



‘It might happen or it might not’: how patients with multiple sclerosis explain their perception of prognostic risk

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Abstract

This qualitative study aimed to examine risk perception and seriousness of wheelchair dependence in patients with multiple sclerosis. Perceived absolute risk and perceived seriousness were assessed for 2-year, 10-year and lifetime prognosis of wheelchair dependence using visual analogue scales (VAS). In semi-structured interviews, patients ($n = 85$) were asked to elucidate these VAS scores. 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. Wheelchair dependence was perceived as a serious outcome 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 seriousness. Comparison of quantitative and qualitative assessments indicated good construct validity for perception of the absolute risk and seriousness of wheelchair dependence.

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Introduction

Multiple sclerosis (MS) is a chronic neurological disease, which commonly starts between 20 and 40 years but affects all ages. Patients with MS face enormous prognostic uncertainty since the variation in type, severity and progression of symptoms is high (Noseworthy, Lucchinetti, Rodriguez, & Weinshenker, 2000). 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 (Buelow, 1991; Kroencke, Denney, & Lynch, 2001; Wineman, Schwetz, Goodkin, & Rudick, 1996). The lack of clinical prognostic information may affect patients' decisions about treatment as well as having children, changing jobs, or buying houses (Brooks & Matson, 1987; Robinson, 1988). 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 (Janssens

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et al., 2003). As anticipated, perceptions of risk were higher among patients with higher levels of clinically assessed disability (Janssens et al., 2003). In addition, patients who experienced more general and disease-related symptoms had higher perceptions of their short- and medium-term risks (Janssens, 2003). Although these studies brought to light some correlates of perception of prognostic risks, such as actual physical limitations and perceived symptoms, they have provided little insight into how these factors affect perception of risk.

The aim of the present interview study is to gain understanding in 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 subsequently elucidated in interviews. The study examines the following questions: (1) What do recently diagnosed persons with MS base their perception of risk, and their perception of the seriousness of future wheelchair dependence on? (2) Do patients distinguish between perceptions across the different prognoses (2-year, 10-year and lifetime) and for what reasons?

Methods

Procedures and participants

One hundred-and-one consecutive patients with a recent diagnosis of MS were recruited through the Departments of Neurology of the Erasmus Medical Center (Rotterdam), three hospitals within the region of this academic hospital, and the Vrije Universiteit Medical Center (Amsterdam) from March 1999 to December 2000. In- and exclusion criteria and non-response analyses have been published elsewhere (Janssens et al., 2003). In these hospitals, the clinical care for patients in the early phase after diagnosis commonly includes several visits to the neurologist in which patients receive information about their condition, brochures from patient organizations and—if available—a referral to a specialized MS nurse.

Patients were given a neurological examination, filled out questionnaires, and were interviewed. Functional limitations were assessed by a trained physician, and rated on the Expanded Disability Status Scale (EDSS; Kurtzke, 1983). This scale ranges from 0.0 (no neurological symptoms) to 10.0 (death due to MS). The psychological 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. 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). Wheelchair dependence was defined as the inability to walk beyond five meters, which equals a score of 7.0 on the EDSS (Kurtzke, 1983). 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 2 years, 20–25% within 10 years and 70–80% over the lifetime (Weinshenker et al., 1989; Myhr et al., 2001). Patients were asked to what extent they thought they would become wheelchair-dependent for distances over five meters within these periods. Although patients were additionally 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) this question was not relevant to them and so will not be discussed further. Perception of risk was assessed by 100 mm visual analogue scales (VAS; Hunter & O'Dea, 1999; Woloshin, Schwartz, Byram, Fischhoff, & Welch, 2000). The end points of the VAS were anchored at 'Definitely not' (0) and 'Definitely' (100). 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-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. Mean perceptions of risk and seriousness, disability status, age and sex did not differ between patients who were included and excluded in the qualitative analyses. Therefore, we can assume that interview data were available from a representative sample of all patients who participated in the study.

