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'IT MIGHT HAPPEN OR IT MIGHT NOT': HOW PATIENTS WITH MULTIPLE SCLEROSIS EXPLAIN THEIR PERCEPTION OF PROGNOSTIC RISK

Abstract

Aim: To examine, in a qualitative study how patients with multiple sclerosis base their perception of the risk and seriousness of wheelchair dependence. **Methods:** Perceived risks, both absolute and comparative, were assessed for 2-year, 10-year and lifetime prognosis of wheelchair dependence using visual analogue scales (VAS). In the semi-structured interviews, patients ($n = 85$) were asked to elucidate these VAS scores. **Results:** Explaining perceived absolute risk, patients mentioned disease-related factors as well as psychological factors. Uncertainty about future disease progression was a predominant factor for all patients, even those with low and high perceptions of risk. In assessing their comparative risk, patients perceived themselves as being equally at risk compared to others, since they did not know what to use as a basis for comparison. Wheelchair dependence was perceived as serious primarily because of its possible implications such as loss of independence. When perceptions of 2-year, 10-year and the lifetime prospect of wheelchair dependence were compared, it was found that patients discriminated in their perception of absolute risk, but less in that of the comparative risk and seriousness. **Conclusions:** Comparison of quantitative and qualitative assessments indicated good construct validity for perception of the absolute risk and seriousness of wheelchair dependence, but not for the comparative prognostic risk.

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Introduction

Multiple Sclerosis (MS) is a chronic neurological disease, which affects young individuals between 20 and 40 years of age. Patients with MS face enormous prognostic uncertainty as the variation in type, severity and progression of symptoms is high.^[1] Although patients are generally aware that the disease may have major consequences for their lives, there is no way to provide them with an individual prognosis. This lack of prognostic information may contribute to the high levels of uncertainty that have been reported in patients with MS and which have been associated with poorer psychological well-being.^[2-4] The lack of clinical prognostic information may affect patients' decisions about treatment as well as having children, changing jobs, or buying houses.^[5,6] Patients are compelled to make these decisions based on uncertain expectations about their future health.

For patients with MS, wheelchair dependence is one of the most serious and recognized consequences of the disease. We have previously studied expectations of wheelchair dependence in recently diagnosed patients and found that they overestimated their 2-year and 10-year risk of wheelchair dependence but underestimated their lifetime risk of wheelchair dependence.^[7] As anticipated, perceptions of risk were higher among patients with higher levels of clinically assessed disability.^[7] In addition, patients who experienced more general and disease-related symptoms had higher perceptions of their short- and medium-term risks (Chapter 8). This relation between perceived symptoms and perception of risk was strongest in patients with higher neuroticism (Chapter 9). Although these studies brought some correlates of perceived risks to light, they have provided little insight into how these factors affect perception of risk.

The aim of the present interview study is to get insight into the perception of prognostic risk of patients recently diagnosed with MS. Perceived risks and seriousness were examined for the short, medium and long-term prognosis of wheelchair dependence using visual analogue scales; these perceptions were further elucidated in interviews. The study examines the following questions: 1) What do recently diagnosed persons with MS use to base their perception of absolute and comparative risk, and the seriousness of future wheelchair dependence? 2) Do patients distinguish between perceptions across the different prognoses (2-year, 10-year and lifetime) and for what reasons?

Methods

Procedures and participants

Participants were recruited through the Departments of Neurology of the Erasmus Medical Center (Rotterdam), three hospitals within the region of this academic

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hospital, and the VU Medical Center (Amsterdam) from March 1999 to December 2000. Patients were eligible if they had been diagnosed with MS^[9] within 2 years before entry in the study, were between 18 and 55 years old, and gave informed consent. Patients with serious co-morbidity 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. Patients who declined to participate mentioned the emotional burden (n=3) or a lack of interest (n=3). Nine patients declined without additional comments, and four never responded to our reminders.

Patients underwent a neurological examination, filled out questionnaires, and were interviewed. The questionnaires were sent one week before the neurological examination and had to be completed before the interview, which was scheduled one week after the examination. Details of the neurological examination have been published elsewhere.^[7] The study protocol was approved by the medical ethical committees of the participating hospitals.

