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## LONGITUDINAL STUDY OF PERCEPTION OF PROGNOSTIC RISK IN RECENTLY DIAGNOSED PATIENTS WITH MULTIPLE SCLEROSIS AND THEIR PARTNERS

### Abstract

**Background:** In a two-year follow-up study, expectations of prognosis with regard to the risk and seriousness of wheelchair dependence were investigated in patients with multiple sclerosis (MS) and their partners. In patients, the determinants of perceived risk and seriousness, as well as the predictors of change were studied. **Method:** Perception of the risk and seriousness were assessed for the 2-year, 10-year and lifetime prognosis of wheelchair dependence. Data were obtained in 101 patients with MS and 78 partners at baseline, six-month, one- and two-year follow-up. Clinical disability, perceived symptoms and illness beliefs were assessed at each visit, whereas personality (pessimism and neuroticism) was measured at baseline only. **Results:** Both in patients and partners, perceptions of the 2-year and 10-year risk of wheelchair dependence significantly increased during the 2-year follow-up. Perceived lifetime risk and perceived seriousness did not change over time. Patients who reported more symptoms had higher perception of their 2-year (regression coefficient  $B = 0.78$ ,  $p < 0.0001$ ) and 10-year risk ( $B = 0.87$ ,  $p < 0.0001$ ) after adjustment for disability status. The relation between perceived symptoms and risk perception was stronger among patients with high neuroticism ( $p = 0.0004$ ) and this effect significantly increased during follow-up ( $p = 0.001$ ). Only changes in perceived symptoms were associated with changed in perception of risk ( $B = 0.786$ ,  $p_{\text{interaction}} = 0.0007$ ). **Conclusions:** Perception of the short- and

medium-term risk of wheelchair dependence increased in the first years after diagnosis in patients and their partners. This increase was associated with increased symptom perception. Our findings suggest that educating patients about MS-related symptoms and their significance for future disease progression can lower perception of risk.

### **Introduction**

Although multiple sclerosis (MS) is a chronic disabling disorder, the majority of patients do not experience major complications in the early phase of disease. Yet, patients are usually informed at diagnosis about the possibility of future disease complications. For patients it may be difficult to comprehend prognostic risks of outcomes such as wheelchair dependence. As a consequence, their expectations may considerably deviate from 'actual' risks. In this study, patients recently diagnosed with multiple sclerosis (MS) and their partners overestimated their short- and medium-term risks of wheelchair dependence (Chapter 6). As expected, higher perceptions of risk were significantly associated with more physical limitations of the patient (Chapter 6). But in addition, patients who reported more symptoms due to their disease had higher perception of risk – after adjustment for differences in clinical disability status (Chapter 8). Since patients' perceptions of the risk and seriousness of major complications are important determinants in major life decisions and emotional well-being, it is important to know how perceptions develop during the first years after diagnosis.

For several reasons, expectations about future wheelchair dependence of patients and partners may change in the first years after diagnosis. In the first place, expectations may change because patients will or will not develop (new) symptoms. Most patients experience variable phases of remission, whereas in others the disease will gradually worsen from onset.<sup>[1]</sup> We and others have shown that patients use their present disease status to predict future disease progression (Chapter 8).<sup>[2-4]</sup> A second reason why expectations may change is coping. Particularly in this early period after diagnosis, patients and partners have to find ways to live with the uncertain prospects of the disease. Also, they may seek information about MS and get better informed about the future complications. Early symptom development and coping may have different effects on perceived risk and seriousness of wheelchair dependence. On the one hand, patients may learn that the risks of major complications are not as high as they thought, or may be encouraged by recovery from early symptoms and the absence of new ones. In these situations, expectations may become more optimistic. On the other hand, expectations may become more pessimistic when patients experience further

disease progression. Both ways predict that patients' clinical status – objective or perceived – is an important determinant of perception of prognostic risk.

