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Perceived health status in multiple sclerosis patients

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General discussion and implications for future research and practice

In the first part of this chapter general considerations regarding perceived health status and its association to the main variables of the study will be discussed. Later, the strengths and some limitations of the study will be reviewed. The chapter will end with some suggestions about directions for future research on perceived health status in MS patients and with a discussion about the implications of the findings for clinical practice.

7.1 Discussion of the main findings

Perceived health status focuses on two areas: physical health status and mental health status. In medical patients, including MS patients, the physical and mental dimensions of perceived health status are related to one another. Many MS patients report a fear of sudden relapses and anxiety about disease progression (4). Consequently, they must resist the intrusion of negative thoughts that result in a bad mood or the stress that comes from the progressive decline in their physical health status. Regarding the aims of this work, Chapter 1 contains the theoretical model used in the study. We focused on the outcomes of the physical and mental health summary scales with the disease process and the functional disability associated with physical health status, as well as the psychosocial factors related to mental health status.

Regarding physical health status, the studies reviewed here provided support for the negative association of disease duration and a higher score in functional disability with the physical health dimensions of the SF-36 (1, 2). Patti et al (2) actually reported a significant association between all SF-36 health dimensions and disease duration. Similarly, Nortvedt et al (5), in a study of 194 MS patients, revealed significantly lower scores in all health dimensions of perceived health status and higher scores in functional disability (5).

The first item of the SF-36 appeared, in a statistical sense, as a strong predictor of employment status in MS patients. In terms of premature retirement, non-employment status mainly affects financial security and leads to a reduced social network and a worsened perceived health status. Despite these results, experience shows that society and employers assess the efforts of MS patients to work as marginal, and a patient's

opportunities for being employed full-time or part-time are genuinely limited. In line with this statement, only about one-third (35.9%) of all patients surveyed were employed full-time or part-time, although the majority of MS patients had the relapsing-remitting clinical course.

The next step focused on psychological well-being and perceived health status in MS patients. Our results show that less depressed and less anxious MS patients assessed their perceived physical and mental health status as significantly better, and that results regarding perceived health status as an important dependent variable related to depression and anxiety are in line with previous findings (5-7).

Social support is considered primarily as a psychosocial construct and to a lesser extent, a physical construct. In line with this statement, our outcomes did not reveal a strong relationship between social support and physical health status. But some studies have consistently shown that social support may be a major factor in adaptation to physical illness, and that positive social interaction is associated with better physical functioning (8, 9). In spite of this fact, social support provided by family and friends was positively associated with all of the individual dimensions of mental health status in MS patients. Thus, the results of this study are in line with the finding that more social support contributes to better mental health (8, 9). Many authors have shown that social support functions as a protective factor against mental health problems (10-12).

Another psychosocial factor studied was mastery. We concluded that higher mastery was associated with better mental health status in MS patients. The fact that worse functional disability, higher mastery and worse perceived health status are more frequently present in the older age group (≥ 45 years) than in the younger one (< 45 years) might suggest that the progress of MS should be taken into account. Other authors have also found that individuals with greater mastery are more likely to use preventive care, have good health behaviours, seek treatment early and use health services properly (13-15).

At the end of the discussion of our main findings, we would like to come back to our earlier statement regarding the fear of sudden relapses and disease progression that deeply affects MS patients. The described variables, including low functional disability, short disease duration, the ability to work and social support provided by significant others, could be factors mainly associated with perceived physical health status in MS patients. Secondly, the studied psychosocial factors, including social support provided by family and friends, higher mastery and the absence of depression and anxiety, could be important determinants of mental health status in MS patients. Our study showed that the physical and mental health dimensions of perceived health status can only be divided for analytical reasons; in reality they operate in patients as a whole.

7.2 Study strengths and limitations

Strengths

With regard to the functional disability of MS patients, not only subjective data on physical health status was collected. EDSS, a measure of functional disability, was used as an objective health indicator focusing on the level of disease severity and was assessed by a neurologist. EDSS was significantly correlated in the total sample of MS patients with the dimensions of the physical health summary scale of the SF-36. This scale therefore could be recognized as an appropriate measure of perceived physical health status. Neurologists, nurses, psychologists and psychiatrists might use it as a quick tool for measuring perceived physical health in MS patients.