Instruments

Perceived risk of becoming wheelchair-dependent was assessed over the short (2-year), medium (10-year) and long term (lifetime). The risk of wheelchair dependence was defined as the inability to walk beyond five meters, which equals a score of 7.0 on the Expanded Disability Status Scale (EDSS).^[10] The actual risks of becoming wheelchair-dependent as a consequence of MS have been derived from epidemiological data and are estimated as 5-10% within two years, 20-25% within ten years and 70-80% over the lifetime.^[11] Patients were asked to what extent they thought they would become wheelchair-dependent for distances over five meters within these periods (absolute risk). In addition, patients were asked to what extent their risk was lower or higher than the risk of other patients of similar age, similar sex and with similar disease symptoms (comparative risk). Perception of risk was assessed by 100mm visual analogue scales (VAS).^[12,13] The end points of the VAS were anchored at 'Definitely not' (0) and 'Definitely' (100) for perceived absolute risk and 'much lower' (0) and 'much higher' (100) for perceived comparative risk. For the 2-year, 10-year and lifetime risk of wheelchair dependence, patients were asked how serious they thought it would be to be wheelchair-dependent by that time. Perceived seriousness was assessed on a VAS from 'Not serious at all' (0) to 'The most serious thing I can imagine' (100).

Patients were interviewed to learn more about their perceptions of risk and seriousness. The interviews were semi-structured and carried out by a psychologist [CJ] at the patient's home. For each question, patients were asked why they put their mark at that specific point of the VAS. Patients' explanations were tape-

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recorded and transcribed verbatim. Sixteen interviews could not be used because patients had not completed their questionnaires at the time of the interview or because tape-recording failed, so that 85 complete interviews remained.

Data analysis

For the presentation of the distribution of perception of the absolute and comparative risk and the seriousness of future wheelchair dependence, VAS scores were recoded into 11 categories: 0-5 into 0, 6-15 into 10, 16-25 into 20, and so on. To determine whether patients discriminated between perceptions of risk and seriousness for the three time frames, difference scores were calculated. Cut-off scores were based on patients' explanations in the interviews. For example, when patients explained that they saw no difference for example between their 10-year and lifetime risk, the difference between these VAS scores was typically between -5 and +5. This margin was therefore taken to determine whether patients distinguished between perception of risk and seriousness of the 2-year and 10-year and between the 10-year and lifetime prospects of wheelchair dependence.

The qualitative analysis of the interview data involved approximately 160 pages of transcribed interviews. An interpretive reading of the interviews was conducted, which involved inferring meaning from the data.^[14] The analysis consisted of two iterative activities: fragmenting and connecting.^[15] In the first activity, the informative parts of each interview were extracted, categorized, and labeled with codes (open coding), using the program *Winmax*.^[16] Some categories such as 'perception of seriousness' and 'comparative risk' were clearly defined by the theoretical framework, whereas others such as 'positive thinking' and 'fear of total dependence' emerged from the data. The second activity in the analysis process consisted of connecting the coded interview parts to patients' VAS scores and identifying explanations for the three different time frames. The first phase of open coding was conducted by one researcher, a sociologist [HB], and the final analysis was discussed with the second researcher [CJ], a psychologist, in order to ensure that the same interpretations were made, and to enhance inter-rater reliability.^[17] Data extracts are presented to illustrate the main lines of reasoning of patients and to provide for a possible control. Reference is made to the different interviews (e.g., R1 = Respondent 1).

Results

The mean age of the participants was 37.5 years (SD 9.5), and 70% were women. The mean time since diagnosis was 7.8 months (SD 6.5), and the mean time since first symptoms 3.7 years (SD 4.6; median 2.1). EDSS scores ranged from 0.0 to 7.0

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(median 2.5). Eighteen percent of the patients already experienced problems in walking, indicated by an EDSS score of 4.0 or higher.