In a two-year follow-up study, we investigated perception of prognostic risk in patients recently diagnosed with MS and their partners. We intended to answer the following questions: (1) Do perceptions of prognostic risk of patients and their partners change in the first two years following their diagnosis? (2) Do factors that were associated to the patients' perceived risk and seriousness at baseline (disability status, perceived symptoms, personality and illness beliefs) also play a role in perceptions of risk at follow-up? (3) Are changes in these determinants associated with changes in perception of risk and seriousness at follow-up?

## Methods

### Participants and procedures

Patients were recruited through the Departments of Neurology of the Erasmus MC (Rotterdam), three hospitals within the region of this academic hospital, and the VU Medical Center (Amsterdam) in the period of March 1999 – December 2000. Patients were eligible if they were diagnosed with definite or probable MS<sup>[5]</sup> within two years before entry in this study, were between 18 and 55 years old, and had given informed consent. Patients with serious comorbidity or with insufficient understanding of the Dutch language were excluded. Of the 120 patients who met the criteria, 101 agreed to participate in the study. Ninety out of 101 patients had a partner, of whom 78 (87%) participated in the study. This prospective study consisted of a baseline and three follow-up assessments (at six months, one year and two years). Of the 101 patients who entered the study, 98 (97%) completed the half-year and 97 (96%) the one-year follow-up. The data-collection is still ongoing, but 81 patients were already invited for the fourth exam, of whom 72 (89%) participated. Seventy-eight partners started the study, of whom 72 (92%) completed the one-year follow-up. Fifty-five partners (out of 66, 83%) already participated in the two-year follow-up assessment. Baseline characteristics of patients and partners are presented in Table 1.

Patients completed questionnaires at all assessments and were scheduled for a neurological examination at baseline, one-year and two-year follow-up and a psychological interview at baseline. At these visits, also partners filled out questionnaires. Questionnaires for patients and partners were sent by mail one week prior to the neurological examinations and had to be handed in at the time of the psychological interview (baseline) or the neurological examinations (follow-up) or returned by mail. At baseline, partners were given their questionnaires at the time of the patient's interview and were asked to complete these in another room.

**Table 1** Baseline characteristics of patients and partners

Time since diagnosis (months):	0-6	7-12	13-24	Total
<b>Patients</b>	n = 58	n = 18	n = 25	n = 101
Age (years)	37.7 (9.0)	40.8 (11.3)	36.6 (9.1)	37.5 (9.5)
Sex (women)	66%	72%	80%	70%
Time since diagnosis (months)	3.1 (1.5)	9.3 (1.7)	17.6 (3.6)	7.8 (6.5)
Time since first symptoms (years)	3.2 (3.7)	4.8 (7.4)	4.2 (4.0)	3.7 (4.6)
Diagnosis (definite MS)	90%	94%	88%	90%
EDSS (median, IQR)	2.5 [2.0, 3.5]	1.5 [1.0, 2.5]	2.5 [2.0, 4.0]	2.5 [1.5, 3.5]
<b>Partners</b>	n = 45	n = 12	n = 21	n = 78
Age (years)	39.0 (8.4)	42.5 (10.2)	38.2 (8.4)	39.3 (8.7)
Sex (women)	44%	25%	24%	36%

Values are means (SD) or percentages, unless otherwise indicated. EDSS = Expanded Disability Status Scale, IQR = inter-quartile range.

At one- and two-year follow-up, patients and partners were mailed their questionnaires simultaneously, with an explicit request to complete the questionnaires on their own. The study protocol was approved by the medical ethical committees of the participating hospitals.

### Measurements

*Perceptions of prognostic risk.* Perception of risk and seriousness was targeted at the risk of becoming wheelchair-dependent as a consequence of MS. Wheelchair dependence was defined as the inability to walk beyond five meters. This definition equals a score of 7.0 on the Expanded Disability Status Scale (EDSS).<sup>[6]</sup> Perception of risk and seriousness were assessed for the short- (2 years), medium- (10 years) and long-term (lifetime) prospects of wheelchair dependence. Perception of risk was measured using a 100mm visual analogue scale (VAS) from 'Definitely not' (0%) and 'Definitely' (100%). Further, patients were asked for each time period how serious they think it is to be wheelchair-dependent by that time. Perceived seriousness was assessed on a VAS from 'Not serious at all' (0) and 'The most serious thing I can imagine' (100). Partners completed the same questions, addressing the patient's risk of wheelchair dependence and the seriousness of their partner becoming wheelchair-dependent.

