and sense of coherence on one hand and quality of life on the other hand is generally unknown, specifically in patients with multiple sclerosis. Multiple sclerosis is a chronic disease with an unpredictable course.[1] Patients may suffer from physical limitations and psychosocial challenges impacting quality of life. Stigma is a psychosocial challenge arising when individuals or groups exhibit characteristics which render them inferior in the eyes of others, resulting in devaluation, rejection or exclusion.[2] A distinction can be made between actual stigmatization, referred to as enacted stigma, and the anticipation, fear or internalization of actual stigma, referred to as felt or self-stigma. Once self-stigma affects a person's identity, it can cause, for example, low self-esteem and depression.[3,4] It is known that stigma impacts quality of life negatively in chronic diseases such as mental illnesses, irritable bowel syndrome and neuromuscular diseases.[5–7]

An important factor regarding the extent to which limitations due to multiple sclerosis and stigma affect quality of life might be a patients' sense of coherence, which according to Antonovsky is a way of perceiving the world that enables patients to cope with encountered stressors.[8] Sense of coherence has been associated positively with quality of life in several chronic diseases, such as inflammatory bowel disease[9] and Parkinson's disease,[10] and has been shown to have mediating and moderating effects on the impact of stressors on health.[11–14] However, knowledge about the combined impact of limitations, stigma and sense of coherence on quality of life in multiple sclerosis patients is lacking.

Therefore, the objective of this study is to examine the impact of perceived limitations, stigma and sense of coherence on quality of life in multiple sclerosis patients. We expect that (a) limitations have a negative impact on stigma, (b) limitations and stigma have a negative impact on quality of life and (c) sense of coherence has a positive impact on limitations, stigma and quality of life.

Methods

We conducted a cross-sectional survey as a part of a cohort study which began in 2004.[15,16] The 2004 cohort initially consisted of 378 multiple sclerosis patients attending the Groningen Multiple Sclerosis Center of the Department of Neurology at the University Medical Center Groningen, the Netherlands. For this study, we checked the vital status of the cohort in the national population register. This yielded 76 deaths in a 10-year period (20%). The remaining patients ($n = 302$) were eligible for assessment in 2014 and received an invitation letter with a request to participate in the study by completing a survey online.

The survey included demographic and disease-related questions and questionnaires for disease severity, stigma, sense of coherence and quality of life. Patients were invited to answer questions online, on a website which was specifically designed for this study. The invitation letter also offered patients the option to request a hardcopy version of the questionnaires, which was then sent by post. After two weeks, non-responders were sent a reminder, which included a hardcopy version of the questionnaires. To reduce item non-response,

patients returning incomplete questionnaires were interviewed by phone. A group of 185 patients agreed to participate in the study (61% response rate). In total, 55 (30%) of these patients completed the survey online. The study was presented to the ethical review board of the University Medical Center Groningen, which deemed further ethical scrutiny unnecessary.

Measurement instruments

All data used in this study were retrieved from the patients' questionnaires. Included background variables were gender, age, marital status, educational level and employment status. Disease-related variables were disease progression, years since diagnosis and level of disability.

To evaluate disease progression, we used a single question asking how the disease had developed during the past six months. Responses can be categorized into three types of progression: relapsing remitting, secondary progressive and primary progressive multiple sclerosis.[17] Since these types are based on self-reports, they are similar but not equivalent to distinctions in disease progression made by a neurologist.

To evaluate the level of disability, we used the valid and reliable ambulation question from the self-report version of the Expanded Disability Status Scale.[18] The score can range from 0 (*no disability*) and can increase with half point increments to a score of 10 (*death due to multiple sclerosis*). Scores can be categorized into three groups: 'walking without assistance' with a walkability of more than 500 m without assistance (Expanded Disability Status Scale 4 or less); 'walking with assistance' comprising a walkability of 300 m or less without help or with canes (Expanded Disability Status Scale 4.5–7) and 'wheelchair or bed' comprising a complete or partial restriction to a wheelchair or bed (Expanded Disability Status Scale 7 or more). These groupings reflect clinical judgement by coinvestigators with expertise in multiple sclerosis care.[18,19]