Perception of absolute risk

Perceived 2-year risk

Figure 1 shows patients' perceptions of the absolute risk of becoming wheelchair-dependent within two years, ten years or during their lifetime. The first graph shows that the majority of patients perceived their 2-year risk of wheelchair dependence as being between 0 and 50%. The qualitative data of the interviews show that these patients did not expect to need a wheelchair within two years, although they were not sure about that:

'I don't think that I'll need a wheelchair and why, I don't know, but well, I don't know. Intuitively, I think I won't, just because I feel that it isn't progressing that fast, that it won't be that fast, but that isn't based on anything, really. It's a bit like you never know for sure. I mean it could happen, but I don't expect it to happen.' (R62)

Some participants indicated in the interview that they were confident that their risk was lower than 50% because they had experienced a benign course so far or had fully recovered from earlier exacerbations. Others were hopeful because previous relapses had not involved their legs, which gave them reason to believe that a future relapse would again not affect their walking ability. Several women perceived their 2-year risk to be lower than 50% because they believed that previous relapses had been triggered by pregnancies and as they did not intend to become pregnant again they reasoned that their risk of relapses was low.

Percentage of patients

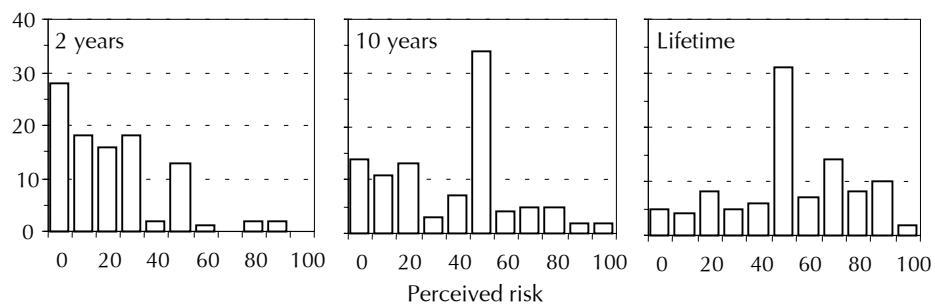


Figure 1 Perceived absolute risk of wheelchair dependence

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Patients not only explained why they did not expect to become wheelchair-dependent within two years, but also why they were not sure. Above all, they mentioned the ubiquitous uncertainty of their disease. One patient, who put his mark close to 'definitely not', explained that 'with this disease you can never say something very definite; there is always a question mark.' Others had some reserves because they had a fresh memory of a recent upheaval of the disease or had recently been confronted with wheelchairs in their environment.

Some participants perceived their 2-year risk to be nil, as they could not imagine their illness progressing that fast. Several patients were convinced that they would not become wheelchair-dependent within two years, because this would be preceded by severe relapses or continuous disease progression, which they had not had so far. Others perceived their risk to be nil because they would not even consider the possibility, rejecting it out of hand:

'Yes, I assume that I have a mild form of the disease, probably also because I simply don't want it. It's just that I don't want to assume this, I don't want to allow the possibility that it may happen, so I don't believe it will happen, no.'
(R70)

Several participants chose to put their marks in the middle of the scale (50%). They argued that they just did not know what would happen and stressed the uncertainty with phrases like 'It might happen or it might not happen,' and 'I have no idea'. Only a few patients perceived their 2-year risk of wheelchair dependence to be higher than 50%. These patients primarily mentioned that they had already experienced severe physical limitations and expected that this progression would continue in the years to come. None of the patients marked the utmost right position of this VAS.

Perceived 10-year risk

The second graph of Figure 1 shows that a substantially larger group of patients put their cross in the middle of the VAS, perceiving their 10-year risk of wheelchair dependence as significantly higher than the 2-year risk. They gave two reasons why they chose the middle more often. The first group of patients stressed that they really did not know what to expect: it might happen or it might not. As one person explained:

'Yes, I don't know, that's why I marked the middle, because I simply don't know. I can't say that I will definitely be in a wheelchair, no, because I simply

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don't know that now. But, I can't say 'definitely not'. It's not even a little more 'definitely yes' or a little more 'definitely not'.' (R51)

Some patients were uncertain about life in general. One woman, who mentioned she had had a sudden onset of MS after her pregnancy, emphasized that 'anything can happen any time. You can be stabbed tomorrow and have a spinal cord injury. You don't know.'