*Perceived symptoms.* Perceived symptoms were assessed using illness identity scale of the Illness Perception Questionnaire (IPQ).<sup>[7]</sup> The identity scale includes intensity ratings of symptoms that are experienced by patients and attributed to their disease. As recommended,<sup>[7,8]</sup> this scale was adapted for use in a MS

population. The adapted scale consisted of 23 symptoms: twelve symptoms were taken from the IPQ list (excluding breathlessness) and eleven were added (concentration problems, coordination problems, muscular pain, numbness of limbs, loss of balance, feelings of depression, blurred vision, diplopia, bladder symptoms, bowel symptoms and spasticity). Answers were scored on a four-point scale: all of the time = 4, frequently = 3, occasionally = 2, and never = 1. These scores sum into a total score ranging from 23 to 92. The scale had good internal consistency reliability (Coefficient  $\alpha = 0.87$ ).

*Illness beliefs.* The Illness Perception Questionnaire (IPQ) and its revised version (IPQ-R) were also used to assess patients' beliefs about the controllability of MS by treatment (treatment control, 3 items), the duration of their disease (chronic timeline, 3 items) and their understanding about the disease (perceived coherence, 5 items).<sup>[7,8]</sup> Answers were rated on a five-point scale ranging from 'Strongly agree' to 'Strongly disagree' (scored 5 to 1).

*Personality.* Neuroticism was included as the dimension of personality consisting of negative emotions such as anxiety and anger, and cognitive and behavioral characteristics such as low self-esteem, preoccupation and insecurity.<sup>[9]</sup> Neuroticism was assessed by the 12-item neuroticism scale of the Eysenck Personality Questionnaire (EPQ).<sup>[10,11]</sup> The scale ranges from 0 to 12, with high scores indicating high neuroticism. Pessimism was assessed using the Life Orientation Test (LOT).<sup>[12,13]</sup> The LOT pessimism scale consists of four negatively formulated items (pessimism) with a possible range of 4 to 20. High scores on the pessimism scale indicate greater pessimism.

*Clinical data.* Neurological examinations were conducted by physicians following a standardized research protocol. Functional limitations were rated on the EDSS,<sup>[6]</sup> which ranges from 0.0 (no neurological symptoms) to 10.0 (death due to MS). Date of first symptoms was assessed during the neurological examination. Date of diagnosis and diagnostic certainty (probable or definite MS) were obtained from the medical records and verified by a senior neurologist.

### **Statistical analyses**

We used the SAS Proc Mixed Repeated measurement procedure for the analyses of longitudinal data. This procedure takes into account that the same individual contributes information at different time points and allows the inclusion of subjects with incomplete follow-up. Available data and the matrix of covariance are used to predict missing data.<sup>[14]</sup> This likelihood-based procedure generates more accurate estimates of the parameters than analyses of available data or of data from patients who completed all measurements only.

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We first examined the course of perceived risk and seriousness of wheelchair dependence in patients and partners by comparison of estimated means using SAS Proc Mixed with time (0, ½, 1 and 2 years) and time since diagnosis at inclusion (0-3, 4-6, 7-12 and 13-24 months) as independent categorical variables. Analyses were conducted for patients and partners and for the perceived risk and seriousness of 2-year, 10-year and lifetime wheelchair dependence separately.

Second, we analyzed the determinants of perception of risk and seriousness at follow-up. Since possible determinants were only assessed in patients, these analyses are limited to patients. Based on results of the baseline analyses (Chapter 6, 8 and 9), the role of disability status, perceived symptoms, personality and illness beliefs as well as their significant interaction effects (perceived symptoms \* neuroticism and disability status \* pessimism) were studied. Whether the impact of determinants changed over time was investigated by the interaction of the main effects with time (0, ½, 1 and 2 years, recoded into 0, 1, 2 and 4). Whether the influence of determinants differed for short-, medium- and long-term prognosis was investigated by the interaction of the main effects with prognosis (2 years, 10 years and lifetime, recoded into 0, 1 and 2). Analyses were adjusted for time since diagnosis, time since first symptoms, age and sex. Using SAS Proc Mixed, the following strategy was used. A full model was tested including aforementioned main and interaction effects. The saturated model was simplified by eliminating non-significant covariates and interaction effects. Elimination was based on the significance of the difference in  $-2$  log likelihood goodness of fit between the reduced and the saturated model. If the p-value was higher than 0.05 ( $\chi^2$ -test), the parsimonious model was considered not significantly different from the saturated model, and used for further simplification. Regression coefficients (B) of the final model were estimated using the restricted maximum likelihood procedure (REML).