Since published studies were lacking on the effect of perceived social support on the health status of MS patients, our study tried specifically to shed more light on this topic. In doing so it revealed that the health dimensions of the SF-36 might be associated with a different type of social support and could contribute to better perceived health determinants. Similarly, little research has thus far been conducted on MS patients regarding the associations between mastery, functional disability and perceived health status.

Limitations

Each of the studies described in this thesis contain a section in which the strengths and limitations of the study have already been discussed, therefore these factors will only be mentioned here very briefly. The studies are cross-sectional, so causal relationships cannot be concluded from the findings. The significantly older age of the non-respondents suggests more disease severity among this group, which affects the ability to generalize from our study outcomes. A further limitation of our outcomes could be the exclusive access of patients under the age of 45 to disease-modifying agents.

However, there are additional issues that should be mentioned. Firstly, the study was carried out in a population of MS patients, but not in a healthy or general population. It is well known from many previous studies on quality of life that MS patients report their health status worse than the general population (5, 16-18). Secondly, we agree with the authors of Perceived Social Support scale that clarification is needed regarding who actually belongs to the significant others subscale (19).

A number of disease-modifying drugs (DMD) have been developed over the past 20 years. Although these drugs have been introduced in Central and Eastern Europe, their high cost means many patients do not have access to them. The unavailability of DMD for patients over the age

of 45 in Slovakia might lead to a certain limitation of this study. There is no doubt that a significant treatment gap exists in approaches to MS between countries. DMD are also costly, requiring € 15.000 to € 26.300 per annum per patient, and are beyond the reach of many patients (20). On 1 July 2008, the Slovak Ministry of Health cancelled the age restriction on the use of DMD. As a result, every MS patient for whom DMD might be helpful now has, according to a neurologist's decision, the opportunity to use this medicine and have the cost covered by their health insurance provider.

7.3 Implications of the findings

Recommendations for future research

As with many neurological diseases, MS is difficult to study. Even after several decades of intensive research activity, it remains a condition with no known pathogen, and there is no consensus on its origin or accepted determinants of its severity. Below are some suggestions for future research based on the findings of this thesis.

Some neuropsychological studies suggest that 40-65% of MS patients show some cognitive dysfunction, prominently involving memory, sustained attention and information processing speed. Cognitive functioning has a dramatic impact on a patient's well-being, influencing role fulfillment in both work and social life (21-23). A patient's cognitive dysfunction could be assessed by specific neuropsychological measures (23). Thus, researchers might want to study how cognitive functioning is associated with perceived health status in MS patients. We might expect some limitations in the dimensions of the mental health summary scale depending on its linkage with cognitive functioning.

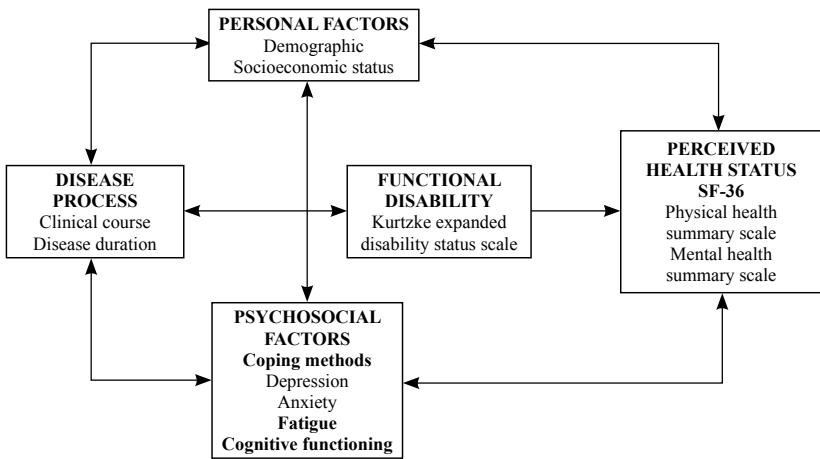
Physical fatigue and mental fatigue are frequently reported negative factors in people with MS. The symptoms of depression and fatigue are very similar, however, and it may be difficult to differentiate them; sometimes a trial of antidepressants may be necessary (20). As the subjective experience of fatigue is one of the most common symptoms in MS patients and is certainly associated with reduced health, the association in which fatigue impacts perceived health status has not yet been clearly defined (24-26). We can assume that since the score in functional disability is influenced by limb and gait dysfunction, fatigue might very well be linked with the physical domain of perceived health status.