For the second group, the 50% response was a balance, a neutral option between two sides of the scale. Some patients who anticipated that they might become wheelchair-dependent marked the middle because they still hoped that their disease would not progress that fast or did not want to believe that it would: 'I've had this wheelchair for more than half a year now, but I've hardly used it. I still hope that I'll recover'. One patient marked the middle of the line because she remembered having read that the risk of becoming wheelchair-dependent within ten years after diagnosis was 50%. Another 50% responder remembered that 80% of patients were still able to walk after ten years:

'Yes, statistics say that ten years after diagnosis 80% are still able to walk, so then I think let's keep it fifty-fifty. I don't know, it's just a guess. Let's say, it's an answer between hope and fear. So that's fifty-fifty.' (R55)

Forty-eight percent of the patients perceived their 10-year risk of wheelchair dependence as less than 50%. Two dominant explanations were put forward by patients: they were only mildly affected by the disease and did not expect to have a progressive form of MS or they hoped to prevent or postpone the need for a wheelchair by adopting a very positive attitude. One woman was optimistic because her doctor had told her it was unlikely that her disease would progress very fast. In addition, other patients explained that so far MS had not affected their legs or motor skills:

'With me it started very different and not in my limbs. It started with my eyesight, with seeing double and I didn't have strange legs or shaky knees or tingling legs, and that's why I don't think there's more than a twenty to thirty percent ten years.' (R73)

While most respondents expressed some hesitation, some patients were convinced that 'it's just not going to happen'. These patients put their mark at the extreme lower end of the scale, because they wanted to be strong and not

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surrender to MS. Again, only a few patients marked the VAS between the middle and the upper end of the scale. These patients referred to the problems they had already experienced walking and expected that their condition would continue to worsen over the next years. However, they were also not sure: with a little luck, exercise and therapy they thought they might be able to postpone the use of a wheelchair for shorter distances.

Perceived lifetime risk

The last graph of Figure 1 shows that a larger group of patients did expect to become wheelchair-dependent over the long term. They acknowledged that MS is a progressive disease and that as time passes their disabilities might worsen despite exercise, medication and therapy. However, with a few exceptions, these patients did not mark the upper end of the VAS ('definitely yes'). They still hoped that they would not become wheelchair-dependent, because 'nobody can tell for sure that you'll need one'. One patient referred to having read that 80% of patients eventually needed a wheelchair, but hoped to be part of the 20% 'for whom a walking stick would be sufficient'. Several patients mentioned that through positive thinking, they might avoid the need for a wheelchair. Only two patients selected the utmost right position for their perceived lifetime risk. These patients were convinced that they would sooner or later need a wheelchair based on what they had read about the disease or heard from their neurologist.

With regard to the perceived lifetime risk of wheelchair dependence, many participants also put the cross in the middle of the scale, again explaining this with expressions such as 'It's a neutral position,' 'I just don't know,' and 'It's fifty-fifty'. Here as well, patients really did not know or chose a balance between two extremes:

'Yes, I put that mark in the middle because I think it might happen sometime, but I don't want to think about that possibility, I simply don't want to think about that. That's it.' (R29)

Patients who perceived their lifetime risk as lower than 50% primarily explained that they did not want to anticipate that possibility, that they hoped it would not happen or that positive attitude would help. A few patients hope that by that time effective medication would have been developed. And finally, several patients commented that they did not mark the lower end of the scale because that would be naive, fooling or lying to oneself, and because one should be honest with oneself.

