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## Parkinson's disease - psychological determinants of quality of life

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# General discussion and implications for practice and future research

The majority of clinical studies, focusing on quality of life of patients with Parkinson's disease, are oriented on the effect of medical treatment of motor and non-motor symptoms in terms of quality of life. Less frequently psychological factors are studied which may contribute to patients' perception of their quality of life. Although personal factors are part of the International Classification of Functioning, Disability and Health (ICF) model such factors, and among them personality, do not belong to the main factors which are taking into account in research in chronic diseases. This thesis explores the association of psychological factors with the perception of quality of life in patients with PD and, in addition, investigates whether psychological factors are associated with patient's help-seeking behavior and contribute to quality of life.

In this chapter firstly the main findings will be presented and discussed. Secondly, the study strengths and limitations of the research are mentioned. Last part is focusing on the implications of the results for practice, for the patients with Parkinson's disease and for further research.

## 7.1 Main findings

The main findings were organized according the main research questions.

### **7.1.1 The exploration of the associations between various personality traits, neuroticism, extroversion, negative affectivity, social inhibition and Type D personality and quality of life in PD patients. In addition, gender differences were examined as well.**

We expected an association between personality traits (neuroticism, extroversion, negative affectivity, social inhibition and Type D personality) and quality of life in patients with Parkinson's disease. We also hypothesized, that each of the domains of quality of life is determined by different predictors. For this reason we used the PDQ-39 and its 8 scales: *mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication and bodily discomfort.*

Into the models variables were added, which may influence the association between personality traits and quality of life: disease severity (measured by UPDRS), disease duration and age. Despite their strong influence, the personality traits explained 8-24% of the variance of 6 dimensions of QoL (Chapter 2 and Chapter 3, Table 2.3, Table 3.3). After the UPDRS, Type D explained most of the variance in the overall model of quality of life for patients with Parkinson's disease and it was strongly associated with the dimensions *emotional well-being*, *stigma*, *social support*, *cognitions* and *communication*, but it was not significantly associated with *mobility*, *activities of daily living* and *bodily discomfort*, which were explained only by the UPDRS. Patients with higher scores on the neuroticism scale from the Eysenck Personality Questionnaire reported similarly like Type D patients a significantly worse status in the domains of *emotional well-being*, *stigma*, *social support* and also, on the contrary to Type D, in *bodily discomfort*, but not in *mobility*, *activities of daily living* and *cognitions*.

In comparisons between genders differences were found. Type D explained *emotional well-being* in both genders. Among men, Type D was an important factor in the models of *stigmatization by illness*, *cognition* and *communication* but personality played no role in these models among women. In both genders, negative affectivity (NA) and neuroticism explained 8.5-13.4 % of the variance in *emotional well-being*. A higher score in NA was associated with a worse score in the dimensions of *stigma* and *cognition* in men, while in women it was associated with a worse score in *social support*. In the model of overall quality of life, NA appeared to be important for both genders, contrary to social inhibition, which did not play a role in the model. Neuroticism played a role in the subscales of *stigma* and *social support* in women, but it did not appear to be important in men.

### **7.1.2 Differences between delayers and non-delayers regarding psychological factors associated with quality of life in patients with PD were explored and additionally the impact of fear and anxiety on help-seeking behavior in non-parkinsonian diseases.**

Psychological factors might play a role in delaying patients and could affect QoL of such patients. The length of the patient's delay might give important information for the clinician. Because of the lack of such papers in neurological journals, we decided to do a review on delay in the field of cancer, a frequently slow developing disease, and acute myocardial infarction, an acute developing disease.

The intensity of fear is a factor, which has an impact on the decision making process of the patient. The higher the level of fear the shorter the time of the arrival to the medical doctor was. 'Being worried'

was not enough for seeking help, but probably it is starting the process of internal thinking about the possibility of being treated. 'Fear' seems to be a factor for longer delay, but the decision process in patients experiencing fear was also influenced by other factors, such as embarrassment, pressure from a patient's relatives or fear of financial consequences. 'Being anxious' and feelings of 'panic' or 'death anxiety' was associated with seeking help within a few hours.

Shortening of the patient's delay has in case of cancer and AMI impact on successfulness of treating and, indirectly, on their quality of life. The aim of our study was to explore, whether patients with PD are different in their quality of life stratified for patient's delay and whether the association of personality traits and quality of life in patients with PD is influenced by delay. Patients with PD who came earlier to see a health care professional differed from delayers by a worse functional status and they had a significantly lower physical quality of life than delayers. In neuroticism no differences were found, for both groups neuroticism was strongly associated with lower quality of life – mental and also physical. However, non-delayers were more extrovertly oriented than delayers.