Data analysis

For the presentation of the distribution of perception of the 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 periods, differences between the VAS scores were

calculated. When these difference scores were lower than -5 and higher than $+5$, patients were considered to discriminate in their perceptions. The categorization and the cut-off scores were obtained from a qualitative analysis of patients' explanations in the interviews. We examined all excerpts in the interviews in which patients commented on the location of their marks on the VAS and on differences in perceptions of risk and seriousness between two time frames. Regarding the localization of the marks, we found that the VAS scores of patients who explained having ticked the lower end of the line were typically between 0 and 5. For the middle of the VAS, the scores were between 46 and 55, and for the upper end between 96 and 100. For that reason, we divided the scale into 11 categories. With regard to the difference between VAS scores of two time frames, we found that the absolute difference in VAS scores was typically between 0 and 5 points in patients who explained that they did not differentiate. For example, when patients explained in the interview that they saw no difference for between their 10-year and lifetime risk, the difference between these VAS scores was typically between -5 and $+5$.

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 (Mason, 1996). The analysis consisted of two iterative activities: fragmenting and connecting (Dey, 1993). In the first activity, the informative parts of each interview were extracted, categorized, and labeled with codes (open coding), using the program *WinMAX* (Kuckartz, 1998). Some categories such as 'perception of seriousness' and 'risk' were clearly defined by the literature, whereas others such as 'positive thinking' and 'fear of total dependence' were identified in the data. In this phase, the coded interview parts were connected to patients' VAS scores to see whether they showed consistency.

The second activity in the analysis process consisted of connecting the coded interview parts and identifying explanations for the three different time periods. 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 (Seale, 1999). Advantage was taken of the different disciplinary backgrounds of the researchers to generate alternative interpretations of patients' explanations (Barbour, 2001). In this way, both the agreements and disagreements in the discussion provided insight for refining the coding process. Data extracts are presented to illustrate the main lines of reasoning of patients and to provide the possibility of verification of the inferences that were made from the data. 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 (median 2.5). Eighteen percent of the patients already experienced problems in walking, indicated by an EDSS score of 4.0 or higher. Ten patients used interferon treatment for MS.

Perception of absolute risk

Perceived 2-year risk

Fig. 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 2 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

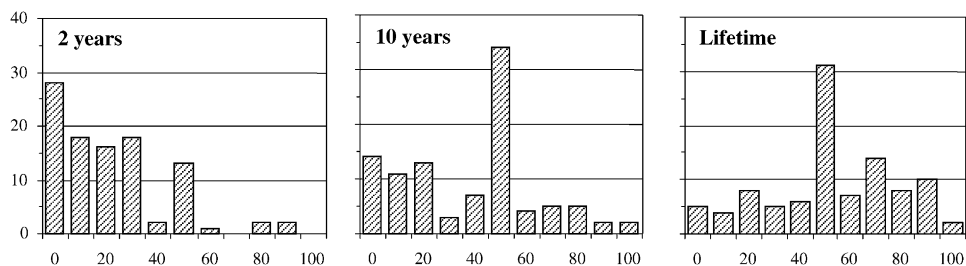


Fig. 1. Perceived absolute risk of wheelchair dependence. Janssens et al., 2003. Reprinted with permission of Blackwell Publishing.

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 of symptoms 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 subsequent relapses was low.

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 reservations because they had a fresh memory of a recent upheaval of the disease or had recently been confronted with wheelchairs in their environment.

Nearly 30% of the participants perceived their 2-year risk to be nil. Some patients could not imagine their illness progressing that fast. Others were convinced that they would not become wheelchair-dependent within 2 years, because this would be preceded by severe relapses or continuous disease progression, which they had not had so far. Again others perceived their risk to be nil because they would not even consider the possibility of it happening, 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 Fig. 1 shows that a substantially larger group of patients put their cross in the middle of the VAS. There were two main reasons why patients chose the middle of the VAS for their perception of the 10-year risk of wheelchair dependence. 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 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 because they 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 of patients, 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 10 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%. Patients put forward two dominant explanations: 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. Other patients added 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 in 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 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 Fig. 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 farthest 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 the possibility of wheelchair dependence, that they hoped it would not happen or that a positive attitude would help. A few patients hoped that by that time effective medication would have been developed. And finally, several patients commented that they did

not mark the very 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 discriminated 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 time periods at all. 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').

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 (Fig. 2), 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

Table 1

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

	Risk	Seriousness
All different	45	25
2–10 years vs lifetime	19	11
2 years vs 10 years—lifetime	25	32
All the same	11	32
Total	100	100

Values are percentage of patients (total $n = 101$).