How perceptions of absolute risk in different time periods are related

Comparing perceived absolute risk of the 2-year, 10-year and lifetime prognosis of wheelchair dependence, it was found that 45% of the patients did discriminate between these time periods (Table 1). They shifted to a higher risk perception from the short to the long term. Even patients who were optimistic about the role of positive thinking on the course of MS moved from the lower end 'definitely not' for their 2-year risk perception to the middle or even higher for the long-term risk: they did not believe that they could fight major disease progression even if they did their utmost. Nineteen percent of the patients made no distinction between the 2-year and 10-year risk but perceived these as lower than the lifetime risk, and 25% made no distinction between the 10-year and lifetime risk but perceived these higher than the 2-year risk. Both groups did not expect to need a wheelchair soon but acknowledged the progressive and unpredictable nature of MS over the longer term. Eleven percent of the patients did not discriminate between the three timeframes. They either consistently marked the VAS at the lower end ('I have a positive attitude'), or at the higher end ('In view of my current health, it's quite possible that I'll need a wheelchair within two years') or in the middle of the VAS ('I don't know').

Table 1 Distinctions between 2-year, 10-year and lifetime prospects in the perception of risk and seriousness of wheelchair dependence

	Absolute risk	Comparative risk	Seriousness
All different	45	16	25
2 years = 10 years ≠ lifetime	19	8	11
2 years ≠ 10 years = lifetime	25	13	32
All the same	11	63	32
Total	100	100	100

Values are percentage of patients.

Perception of comparative risk: comparison with other patients

When asked to compare their risk with that of other patients, the vast majority of patients responded in the middle of the VAS (Figure 2) explaining that all patients of the same age, sex and with the same symptoms have equal chances:

'Umm, that's looking into the future, why should I have a lower chance than anybody else? That's such an uncertain factor and my chance is as high or as low as the next person. So, I just don't know.' (R72)

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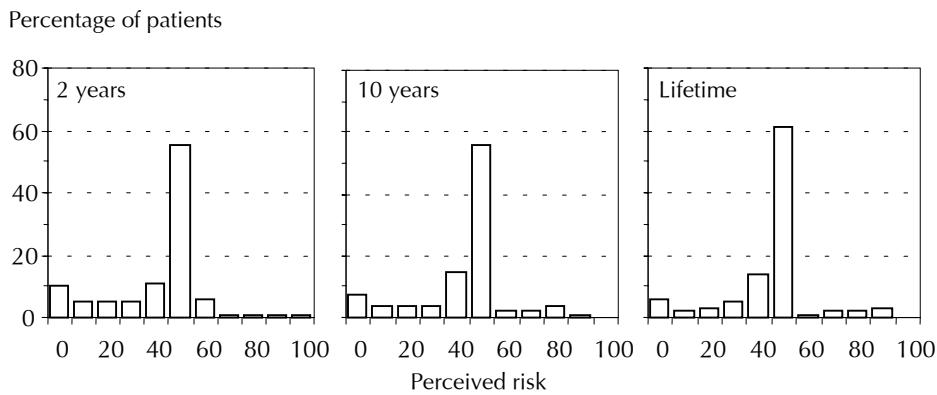


Figure 2 Perceived comparative risk of wheelchair dependence

Several patients in this group stated that they were no better than anybody else and did not want to act arrogantly. Others referred to this as just being a neutral answer.

Some patients believed they had a lower chance of needing a wheelchair because they would try to influence their illness with their willpower and would therefore have a lower risk of wheelchair dependence compared to others who did not make a comparable effort. Few patients thought their chances were higher, acknowledging they might have a malignant type of MS, which would probably have a faster disease progression in the future.

Many patients had great difficulty imagining a group of patients of similar age, similar sex and with similar symptoms ('I don't know anyone comparable') and some compared themselves with MS patients they knew or with other persons they knew who were wheelchair-dependent. Four patients would not answer these questions on perceived comparative risk at all: they were unwilling to compare themselves with hypothetical others.

How perceptions of comparative risk in different time periods are related

Sixty-three percent of the patients did not make a distinction between their perceived comparative risk for the 2-year, 10-year and lifetime prognosis of wheelchair dependence (Table 1). Of these patients, 85% evaluated their risk the same as other patients and 13% perceived themselves at lower risk. Patients who made a distinction (37%) primarily tended to perceive their 2-year risk as lower than that of others and their lifetime risk as higher, but they had no explicit explanations for these differences.

