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Parkinson's disease - psychological determinants of quality of life

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Summary

Nowadays, approximately 6 million people are affected by Parkinson's disease (PD) worldwide, but this number is not exact, because many people remain undiagnosed. The motor impairment, which is the most visible symptom of the disease, affects all domains of the patient's life – physical, psychological and social. A slow and uncertain movement, tremors and falls inhibit patients to do activities of daily living, to fully use the leisure time, and to be active in social life. Although there are many studies, which are focused on measurement the quality of life (QoL) of those patients, studies about their personality and other psychological factors associated with QoL in PD patients are scarce. In our research we focused mostly on personality (extraversion, neuroticism, type D personality, negative affectivity and social inhibition) and mood disorders (depression, anxiety) as factors associated directly with QoL or indirectly – through patient's delay (Figure 1.3).

The first aim of *Chapter 2* was to explore whether neuroticism and extraversion contribute to the variance in QoL in patients with Parkinson's disease. Multiple linear regression analyses were performed to identify how much the variance of the dependent variables, dimensions of the questionnaire PDQ-39 (*mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication and bodily discomfort*), could be explained by the personality traits if controlled for the relevant sociodemographic (age and gender) and clinical variables (disease severity and disease duration). After disease severity, which we expected as the most important factor influencing QoL, neuroticism was the second most important variable in the model of QoL, particularly in domains associated with psychological processes: *emotional well-being, social support, stigma* and *bodily discomfort*, explaining 5-24% of the variance of QoL. The second aim of the study was to explore gender differences in the variables in the models of QoL. A higher score in extraversion was significantly associated with better *emotional well-being* in males, but surprisingly, with worse *emotional well-being* in females. According results we can hypothesize, that neuroticism is affecting the perception of QoL and in further research gender differences - males and females develop different ways of coping and experiencing the world - can be taken into account.

In the *Chapter 3* we continued in line with results presented in *Chapter 2*. The aim of this study was to evaluate whether Type D personality, and its two subscales – negative affectivity (NA) and social inhibition (SI), predicts QoL in patients with PD and, in addition, gender differences in Type D personalities were explored. Type D was negatively

associated with overall QoL in PD patients and with all dimensions except *mobility, activities of daily living* and *bodily discomfort*. In women, a higher NA explained the higher dissatisfaction with *social support*. For overall QoL, NA explained 13.2% ($P<0.001$) of the variance in males and 9.3% ($P<0.01$) of the variance in females. SI also explained a maximum of 5.5% ($P<0.05$) of the variance in *communication* in men and 7.3% ($P<0.05$) *stigma* in women. In short, personality traits play an important role in the explanation of QoL in PD patients. The gender differences suggest that models of QoL for men and women are composed from different variables.

Chapter 4 presents a systematic review focusing on the role of the intensity of fear in patient's delay in seeking medical help. We used studies about rather common diseases - cancer and myocardial infarction, mostly for the reason of quantity of such kind of studies in those diseases. In a search of literature published between 1990 and June 2009, 161 articles were found. After the use of inclusion and exclusion criteria, 11 articles in cancer and 4 articles in myocardial infarction remained. Fear ranged on a scale from the lowest level of 'being worried', which is not enough to initiate the early contacting of a specialist, to the level of 'panic'. People who were extremely alarmed about the first signs of their disease were ready to consult their general practitioner (GP) within a few hours. The main result of this review was to show, that the level of fear influenced decision-making. This important factor should be taken into account when facilitating help-seeking by patients, and especially in cases of low level of fear, encouraging them to seek medical care.

Patient's delay was also the topic of *Chapter 5*. Here we explored whether QoL in PD patients who delayed in seeking help was associated with personality traits. Because of the intermittent occurrence and slow progress of symptoms in the first phase of the disease, in several cases patients who sought medical help within 1 year of the appearance of the first signs and symptoms of the disease were marked as 'non-delayers' and those over 1 year as 'delayers'. This period was defined on the basis of interviews with patients - when the onset of disease was not dramatic, people attributed them frequently to 'stress'. Non-delayers scored higher in extroversion, which was associated also with better scores in physical and mental health summary score. Results showed, that social interactions, associated with an extrovertly oriented personality, can force decision making on help-seeking.

Many studies confirmed that anxiety and depression were assumed to be the variables associated with worsening QoL in various diagnoses. Because in previous studies we concluded, that personality traits (especially Type D and neuroticism) are determinants of quality of life, in *Chapter 6* we examined whether Type D is associated with the mental and physical health status of quality of life in PD and in patients with multiple sclerosis (MS) even when depression and anxiety were added to the model.

Our findings showed that higher scores in anxiety and depression were strongly associated with QoL in both diseases. Although initially Type D personality was associated with both dimensions of QoL – physical and mental health summary score, this association disappeared in both dimensions in MS and in the mental dimension in PD when the variables anxiety and depression were added to the model. Our findings suggest a combined pathway from personality via mood variables to quality of life.

In *Chapter 7* the main findings were discussed and implications for practice and for further research were formulated. In line with our results, we can state, that quality of life in patients with Parkinson's disease can be partially explained by personality traits and also the gender aspect of quality of life appeared to be an important topic contributing to the knowledge about psychological differences between men and women with PD. Actual mood disorders, depression and anxiety, are modifying the importance of personality traits in QoL and they seem to have more serious impact on quality of life than personality traits not only in PD patients, but also in patients with multiple sclerosis. According to our findings, delayers and non-delayers among PD patients differed regarding extraversion, which positively correlates with social activity and social support. Therefore, patients extravertly oriented who have the possibility to share feelings with somebody, seek help sooner than patients with low score in extraversion.

The limitation of the study was the relatively low response rate, which may have an impact on generalization of the results to the total population of PD patients. Also using longitudinal data in further research could help us better explaining causal relationships between variables. Further research of patient's delay should also combine qualitative and quantitative research for more precise interpretation of findings. Using qualitative methods could help to understand the meanings, practices and context of measured variables. To choose the most effective interventions in the framework of treatment, neurologists should take into account their patient's personality and his actual mood or motivation, next to the worsening or improving of the symptoms of the disease.