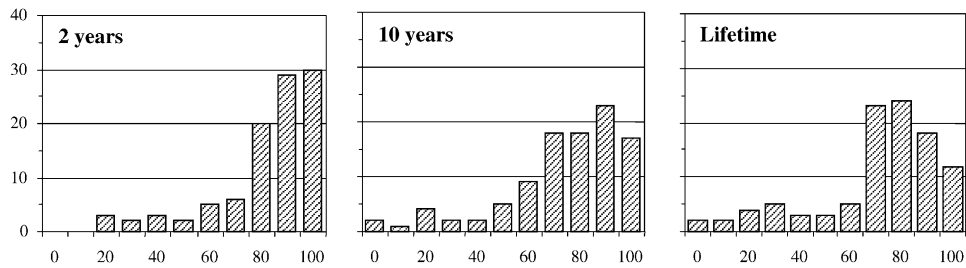


Fig. 2. Perceived seriousness of wheelchair dependence.

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 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 2 years was perceived as equally serious as

needing a wheelchair within 10 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 (Buelow, 1991; Kroencke et al., 2001; Wineman et al., 1996). 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 5 m, and though the patients were all assessed within a short period after diagnosis, they 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 findings confirm the findings from our quantitative studies in which we found that patients' symptom reporting was primarily associated with perception of the 2-year risk of wheelchair dependence, and not with perception of the lifetime risk (Janssens, 2003). Also, increased symptom reporting at the 2-year follow-up assessments was associated with higher perception of the 2-year risk, but not with perception of the lifetime risk (Janssens, 2003).

These qualitative data demonstrate that the VAS measurements reflected expectations about future wheelchair dependence. With the exception of one patient, none of the respondents used knowledge of actual risks to explain their perception of risk. Therefore, these expectations were clearly from an individual perspective, rather than based on knowledge of population risks. This was clearly demonstrated in the elucidations of patients who used the 50% response. As reported in other studies, these subjects did not necessarily believe that the 'actual' population risk is 50% (Fischhoff & Bruine de Bruin, 1999). We argue that this does not threaten the validity of perception of absolute risk assessment, since this assessment 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. Heuristic principles refer to short-cut strategies that reduce complex judgment tasks into simple ones (Tversky & Kahneman, 1974). These heuristics are often very useful in perception of risk, but can lead to systematic over- and underestimations. Tversky and Kahneman (1974) identified the heuristics of availability, representativeness and anchoring and adjustment. First, the heuristic of availability predicts that patients who can easily imagine themselves as being wheelchair-dependent will overestimate their risk of wheelchair dependence. In the interview, we found that several patients could not imagine that they would become wheelchair-dependent and perceived their risks to be low, which literally follows this heuristic. 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, the heuristic of representativeness predicts that patients who considered themselves to be more like patients who are wheelchair-dependent would perceive themselves at higher risk. In the interview data, we found that patients who had not experienced symptoms that in their view are related to wheelchair dependence, such as walking limitations and severe relapses, considered themselves at lower risk. The third heuristic, anchoring and adjustment, assumes a two-step judgment process in which

people start from an initial perception which they adjust into a final answer. These adjustments from the initial values or anchors are typically insufficient (Tversky & Kahneman, 1974). In our study, this would result in an excess use of the ends or the middle of the VAS, such as the peaks of 50%-responses in the perception of absolute risks. In the interview data, we found that patients who used the 50%-response generally did not explain why 'it might happen or it might not'. They may have refrained from further evaluation because thinking about the possibility was too threatening.

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 (Brooks & Matson, 1987; Fournier, de Ridder, & Bensing, 1999). 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 (Boeije, Duijnste, Grypdonck, & Pool, 2002). Current professional practice in helping them to deal with uncertainty is diverse. Besides giving out written information about MS and about patient organizations, most neurologists meet their patients in a few follow-up visits in the year after diagnosis and other patients are appointed to counselling sessions by MS nurse specialists. Our findings bring to light the importance of discussing short-term prognosis with patients and their families. Being too optimistic may lead to later disappointment, whereas being too pessimistic may be accompanied by increased worry.

Professionals may discuss the hope and expectations of patients with regard to the near future. When communicating with patients, it is important for health professionals to first verify what consequences are of major concern to the patient. A simple device like the VAS that was used in this study, stimulates a more systematic thinking about the topic and might encourage people to express one's expectations. 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. Patients may even benefit when prognosis of the outcomes that matter most to them are discussed under the condition of modest uncertainty (we don't know for sure) rather than complete uncertainty (we don't know at all). This may give them some idea about their short-term prognosis and help them to cope with their illness.

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