To assess the extent of their limitations, patients were asked to give an overall rating of the extent of limitations they experience by answering the question 'To what extent are you limited due to multiple sclerosis?' on a visual analogue scale, ranging from 0 (*not limited*) to 10 (*severely limited*).[20]

Quality of life was assessed using the Dutch World Health Organization Quality of Life measurement instrument – abbreviation version.[21] This measurement instrument consists of 24 items distributed across four subscales. The subscales assess four quality-of-life domains: physical health, psychological health, social relations and environmental aspects. Each scale item was summed and transformed to a scale ranging from 0 (*worst health*) to 20 (*best health*). The Dutch version showed good reliability.[16]

To assess stigma, we used the Dutch version of the Stigma Scale for Chronic Illness.[22] The Stigma Scale for Chronic Illness consists of 24 items, distributed across two subscales: enacted stigma (11 items) and self-stigma (13 items). The enacted stigma scale measures experienced discrimination and exclusion. The self-stigma scale measures shame and fear of discrimination and exclusion. Response options range between 0 (*never*) and 4 (*always*). Items for each scale were summed to a total score (0–44 enacted stigma and 0–52 self-stigma). Higher scores indicate more stigma. The Dutch version showed good internal consistency among patients.[7]

Sense of coherence was assessed using the Dutch version of Antonovsky's Sense of Coherence Scale.[23,24] The Sense of Coherence Scale consists of 13 items and assesses three theoretical components: comprehensibility, manageability and meaningfulness. Scores range from 1 (*very seldom or never*) to 7 (*very often*) and were summed to a total score (ranging from 13 to 91). The Sense of Coherence scale showed satisfactory levels of internal consistency.[25]

Analysis

We first used descriptive statistics to examine patient characteristics, the extent of limitations, stigma, sense of coherence and quality of life. Next, we performed a series of reversed hierarchical regression analyses. Before examining regression assumptions and performing the regression analyses, we centred the data to control for multicollinearity using the deviation

score approach (subtracting the mean).[26] The Kolmogorov–Smirnov test affirmed that the distribution of both stigma scales was not normal ($P < 0.05$). Because we also found heteroscedasticity (increasing variance with higher predicted scores), we chose to perform the stigma models using gamma regression analyses. According to Kolmogorov–Smirnov tests, the errors in the quality-of-life models were not normally distributed either, but they did not display a definite pattern. We therefore performed the quality-of-life models with a normal regression using Huber–White robust estimators. When using Huber–White robust standard errors, there is no longer a single population variance; standard R^2 measures become meaningless and, if used, should be interpreted with great care. To assess model fit, we therefore report likelihood ratio tests, instead. These tests compare the fitted model with the 'intercept-only' model.

One regression model was performed for the extent of limitations. Two regression models were performed for stigma: one predicting enacted stigma and one predicting self-stigma. Four regression models were performed for quality of life, one for each subscale. We then excluded variables from further analysis based on their P-value, starting with the highest P-value, following a backwards elimination procedure.[27] We stopped the deletion of variables once only significant effects remained (cut-off alpha 0.05, one-tailed). We also used log-likelihood ratio tests in this deletion procedure to assess whether our model deteriorated significantly with the deletion of each variable.

This procedure enabled us to greatly reduce the risk of finding spurious results, because we began with our directed expectations (as formulated in the introduction) and weeded out the non-significant effects. We used one-tailed tests for our directed expectations; the tables in the results section, however, flag the conventional two-tailed P-values. Since in the symmetric t-distribution a two-tailed P-value of 0.1 is equivalent to a one-tailed P-value of 0.05, we flagged 0.1 as the first significance level.

Results

A total of 185 patients (61% response rate) participated in the study. Non-respondents did not differ from respondents in gender ($\chi^2 = 1.506$, not significant (ns)), age ($t = -1.964$, ns) and years since diagnosis ($t = -0.466$, ns).