Third, to determine whether changes in disability status and perceived symptoms were associated with changes in perception of risk and seriousness of wheelchair dependence, the analyses were repeated using difference scores for perception of risk and seriousness and differences in scores of determinants mentioned above. These difference scores were obtained by extracting baseline values from scores at one- and two-year follow-up. Baseline values of neuroticism and pessimism were taken to assess their influence in the change of perception of risk and seriousness. As above, we investigated whether changes differed for short-, medium- and long-term prognosis by including interaction effects of the main effects with prognosis (2 years, 10 years and lifetime). The same strategy for model simplification was used. P-values < 0.05 were considered statistically significant.

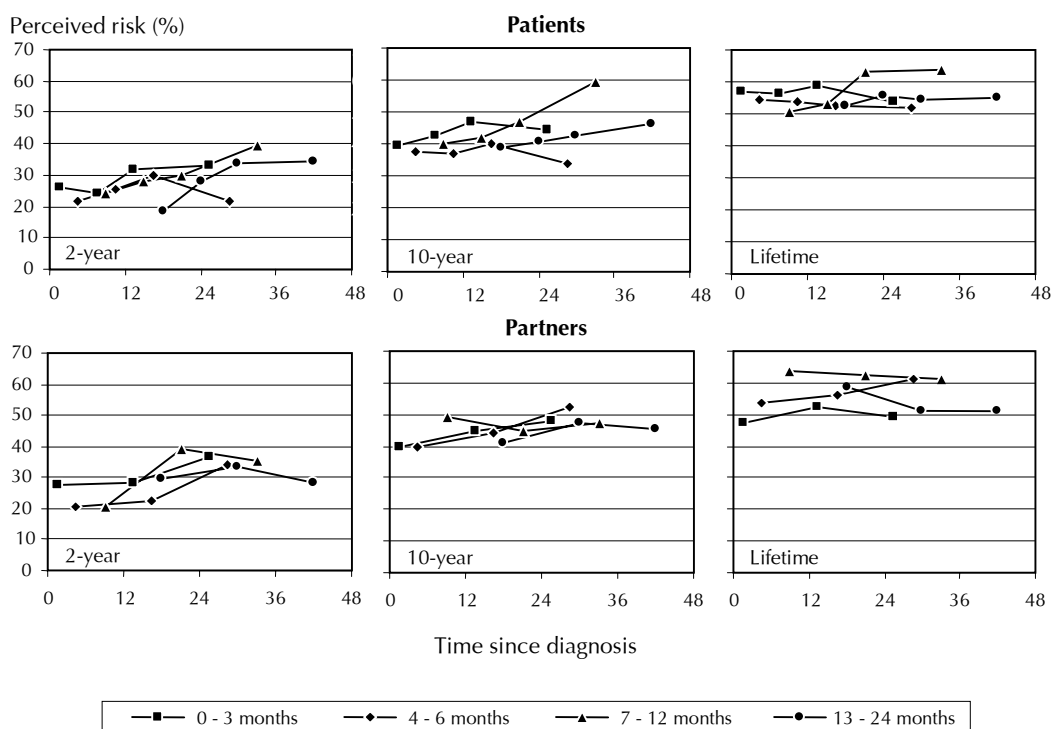
## Results

### Disability status and perceived symptoms during 2-year follow-up

Median EDSS scores did not change during the 2-year follow-up (median = 2.5 at each visit). Also, the means of perceived symptoms did not change significantly: the mean score of perceived symptoms was 39.5 (SD 9.3) at baseline, 39.6 (SD 9.2) and 40.1 (SD 9.7) at follow-up (B for linear trend = 0.20,  $p = 0.17$ ).