It would be interesting to ascertain whether positive experiences directly enhance the perceived physical and mental health status of MS patients. How MS patients cope with stressors may be affected not only by their mastery over life circumstances but also by the social support

provided. People with a diagnosed disorder might differ from those who score high on psychological symptom scales in social characteristics and in life event experiences. Additionally, hardiness, a sense of coherence, and Type A characteristics such as impatience and hostility have been studied as factors relevant for coping with disease. Pearlin and Schooler (27) distinguished between perception-focused coping strategies and emotion-management strategies. Furthermore, behavioral self-efficacy has been related to health-promoting behaviour and to positive physical health outcomes (27-30). Focusing more on stress and the coping strategies used by MS patients could be a very important part of future research.

The extended model, with elements of cognitive functioning, fatigue, stress and coping strategies, might serve as a framework for future research on MS patients (Figure 1). This model with perceived health status might also be studied in a comparison of MS patients and the general population within a cross-sectional theoretical framework.

Figure 1 Framework for future research



MS patients are usually diagnosed in the first part of their life trajectories, when career and starting a family are major issues. With a renewal of the theoretical framework, future research could focus on if and how the life plans of younger MS patients might change and be affected by such a distressing factor. A longitudinal study would be appropriate for revealing these changes in MS patients over time. Furthermore, longitudinal data would be needed to further unravel the complex interplay between psychological well-being and changes in perceived health status in MS patients during and after treatment with the disease-modifying agents.

Clinical implications

MS patients achieved an average score in perceived physical and mental health status; thus, many MS patients experienced good health status. But a minority of them, mainly older people with MS, does not experience a satisfactory physical health status.

Even though drug treatment options are relatively limited, significant improvements in the well-being of people with MS might be supported by more intensive rehabilitation approaches. For patients with relatively moderate disability, both aerobic and non-aerobic exercise, for example, has been found to be very useful. There is a need for more studies evaluating the rehabilitation needs of MS patients experiencing with more severe disability. Similarly, neuro-rehabilitation aiming to improve independence leads individuals with MS to adapt their lifestyle.

People with MS might also benefit from psychosocial intervention. Cognitive-behavioural therapy focuses on unrealistic beliefs and replaces them with realistic beliefs. Such therapy might help patients adapt to life circumstances that are beyond their control. A good family background and a network of friends have been shown to be important for mental health status. If social support is lacking, intervention programmes might therefore be of help. Additive psychosocial treatment, including support groups and family therapy, should focus not only on patients, but also on wider family interactions.

There is still a need for a multidisciplinary MS service and multimodal approach to symptom management. Caring for MS patients used to increase in line with worsened functional disability. Uncertainty over the origin or progression of MS indicates that prevention is currently not a realistic option. An approach in managing treatment, centered on MS patients should include medication appropriate to the level of functional disability, followed by management of additive symptoms, mainly including fatigue, spasticity, pain, anxiety, depression, bladder and bowel dysfunction, imbalance, visual loss, cognitive impairment, etc. (20).

National MS societies, MS patients, their families, governments, health, social and care providers, employers, researchers and others might try to use services and improvements in their programmes which include independence, medical care, long-term care and social care, health promotion, support for family members, transportation, employment and volunteer activities, disability benefits, cash assistance and education for MS patients. MS patients should be educated about the possibilities of MS development and regarding how to adopt satisfactory coping strategies. Such a health care network should consist not only of neurologists, but also nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, social workers and psychiatrists who should stress this goal (20).

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