Table 1 presents the background, disease-related and study variables of respondents. Patients were most female (68%), with an average age of 60 years, mean number of years since diagnosis was 23.6 years and most participants were able to walk (with or without assistance). Most patients had a relapsing remitting or secondary progressive disease course and experienced moderate to serious limitations. All patients experienced stigma, but severity levels were low. Patients experienced good levels of sense of coherence and moderate to good levels in all quality-of-life domains.

Table 2 shows that patients who experienced a higher level of limitations suffered more from stigma: enacted stigma ($B = 0.044$, $P < 0.05$) and self-stigma ($B = 0.063$, $P < 0.01$). However, patients with a higher sense of coherence experienced a lower level of limitations ($B = -0.063$, $P < 0.01$) and suffered less from stigma: enacted stigma ($B = -0.030$, $P < 0.01$) and self-stigma ($B = -0.037$, $P < 0.01$).

Table 3 shows that patients with a higher sense of coherence experienced better quality of life: physical health ($B = 0.059$, $P < 0.01$), psychological health ($B = 0.062$, $P < 0.01$), social relationships ($B = 0.052$, $P < 0.01$) and environmental aspects ($B = 0.030$, $P < 0.01$). Patients who experienced a higher level of limitations experienced poorer quality of life. However, this effect was present in only two quality-of-life domains: physical health ($B = -0.364$, $P < 0.01$) and psychological health ($B = -0.089$, $P < 0.05$). Patients who suffered more from stigma also experienced poorer quality of life. Self-stigma was negatively related to all quality-of-life domains: physical health ($B = -0.073$, $P < 0.01$), psychological health ($B = -0.089$, $P < 0.01$), social relationships ($B = -0.124$, $P < 0.01$) and environmental aspects ($B = -0.052$, $P < 0.01$). Enacted stigma was negatively related only to physical health ($B = -0.085$, $P < 0.10$).

Discussion

We examined the impact of perceived limitations, stigma and sense of coherence on quality of life in

Table 1. Patient characteristics and study variables (*n* = 185).

Variable	Cohort
Gender, *n* (%)	
Male	59 (32)
Female	125 (68)
Age (years)	
Mean (SD)	60.0 (10.8)
Range	33–88
Marital status, *n* (%)	
Married/partnership	139 (76)
Unmarried/widowed/divorced	44 (24)
Educational level, *n* (%)	
Primary or secondary school/vocational training	139 (76)
Higher professional education/university	43 (24)
Employment status (more answers possible), *n* (%)	
Employment	18 (10)
Voluntary work	14 (8)
(Partially) retired due to multiple sclerosis	97 (52)
Housewife/househusband	47 (25)
Retired due to age	48 (26)
Disease progression multiple sclerosis, *n* (%)	
Primary progressive	9 (5)
Secondary progressive	84 (46)
Relapsing remitting	89 (49)
Years since diagnosis	
Mean (SD)	23.6 (8.4)
Range	6–66
Walking ability (EDSS), *n* (%)	
0–4.5 (walk without assistance)	67 (37)
≥4.5–<7 (walk with assistance)	66 (36)
≥7–<10 (wheelchair or bed)	49 (27)
Extent of limitations[a]	
Mean (SD)	5.6 (2.9)
Stigma (SSCI)[a]	
Enacted stigma	
Prevalence (>0)	170 (100)
Mean (SD)	7.2 (5.9)
Self-stigma	
Prevalence (>0)	154 (91)
Mean (SD)	11.4 (9.2)
Sense of coherence (SOC-13)[a]	
Mean (SD)	67.5 (13.3)
Quality of life (WHOQOL-BREF),[a] mean (SD)	
Physical health	13.5 (3.0)
Psychological health	13.4 (2.0)
Social relationships	14.6 (2.8)
Environmental aspects	13.7 (1.4)

EDSS: Expanded Disability Status Scale (score range, 0–10); SSCI: Stigma Scale for Chronic Illness: enacted stigma (score range, 0–44), self-stigma (score range, 0–52); SOC: Sense of Coherence Scale (score range, 13–91); WHOQOL-BREF: World Health Organization Quality of Life measurement instrument – abbreviation version (score range, 0–20).
[a]Higher scores indicate a higher extent of limitations, more stigma, a higher sense of coherence and better quality of life.