Perception of the seriousness of future wheelchair dependence

When asked whether they considered wheelchair-dependence within the short, medium or long term having serious consequences (Figure 3), three groups could be identified. The first and largest group found the image of using a wheelchair daunting. Loss of mobility, loss of independence, a shrinking social world, adaptations in the house or even having to move, and the need for help were mentioned as things they considered serious consequences. At the same time, these patients believed they might regard the wheelchair as an increase of mobility after a period of having walked with great difficulty and expected that they would therefore get used to it.

Although these patients considered wheelchair dependence having serious consequences, they could still think of more serious ones. Examples of more serious consequences included dying of MS, losing vision, speech, hearing, cognitive functions, hand and arm function, or becoming incontinent.

'Yes, for sure it's serious, but not as serious as if I lost my vision or if I went insane; a wheelchair isn't the most serious thing. I think if I lose my vision, that's serious, or if I go insane, that something is wrong with my brains, that I no longer remember what day it is or when I say this isn't my husband, or if I'm not able to respond.' (R52)

One patient mentioned that wheelchair dependence would be particularly bad if people ignored and isolated you as a result of being wheelchair bound. Several other patients mentioned worse events not related to MS such as cancer, pain, stroke or a serious accident. Others found it worse if something terrible were to happen to their children, their partner or other close family members. And others

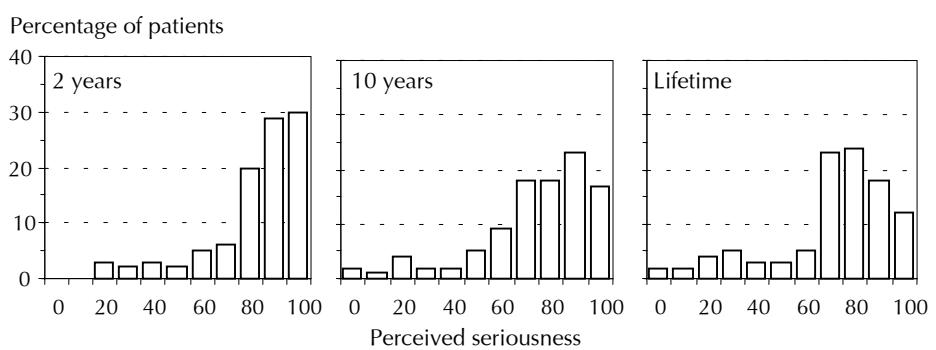


Figure 3 Perceived seriousness of wheelchair dependence

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put their illness into perspective, saying that the world goes on and that a world war would be far worse.

The second group considered wheelchair dependence the worst thing that could happen to them because their visible disability would encourage other people to treat them as disabled persons and pity them or because they would lose all their independence. Finally, the third group consisted of a small group of patients who were glad that they were still alive and saw the wheelchair as a minor inconvenience.

How perceptions of seriousness in different time periods are related

One-third of the patients did not discriminate in the seriousness of the 2-year, 10-year and lifetime prognosis of wheelchair dependence: the need of a wheelchair within two years was perceived as equally serious as needing a wheelchair within ten years or after an even longer period. Another third of the participants distinguished between the short-term risk of wheelchair dependence on the one hand, and the 10-year and lifetime prospect on the other. They reasoned that there would not be enough time to get used to the idea and there would be less time left for things they wanted to do, for instance enjoying the relationship with the partner, raising children, working or traveling. Patients also considered wheelchair dependence within two years as being more serious, because this would indicate a rapidly progressing form of MS:

'Yes, I think that's serious, because then it's only two years, I still would have liked to do this and this, but than it goes very, very fast. That would be frightening, yes. Because, when the disease progresses very slowly, than you get worse step by step, that may be easier to accept. And if I need a wheelchair in two years, what will happen in four years? Ten years, that's still a long way off, then I can still do a lot of things in the years to come.' (R68)

Discussion

In this study, perceptions of prognostic risk of patients with MS were investigated with a focus on the risk of wheelchair dependence. The predominant finding is the omnipresence of disease uncertainty, which is in line with previous studies on uncertainty in MS.^[2-4] Uncertainty not only explained the 50% scores of patients, but lower and higher perceptions of risk were also explained as being based on the uncertainty about what would happen. Although wheelchair dependence was defined as being unable to walk more than five meters, and though the patients

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were all assessed within a short period after diagnosis, patients did not feel confident ruling out the short-term possibility of wheelchair dependence.