### Perception of risk and seriousness during 2-year follow-up

Figure 1 shows estimated means of perceived risk of patients and partners. Means are presented for four groups defined by time since diagnosis at inclusion in the study (0-3, 4-6, 7-12 and 13-24 months). Because patients were diagnosed up to 2 years prior to study entry, the present data cover the first four years after diagnosis. In both patients and partners, perception of the 2-year and 10-year risk



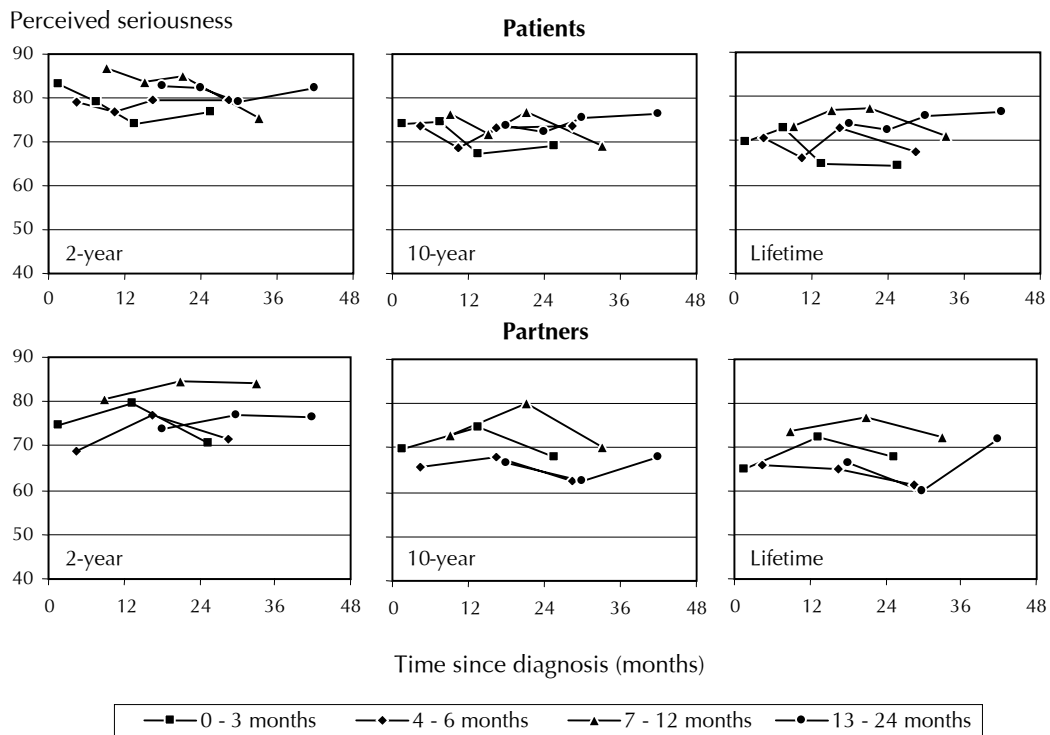
**Figure 1** Estimated means of perceived risk of wheelchair dependence of patients and partners during follow-up

Groups are defined by time since diagnosis at baseline (see Methods).

increased significantly during the 2-year follow-up ( $p < 0.05$ ), but the mean perception of the lifetime risk did not change over time. Patients and partners considered wheelchair dependence a serious consequence of MS, and this evaluation of seriousness did not change at follow-up ( $p > 0.05$ ; Figure 2).

**Determinants of perceived risk and seriousness**

We investigated the determinants of perceived 2-year, 10-year and lifetime risk in a simultaneous analyses of the cross-sectional data over time. Table 2 first shows that perception of risk was significantly different for the three prognoses (mean 2-year risk = 22.9%, 10 years 38.9% and lifetime 54.5%). Also after adjustment for other determinants the increase in perception of risk was significant for the 2-year ( $B = 2.15$ ,  $p = 0.0004$ ) and 10-year prognosis ( $B = 1.55$ ,  $p = 0.02$ ). Further, perception of risk was significantly higher among patients with higher disability



**Figure 2** Estimated means of perceived seriousness of wheelchair dependence of patients and partners during follow-up

Groups are defined by time since diagnosis at baseline (see Methods).