Table 2. The impact of sense of coherence on self-perceived limitations and the impact of sense of coherence and self-perceived limitations on stigma (n = 185).

Dependent variable	Extent of limitations				Enacted stigma (SSCI)				Self-stigma (SSCI)			
	Normal regression analyses				Gamma regression analyses							
	Full model		Most parsimonious model		Full model		Most parsimonious model		Full model		Most parsimonious model	
	B	SE	B	SE	B	SE	B	SE	B	SE	B	SE
Constant	5.668	0.201	5.646	0.200	1.922	0.0608	1.917	0.0605	2.399	0.0544	2.399	0.0523
Gender	−0.239	0.435			−0.021	0.1305			−0.015	0.1172		
Age	0.057	0.020***	0.044	0.019***	0.006	0.0071			0.003	0.0058		
Years since diagnosis	−0.027	0.026			−0.002	0.0077			−0.004	0.0071		
Extent of limitations					0.038	0.0229*	0.044	0.0213**	0.062	0.0192***	0.063	0.0185***
Sense of coherence (SOC-13)	−0.061	0.015***	−0.063	0.015***	−0.030	0.0050***	−0.030	0.0050***	−0.037	0.0043***	−0.037	0.0043***
Scale					0.583	0.0599	0.586	0.0602	0.442	0.0460	0.443	0.0461
R^2	0.121		0.116									

SSCI: Stigma Scale for Chronic Illness; SOC: Sense of Coherence Scale (13-item version).
*Significant at $P < 0.1$, **significant at $P < 0.05$, ***significant at $P < 0.01$; two-tailed test.

Table 3. The impact of sense of coherence, self-perceived limitations and stigma on quality of life (n = 185).

Dependent variable	Physical health (WHOQOL-BREF)				Psychological health (WHOQOL-BREF)				Social relations (WHOQOL-BREF)				Environmental aspects (WHOQOL-BREF)			
	Full model		Most parsimonious model		Full model		Most parsimonious model		Full model		Most parsimonious model		Full model		Most parsimonious model	
	B	SE	B	SE	B	SE	B	SE	B	SE	B	SE	B	SE	B	SE
Constant	13.628	0.1576	13.612	0.1158	13.415	0.0971	13.421	0.0979	14.633	0.1869	14.634	0.1859	13.857	0.0929	13.874	0.0940
Gender	−0.092	0.3415			−0.489	0.2031**	−0.491	0.2033**	0.378	0.4053			0.062	0.1989		
Age	0.013	0.0160			0.033	0.0104***	0.034	0.0105***	0.000	0.0218			−0.006	0.0091		
Years since diagnosis	−0.011	0.0198			−0.031	0.0114***	−0.031	0.0113***	0.001	0.0266			−0.010	0.0104		
Extent of limitations	−0.370	0.0565***	−0.364	0.0566***	−0.088	0.0375**	−0.089	0.0379**	−0.060	0.0639			−0.047	0.0338		
Sense of coherence (SOC-13)	0.060	0.0159***	0.059	0.0160***	0.063	0.0100***	0.062	0.0099***	0.050	0.0191***	0.052	0.0189***	0.029	0.0079***	0.030	0.0085***
Enacted stigma (SSCI)	−0.086	0.0426**	−0.085	0.0436*	0.021	0.0253			−0.044	0.0458			0.008	0.0211		
Self-stigma (SSCI)	−0.074	0.0260***	−0.073	0.0263***	−0.097	0.0191***	−0.089	0.0164***	−0.103	0.0310***	−0.124	0.0258***	−0.051	0.0154***	−0.052	0.0124***
Scale	3.481	0.4033	3.498	0.4052	1.371	0.1583	1.380	0.1594	5.060	0.5842	5.155	0.5953	1.277	0.1475	1.311	0.1514
LR χ^2	136.282		135.559		161.300		160.313		70.324		67.515		64.890		60.990	
df	7		4		7		6		7		2		7		2	
P	<0.001		<0.001		<0.001		<0.001		<0.001		<0.001		<0.001		<0.001	