To explain their perceptions of risk, patients mentioned disease-related factors such as presence and type of symptoms, the course of MS, recent disease progression and medication. But psychological factors such as hope and fear were also considered important, in particular for medium- and long-term risk perception. These qualitative data demonstrate that the VAS measurements directed the expectations about future wheelchair dependence. Because our patients were not hindered by knowledge of actual risks, which are generally not communicated to MS patients, expectations were clearly from an individual perspective, rather than based on knowledge of population risks. This can be seen in the elucidations of patients who used the 50% response. As has also frequently been found in other studies,^{e.g.[18]} these patients did not necessarily believe that the 'actual' population risk is 50%. We argue that this does not threaten the validity of perception of absolute risk assessment, since perception addresses individual beliefs rather than knowledge of epidemiological risks.

In the interview study, we found ample evidence that patients used heuristic reasoning to perform their risk analysis.^[19] First, the fact that several patients could not imagine themselves being wheelchair-dependent and perceived their risks to be low, literally follows the heuristic of availability. In addition, the reason why vivid memory of recent relapses and the familiarity with wheelchair-dependent patients were mentioned by patients to explain why their risk would be higher, is explained by the same heuristic. Second, patients mentioned factors that would indicate a higher risk, such as previous symptoms affecting walking ability, severe relapses or continuous disease progression, and, as they had not experienced these symptoms, concluded that they were at lower risk. This reasoning is according to the heuristic of representativeness.^[19] And finally, according to the heuristic of anchoring and adjustment, patients who responded with 50% may have refrained from further adjustment or evaluation whether their risk would be more or less likely,^[19] perhaps because thinking about the possibility was too threatening. This heuristic may also explain the 50% responses, since patients who primarily stressed that they did not know what to expect, did not usually add reasons why it would not be more or less likely.

Our study demonstrated that patients had difficulty comparing themselves with hypothetical others. A few patients would not answer these questions, whereas others compared themselves with patients they knew or with the average MS patient. One explanation, also put forward by the participants themselves, is that they did not know whom to compare with. Earlier studies on unrealistic optimism,

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where subjects on average perceive their risks to be lower than those of others, have shown that this lower perception of comparative risk is associated with the attribution of preventive actions to oneself and not to others.^[20] In MS, opportunities to control the disease by medication or lifestyle changes are limited, and this may be the reason why patients feel their risk to be equal to that of others. Further, most patients did not discriminate between the three time periods. We therefore conclude that the usefulness of comparative risk perception is questionable for unpredictable and poorly controllable (prognostic) risks. Thus, comparison of quantitative and qualitative assessments indicated good construct validity for perception of the absolute risk and seriousness of wheelchair dependence, but not for the comparative prognostic risk.

In coping with the uncertainty of their illness, MS-patients tended to focus on controlling their state of mind and their optimism, lacking other means of control.^[5,21] Seeing oneself in the distant future and giving meaning and direction to a life with MS, seems an almost impossible task for patients and decreases their well-being.^[8] Therefore, it is deemed clinically important to help them deal with uncertainty. For many MS patients, in particular those who have been diagnosed recently and those with minimal neurological symptoms, short-term risks of serious consequences of MS are low or unlikely but far from completely uncertain. Our study implies that when communicating with patients, it is important for health professionals to first verify what consequences are of major concern to the patient and then to discuss the prognosis of these outcomes under the condition of modest uncertainty (we don't know for sure) rather than complete uncertainty (we don't know at all). Patients may even benefit from this uncertain information as it may give them some idea about their prognosis in the near future and help them to maintain a grip on life.

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