### **7.1.3 The comparison of the role of the association of psychological factors – Type D personality, anxiety and depression – with quality of life in patients with PD and multiple sclerosis (MS).**

Mood disorders, especially depression, are among the clinical symptoms of both diseases [1,2]. Because in previous studies we concluded, that personality traits (especially Type D and neuroticism) are determinants of quality of life in patients with Parkinson's disease, we explored whether Type D was associated with quality of life in PD and MS patients even when depression and anxiety was added to the model of patients' self-perceived quality of life.

Type D personality significantly associated with worse mental health status of PD patients and with decreasing scores in mental and physical domains of quality of life in MS patients. However, when the actual mood factors depression and anxiety were added, the significant association of personality traits with quality of life disappeared. This finding, the disappearing significance between personality and QoL after adding mood variables, suggests a combined pathway from personality via mood variables to quality of life.

## 7.2 Discussion of the main findings

### *Personality traits and quality of life*

Findings from longitudinal studies show that Parkinson's disease affects patients' lives in a broader sense than by physical impairment, and that despite modern treatment, the impact of the disease increases as the disease progresses [3]. Personality, according to the ICF model, belongs to the contextual factors, which influence patient's functioning and disability [4]. Furthermore, a review indicated that psychological and social variables influence perception of health status, mostly in case of pain, more powerfully than biological factors [5]. Several studies confirmed that personality affects patients' reports of symptoms of disease; especially neuroticism and extraversion were associated with the tendency to recall physical symptoms as being worse than they really were [6,7]. In addition, extraversion influences the level of coping with chronic disease, which influences, negatively or positively, the level of quality of life [8,9]. In this thesis it was shown, that in case of patients with Parkinson's disease, personality traits (directly, and also indirectly through the actual mood) play an important role in quality of life assessment, as well. 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.

In other studies gender differences were observed in patients with Parkinson's disease. Mildly significant differences in disability and quality of life have been noted between genders in parkinsonian patients: women reported more disability and reduction of quality of life than men [10]. Findings of Huang (2007) showed that women reported more problems in stigmatization, and men reported more problems in activities of daily life. The author also observed, that women with higher levels of facial expressivity felt less problems in social support and communication than women with less facial expressiveness due to the Parkinson mask [11]. Worse score in social support in women in our study was explained by negative affectivity, but it could be also associated with their worse communicational ability associated with the decreased facial expressiveness as showed by Huang's study [11]. The aim for further studies is to compare these results with studies in gender differences of other diseases for better understanding of the impact of psychological factors like personality on patients' complaints.

### *Delayers and non-delayers and quality of life*

Even though Parkinson's disease has no such fatal consequences for surviving or successfulness of treatment as other diseases, e.g. acute myocardial infarction or cancer, patient's delay is an interesting phenomenon in this case. Outpatient neurologists report differences

in assessment of impairment by PD patients themselves, which may caused early or late help-seeking – patients with serious impairment sometimes do not seek help so early, as it would be expected. According to our findings delayers and non-delayers among PD patients differed, except disease severity, but also regarding extraversion (Chapter 5). Extraversion positively correlates with social activity and social support [12,13]. Therefore, patients with health complaints with a supporting environment tend to seek help sooner. The possibility of sharing feelings with somebody has a significant impact on the decision to consult a specialist [14-16]. Late help seeking could be associated with three main reasons: a) a low disease severity; b) introversion and/or lack of social contacts; c) fear from consequences of the visit medical care, leading to delay. Prevention of patient's delay in PD patients should be based on providing information how to recognize symptoms of disease and also about treatment and rehabilitation. This may lead to minimize fear from the unknown for the people involved, and for other people from society it can help to act and help to people from their surrounding.

#### *Personality, mood disorders and quality of life*

In accordance with results presented in Chapter 6 we can suppose that actual mood disorders, depression and anxiety, have more serious impact on quality of life than personality traits not only in PD patients, but also in patients with multiple sclerosis. However, predispositions to depression and anxiety are closely associated with neuroticism and extraversion. As results of several study shows, high extraversion scores may protect against depression and neuroticism reflects symptoms of depression [17-19]. Therefore, for further research in factors of quality of life can be hypothesized, that mood disorder may mediate the relationship between personality traits and quality of life. Mood variables mediating the relationship from personality to QoL was recently suggested by Bartels and colleagues in the field of tinnitus. The authors in that study presented a model in which Type D personality on quality of life is mediated by anxiety and depression in patients with tinnitus [20]. A similar model could be assumed for Parkinson's disease, as well.

### **7.3 Study strengths and limitations**

The thesis is focused on psychological factors relevant for Parkinson's disease, a topic which is not included into most clinical studies. These factors contribute to a comprehensive picture of the total disease impact on patients' quality of life. Main strength of the thesis is the use of psychological factors as independent variables associated with quality of life in patients with Parkinson's disease. Most studies about quality of

life in those patients are focusing on the association of clinical symptoms and their influence on patient's overall quality of life or on the effect of the treatment process. Studies explaining the impact of psychological factors on perception of quality of life in this group of patients, except mood disorders, are missing. The results of our thesis could be helpful for understanding the complexity of quality of life and its factors in patients with Parkinsonism. Although the association between patients' delay and personality traits was still not been adequately explained, we try to contribute to the knowledge about this interesting phenomenon.

