

## SUMMARY

The present study describes expectations of prognosis of recently diagnosed MS patients and their partners with a focus on the risk of wheelchair dependence. The three main questions in this thesis were: (1) How do recently diagnosed patients and their partners perceive the risk of wheelchair dependence? (2) How do perceptions of risk relate to psychological well-being? (3) What are the determinants of perception of prognostic risk? Before answering these key questions, the psychological burden of disease and the quality of life (QoL) of patients and partners in the early phase of MS are examined.

The thesis starts with a description of the disease and a summary of previous studies on psychological aspects of MS (**Chapter 1**). Discussed are findings on diagnostic and prognostic uncertainty, poorer health-related quality of life (QoL), higher levels of depression and anxiety, and the high psychological burden for partners. These psychological aspects have not been investigated in the early phases of disease. Also, to date, expectations of future disease progression – or perceptions of prognostic risk – of patients and partners have not been studied in MS or other chronic diseases. **Chapter 2** describes the design of the study, procedures of data collection, selection of participants, the instruments used and their psychometric properties. The prospective follow-up study consists of psychological and neurological assessments at four measurements within two years and of interviews at baseline. Hundred-and-one patients and 78 partners were included.

As an indication of the burden of uncertainty prior to the diagnosis, patients' satisfaction with the timing of diagnosis was investigated (**Chapter 3**). We found that the probability of patients being satisfied with the timing of diagnosis was highest in patients diagnosed with MS within the first year after the first visit with the neurologist. Patients explained that they preferred an early diagnosis because the burden of diagnostic uncertainty was considerable.

**Chapter 4** shows that at baseline, on average eight months after diagnosis, both patients and partners had high levels of anxiety and distress. In addition, patients but not partners reported poorer health-related QoL compared to controls. As expected, poorer psychological well-being and QoL were primarily found in patients with higher disability. In **Chapter 5**, we show that disability status was significantly related only to three out of four SF-36 physical health scales, after adjustment for anxiety and depression. The relation between EDSS and these SF-36

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scales was consistently higher in patients with more symptoms of anxiety or depression, suggesting that anxiety and depression strengthened the association of EDSS and these SF-36 physical health scales. The finding that EDSS was not significantly related to the SF-36 mental health scales and the general health scale when adjusting for anxiety and depression, is compatible with the hypothesis that anxiety and depression are intermediate factors in the association of EDSS with these SF-36 scales.

**Chapter 6** addresses the question how recently diagnosed patients and their partners perceived the risk of wheelchair dependence. In comparison with actual risks obtained from epidemiological studies, patients and partners overestimated their 2-year and 10-year risks of wheelchair dependence, but underestimated their lifetime risks. A large number of patients were uncertain about their 2-year risk, even those with no or only minimal disability (EDSS < 3.0). One-third of the patients perceived the 10-year and lifetime risk to be 50%, which, as they explained in the interviews, reflected their uncertainty: they did not know what to expect. Patients with more functional limitations had higher perceptions of risk, but perceived wheelchair dependence as being less serious.

In **Chapter 7**, the relationship between perceived risk and seriousness and anxiety, depression (HADS) and disease-related distress (IES) was examined. We found that patients with higher perception of the risk and seriousness of wheelchair dependence had significantly higher levels of distress, after adjustment for clinical disability status. Relations were found for the 2-year, 10-year and lifetime prognosis of wheelchair dependence. Only perception of the 2-year risk and seriousness of wheelchair dependence was significantly associated with higher levels of anxiety and depression.

In Chapter 8, 9 and 10 the determinants of perception of risk were studied. **Chapter 8** focuses on the role of illness beliefs such as beliefs about the controllability, duration, and symptoms of the disease. Patients who reported a higher intensity of disease-attributed symptoms had higher perceptions of the 2-year and 10-year risk of wheelchair dependence, after adjustment for clinical disability status. None of the other illness beliefs were significantly related to perceived risk or seriousness of wheelchair dependence. In **Chapter 9**, we present the finding that neuroticism strengthens the relationship of perceived symptoms with perception of the risk and seriousness of wheelchair dependence. Patients who were more pessimistic reported more symptoms after adjustment for disability status and considered wheelchair dependence to be more serious. Optimism and pessimism were not associated with perception of risk. Our findings suggest that personality factors directly (neuroticism) and indirectly (pessimism) affect

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perception of risk and seriousness of wheelchair dependence. Findings of the qualitative study of perception of prognostic risk are reported in **Chapter 10**. In line with the quantitative analyses presented in Chapter 8, patients mentioned disease-related factors such as presence of symptoms and recent disease progression to explain their perception of risk. In addition, psychological factors such as hope, fear and positive thinking were identified as determinants. Uncertainty about future disease progression was found to be omnipresent in the explanations of perceived risks. With regard to the perceived seriousness of wheelchair dependence, three groups could be distinguished: a group considering a wheelchair the worst thing that can happen, a group thinking it is serious but worse things can happen and a group considering it just a small inconvenience.

In **Chapter 11**, the course of perception of risk and seriousness and the longitudinal findings on the determinants are described. 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. Relationships of disability status and perceived symptoms with perception of risk were confirmed in the cross-sectional analyses of the follow-up data. Changes in perceived symptoms were associated with changes in perception of risk, confirming that perceived symptoms play an important role in perception of prognostic risk in recently diagnosed MS patients.

In **Chapter 12**, the relationship between perception of risk and psychological well-being was investigated in a follow-up study. Mean levels of disease-related distress decreased significantly both in patients and their partners, but the high levels of anxiety remained unchanged. In patients, higher perception of the 2-year and 10-year risk of wheelchair dependency was again significantly related to poorer psychological well-being, whereas higher perception of seriousness was consistently related to higher distress and anxiety. Most importantly, an increase in perception of the 2-year and 10-year risk of wheelchair dependence was associated a significant increase in levels of anxiety, depression and distress.

In conclusion, we have demonstrated that the early period after diagnosis of MS puts a substantial emotional burden on patients and their partners. Patients and partners overestimated the short- and medium-term risks of wheelchair dependence, but underestimated the lifetime risk. Moreover, higher perceptions of the short- and medium risks were found among patients with higher symptom perception, and were associated with poorer psychological well-being. These findings are interpreted from a psychological and clinical perspective (**Chapter 13**). Further, in this chapter, suggestions for future research are discussed.