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status, as measured by the EDSS ( $B = 3.39$ ,  $p < 0.0001$ ). The impact of EDSS did not change over time and did not differ between the three prognoses, because these interaction effects were not statistically significant. After adjustment for EDSS, it was found that patients who reported more symptoms of their disease had higher perception of the 2-year ( $B = 0.78$ ,  $p < 0.0001$ ) and 10-year risk ( $B = 0.87$ ,  $p < 0.0001$ ). The association between perceived symptoms and perception of risk increased during the 2-year follow-up, as indicated by the significant interaction term ( $B = 0.20$ ,  $p = 0.001$ ). Patients who thought they had a better understanding of their disease had higher perception of risk at baseline, but this effect of perceived coherence was less pronounced at follow-up. Finally, neuroticism modified the effect of perceived symptoms: the relation between symptom reporting and perceived risk of wheelchair dependence was significantly stronger in those scoring high on neuroticism ( $B = 0.20$ ,  $p = 0.0004$ ).

Using a similar strategy, the determinants of perceived seriousness were investigated (Table 3). The table first shows that perceived seriousness of the 2-year prognosis (mean = 81.3%) was significantly higher than the seriousness of

**Table 2** Determinants of perceived risk of wheelchair dependence: cross-sectional analysis of follow-up data

		B [95% CI]	p
Prognosis	2 years	22.91 [19.59, 26.23]	
	10 years	38.94 [34.92, 42.96] ***	
	Lifetime	54.50 [50.08, 58.93] ***	
Prognosis · time	2 years	2.15 [0.99, 3.32]	0.0004
	10 years	1.55 [0.30, 2.80]	0.02
	Lifetime	0.01 [-1.31, 1.33] **	0.99
Disability status		3.39 [1.77, 5.00]	< 0.0001
Perceived symptoms · prognosis:	2 years	0.78 [0.41, 1.15]	< 0.0001
	10 years	0.87 [0.48, 1.26]	< 0.0001
	Lifetime	0.27 [-0.15, 0.69] *	0.20
Perceived symptoms · time		0.20 [0.08, 0.31]	0.001
Perceived coherence		0.70 [0.04, 1.37]	0.04
Perceived coherence · time		-0.38 [-0.65, -0.11]	0.006
Neuroticism		-0.67 [-1.76, 0.42]	0.22
Neuroticism · perceived symptoms		0.20 [0.09, 0.31]	0.0004

SAS Proc Mixed Repeated Measurements. B = regression coefficient, CI = confidence interval. Non-significant covariates and interaction effects were removed from the model using a backward selection strategy (see Methods). \*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$  indicate significance of differences between interaction effects (2-year period = reference).

**Table 3** Determinants of perceived seriousness of wheelchair dependence: cross-sectional analysis of follow-up data

		B [95% CI]	p
Prognosis	2 years	81.29 [77.84, 84.74]	
	10 years	74.83 [71.09, 78.57] ***	
	Lifetime	73.31 [69.59, 77.03] ***	
Disability status		-3.44 [-5.55, -1.34]	0.0002
Disability status · time		0.82 [0.14, 1.51]	0.02
Perceived symptoms · prognosis:	2 years	-0.04 [-0.38, 0.30]	0.81
	10 years	0.16 [-0.19, 0.51] *	0.37
	Lifetime	0.39 [0.01, 0.76] ***	0.04
Pessimism		1.88 [0.32, 3.44]	0.02
Pessimism · disability status		-0.32 [-1.02, 0.39]	0.38
Neuroticism		-0.80 [-2.23, 0.64]	0.27
Neuroticism · perceived symptoms		-0.05 [-0.18, 0.08]	0.44
Treatment control		-1.26 [-2.54, 0.01]	0.05
Chronic timeline		-1.47 [-2.70, -0.25]	0.02
Perceived coherence		-0.71 [-1.46, 0.04]	0.08