WHOQOL-BREF: World Health Organization Quality of Life measurement instrument – abbreviated version; SOC: Sense of Coherence Scale (13-item version); SSCI: Stigma Scale for Chronic Illness; LR χ^2: likelihood ratio chi-square test.
*Significant at P < 0.1, **significant at P < 0.05, ***significant at P < 0.01; two-tailed test.

multiple sclerosis patients. Our results showed that most patients experienced moderate to severe limitations, while all patients experienced stigma with low to moderate severity levels. Patients experienced a relatively high sense of coherence and moderate to good levels of quality of life in all domains. In addition, we found that patients with more limitations and stigma experienced poorer quality of life, while patients with a higher level of sense of coherence experienced better quality of life. We also found that patients with a higher sense of coherence experienced a lower level of limitations and less stigma.

To our knowledge, no previous studies have examined the effect of sense of coherence, perceived limitations and stigma on quality of life in multiple sclerosis patients. However, our findings are in line with studies which have found a positive relationship between sense of coherence and quality of life in other patient groups[11] and studies which have found a negative relationship between stigma and quality of life in multiple sclerosis.[28]

This is the first study that examined the impact of sense of coherence on limitations, the impact of sense of coherence and limitations on stigma and the impact of sense of coherence, limitations and stigma on quality of life in multiple sclerosis in a relatively large sample of multiple sclerosis patients. A potential limitation might be that this study was part of a cohort study. Since this cohort did not include new patients (≤10 years since diagnosis), the average age of the multiple sclerosis patients was higher than in multiple sclerosis patients in a Dutch epidemiological study.[29] The ratio of female to male patients was slightly above 2:1, which is equal to the ratio found in other Dutch and international studies.[28–31] We therefore recommend some caution in generalizing our results to other populations of multiple sclerosis patients. We also recommend caution in generalizing these results to other patient groups, even though we would expect to find similar results in patients with comparable chronic diseases. Since we found no significant difference between respondents and non-respondents in terms of gender, age and

years since diagnosis, it is safe to presume that non-response did not alter our findings. Finally, even though patients with a higher sense of coherence experienced a lower level of limitations, less stigma and better quality of life, we must emphasize that we performed an explorative study and therefore cannot determine causal effects. We do, however, believe that we can reasonably speculate on the clinical implications of our findings and recommend further research.

The measurement instruments used in this study could be applied by clinicians for screening purposes. When considering stigma reduction strategies and improving patients' sense of coherence and quality of life, clinicians should be alert to selecting patient-centred interventions which employ direct social contact. For example, group-based cognitive behavioural therapy has proved a promising intervention for reducing stigma and increasing multiple sclerosis patients' sense of coherence, self-efficacy and quality of life.[32–34] Policymakers and social scientists play an important role in improving public awareness of issues such as stigma and could make a larger contribution to alleviating these issues by examining and developing interventions which focus on improving participation, social inclusion and quality of life for vulnerable groups in society.[34]

Our study was the first to combine and examine the impact of sense of coherence, perceived limitations, stigma and quality of life in multiple sclerosis. Therefore, we recommend confirmative studies to assess these associations, preferably longitudinally and in a cohort of patients comparable in age to the population. Further research should focus on examining whether sense of coherence is a buffer for the negative impact of perceived limitations and stigma on quality of life. Further research should also focus on developing interventions which reduce stigma and improve sense of coherence and quality of life in multiple sclerosis patients.[32–34]

This study showed that stigma is prevalent among multiple sclerosis patients with limitations, while the extent to which limitations and stigma impact quality of life might depend on patients' sense of coherence. To improve a patient's quality

of life, clinicians can consider patient-centred interventions to improve sense of coherence and to reduce limitations and stigma.

> **Clinical Messages**
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> - Stigma was highly prevalent among multiple sclerosis patients.
> - Patients with a higher level of limitations experienced more stigma.
> - Perceived limitations and stigma were detrimental to quality of life.
> - Patients with a higher sense of coherence experienced less limitations, less stigma and better quality of life.

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