The low response rate was a limitation of this study. It may have an impact on generalization of the results to the total population of PD patients. Non-respondents were older than respondents, so it may be hypothesized that they refused to participate in the study because of serious motor complications found in the higher stages of PD and due to the need for help from their social surroundings. Regrettably, we have no information about disease duration and disease severity of non-respondents. Another limitation was the cross-sectional design of the study, not enabling us to explore causal relationships between variables. However, we would like also to point out, that the tendencies in the majority of the present studies are focused on the objectification of the patient's perception of quality of life and furthermore on studying factors, which could explain totally the model of quality of patient's life. However, these study approaches are not centered to the patient and his quality of life. Quality of life starts to be an abstract concept, which is related to answers of the sample of the patients with a certain diagnosis and which disease is measured by objective and valid instruments. Duchan warns against the danger of this kind of studies - our own study belongs to this type - because they could lead to ignore patient's experience as something unscientific and too subjective [21]. As was pointed out, without adequate preliminary qualitative research, quantitative research might risk a misanalysis of the target phenomenon, at the very least by the omission of relevant factors and inclusion of irrelevant ones [22].

## **7.4 Implications of the findings**

### **Implications for practice**

More knowledge about the association of personality traits and their contribution on patients' quality of life may give a clearer view on how to evaluate patient complaints in the case of worsening quality of life, especially in patients with Parkinson's disease. Assessment of quality of life of patients is not easy for clinicians especially because of blank stare and low mimic ("Parkinson's mask") which complicate communication

and decrease the validity of information about the well-being or the health status from the patient. Health-care providers should be aware of the potential relationship between facial expressiveness and the relationship with the patient, which brings implications for family, community, and therapeutic relationships [11]. Neurologists should be aware of factors associated with patient's quality of life in order to be able to choose the most effective interventions in the framework of treatment.

The gender aspect of quality of life appears to be an important topic, contributing to the knowledge about psychological differences between men and women. Consequently, coping styles and self-management skills in both genders might also differ, as has been shown in several studies on cancer and chronic pain [23,24]. For adjustment to the chronic pain problems the aforementioned coping styles were more important in women, whereas possessing a trusting relationship was more important for men in their adjustment process [22]. In cancer patients men are focusing on the positive sides more often than women did ( $P < 0.01$ ) [25]. Women, during stressful times, prefer to talk about it and share their feelings with others, but men with cancer would rather not [26]. Differences between men and women could be determined by cultural roles [26,27]. Different needs of men and women with PD should be taken into account in psychological intervention programs, which need to be different for both genders.

Quality of life of PD patients is closely associated with their functional status and reducing their activities of daily living, losing ability to devote to their hobbies and, consequently, reducing their participation in social life. Their social surrounding taking care on them and it could evoke feeling of guilt and dependence. Early help-seeking could prolong their active life and improve quality of life, especially in patients with diseases, which affect motor abilities, e.g. Parkinson's disease.

## **Recommendations for future research**

One of the limitations of the study was the low response rate. Patients, even they were contacted via phone, had several problems to participate in the study. The possibility of visiting patients at home could increase their willingness to agree with participation.

For quantitative studies the ICF model helps the researcher to include all important factors to the research project and it helps to understand the concept of quality of life in a broader context. Well-designed gender studies are of importance for a profound understanding of the impact of gender on the perception of quality of life and it can improve medical care. The need to differentiate between women and men is observed also in other diseases than PD, e.g. in oncological patients [28]. Gender influences



social roles of patients with Parkinson's disease, thus it can moderate the patient's perceptions of quality of life [11]. Further studies are needed to explore the health and psychosocial consequences of the gender difference in self-rated social status – models of quality of life for men and women could be composed from different variables. The important question is whether gender differences are disease specific or that they are a constant phenomenon also present in other diseases. Therefore, psychological factors should be an important part of the diagnostic and treatment process of patients with Parkinson's disease, because the report of the patient about his/her symptoms may be distorted by his actual psychological status or personality and more studies based on qualitative analyses are needed. Qualitative studies could help us to interpret quantitative findings and they might help to understand the meanings, practices and context of measured variables.

## Conclusion

Because of the increasing mean age of European population, it is more and more important to provide care for patients in a higher age. With increasing age a decreasing quality of life is associated not only because of the increasing occurrence of various diseases, which limit patients in his/her activities of daily living, but also because of factors associated with social conditions and psychological factors. Knowledge about factors associated with decreasing (but also increasing) quality of life in aged people means a challenge for future research and personality traits should be one of important variables of the models. Developing effective disease-management programs for patients with chronic diseases such as Parkinson's disease incorporating all possible knowledge about influencing factors is needed.

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