SAS Proc Mixed Repeated Measurements: B = regression coefficient, CI = confidence interval. Non-significant covariates and interaction effects were removed from the model using a backward selection strategy (see Methods). \* p for interaction < 0.05, \*\* p < 0.01, \*\*\* p < 0.001 indicate significance of differences between interaction effects (2-year period = reference).

wheelchair dependence for the 10-year (74.8%) and lifetime prognosis (73.3%). Patients with higher EDSS scores thought wheelchair dependence to be less serious (B = -3.44, p = 0.0002). This association was less pronounced at follow-up as indicated by a significant interaction effect in the opposite direction (B = +0.82, p = 0.02). Perceived symptoms were significantly related to perceived seriousness of the lifetime prognosis of wheelchair dependence (B = 0.39, p=0.04). Patients who were more pessimistic considered wheelchair dependence to be more serious (B = 1.88, p = 0.02). The interaction effects of perceived symptoms and EDSS with personality were not significant in this cross-sectional analysis of the follow-up data. Both patients who had a stronger belief that MS is controllable by medication (B = -1.26, p = 0.05) and those who had a stronger belief that the disease is chronic (B = -1.47, p = 0.02) perceived wheelchair dependence to be less serious. Neither perception of risk nor perception of seriousness was significantly related to time since diagnosis, time since first symptoms, age and sex.

**Table 4** Predictors of change in perceived risk and seriousness of patients

		$\Delta$ Perceived risk		$\Delta$ Perceived seriousness	
		B [95% CI]	p	B [95% CI]	p
Prognosis	2 years	8.58 [4.44, 12.72]	< 0.0001	-5.19 [-9.40, -0.99]	0.02
	10 years	5.69 [1.48, 9.89]	0.008	-2.81 [-7.31, 1.68]	0.22
	Lifetime	1.68 [-2.84, 6.17] **	0.47	-1.03 [-6.00, 3.94] *	0.68
$\Delta$ disability status		-0.29 [-2.72, 2.14]	0.82	0.27 [-2.41, 2.95]	0.84
$\Delta$ Perceived symptoms		0.76 [0.32, 1.19]	0.0007	0.17 [-0.29, 0.62]	0.47
Pessimism		-		0.33 [-1.46, 2.12]	0.71
Pessimism * $\Delta$ disability status		-		-1.46 [-2.55, -0.36]	0.01
Neuroticism		1.35 [0.07, 2.63]	0.04	-0.17 [-1.84, 1.51]	0.84
Neuroticism * $\Delta$ perceived symptoms		0.16 [-0.01, 0.34]	0.07	-0.00 [-0.20, 0.19]	0.96
$\Delta$ Treatment control		-		-1.06 [-2.62, 0.51]	0.18
$\Delta$ Chronic timeline		-		-1.44 [-2.97, 0.10]	0.07
$\Delta$ Perceived coherence		-0.13 [-1.04, 0.78]	0.78	-0.22 [-1.25, 0.81]	0.67

SAS Proc Mixed Repeated Measurements. B = regression coefficient, CI = confidence interval. Non-significant covariates and interaction effects were removed from the model using a backward selection strategy (see Methods). \* p for interaction < 0.05, \*\* p < 0.01, \*\*\* p < 0.001 indicate significance of differences between interaction effects (2-year prognosis = reference).

#### Determinants of change in perceived risk and seriousness

Finally, we investigated whether changes in determinants were associated with changes in perception of risk and seriousness. Table 4 first shows that changes in perception of the 2-year and 10-year risk (mean increase 8.58 and 5.69, respectively) were significantly higher than the change in perceived lifetime risk (mean increase 1.68). Further, changes in perceived symptoms were accompanied by significant changes in perception of risk (B = 0.76, p = 0.0007). As indicated by the borderline significant interaction term (B = 0.16, p = 0.07), this effect was stronger in patients with higher neuroticism. Changes in EDSS were not significantly related to changes in perceived risk. Since perceived symptoms may be in the 'causal' pathway between EDSS and perceived risk, the analyses were repeated without perceived symptoms in the model. However, in this model EDSS was still not significantly related to perceived risk (B = 0.76, p = 0.57). The second column shows that the decrease in perceived seriousness of the 2-year prognosis of wheelchair dependence was significant after adjustment for the other variables in the model (B = -5.19, p = 0.02). Of all determinants, only the interaction effect between pessimism and disability status was significant (B = -1.46, p = 0.01).

## Discussion

This paper aimed to investigate perception of risk and seriousness of wheelchair dependence in the first years after the diagnosis of MS. Several findings can be deduced from this study. First, perception of the 2-year and 10-year risk of wheelchair dependence significantly increased during the 2-year follow-up, both in patients and in partners. Perceived lifetime risk and perception of seriousness did not change over time. The lack of association of perceived lifetime risk with putative determinants such as clinical status and perceived symptoms in our study contradicts with similar studies on risks of cardiovascular disease and cancer. These studies reported that perceived lifetime risks were associated with self-reported risk factors or did find that patients discriminated between different lifetime risks.<sup>[4,15]</sup> The absence of associations may be explained by the unpredictable nature of the disease; a benign early course of disease does not guarantee a favorable lifetime prognosis, and minor changes in early symptoms may not need to have significant consequences to patients for the perceived lifetime risk.

Second, disability status, as measured by the EDSS, was significantly associated with perception of risk and seriousness at baseline (Chapter 6) and in the cross-sectional analyses of the follow-up data (Table 2): patients with higher disability have higher perception of risk and lower perception of seriousness. However, disability status was not associated with perceived risk and seriousness in the analyses of changes over time (Table 4). This lack of association may be explained by the fact that, overall, EDSS did not change during our 2-year follow-up, either because there was no progression in disability status, or that progression was too minor to change EDSS scores.<sup>[16]</sup> It is also likely that changes in disability status are actually not accompanied by changes in perception of risk, because other factors are more important.

Third, perceived symptoms were significantly related to perceived risk in all analyses. Even though patients' subjective evaluations of symptoms on average as a group did not change over time, individual changes in perceived symptoms were associated with changes in risk perception. From an epidemiological perspective, this is strong evidence for a causal relation. This finding is compatible with the view that patients extrapolate their present symptoms into expectations of future wheelchair dependence. Yet, the opposite reasoning – that perception of risk influences symptom reporting – cannot be ruled out. Patients who do not want to face their higher risks of wheelchair dependence – and who will likely indicate that this risk is low – may underestimate or even deny the presence of symptoms.<sup>[17]</sup> This is a plausible explanation, but will likely be found in only a

subgroup of patients. For the majority, we argue that it is more likely that the perceived presence and intensity of symptoms determines their expectations of future disease progression (see also Chapter 10).

The wide variety of symptoms that can occur in MS makes it difficult for patients to know the difference between common symptoms and MS-related symptoms. This may be particularly a problem in the early phase of the disease in which symptoms are generally mild. Attributing common health problems to MS may lead to the impression to the patient that one is more ill than one actually is, and may consequently result in pessimistic expectations about wheelchair dependence and other consequences that are not clinically justified.<sup>[18]</sup> In our study, it was consistently found that patients who reported more symptoms due to their disease had higher perception of risk. It is important to note that this symptom questionnaire included both common non-MS-related health problems and MS symptoms. Further, this relationship between perceived symptoms and perception of risk was found in all analyses, after adjustment for clinical disability status. These findings combined suggest that patients may have inaccurate perception of their present symptoms, and most likely overestimate their present health status by attributing common non-MS-related symptoms to their disease. Given the implications for patients' expectations about future disease progression, it will be important to investigate the accuracy of symptom perception in further detail.

In conclusion, patients' evaluations of their symptoms are consistently associated with perception of the short- and medium-term risk of wheelchair dependence. These findings imply that for their consultations with patients, neurologists and other health professionals may improve the understanding of disease of patients considerable by discussing the symptom perception of patients in order to help them distinguish MS symptoms from symptoms of other common diseases. This may eventually result in more appropriate expectations about future disease progression.

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