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

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# General introduction

People in present days in Western Europe are achieving a higher age than ever and its population is getting older. Based on recent surveys, the prevalence of neurologic diseases within aging population is increasing [1]. One of them is Parkinson's disease (PD), which affects mostly people in the age over fifty. Worsening mobility, causing problems with activities of daily living, pain and communication problems due to rigidity of facial muscles, are the main reasons of their decreasing quality of life [2]. This study is focused on the role of psychological variables, which could be associated with quality of life in PD patients. After their identification a discussion about opportunities of improvement patient's quality of life can be opened. In the first chapter a description of PD, the main aims of the thesis, theoretical models and research questions will be presented.

## 1.1 Parkinson's disease

In 1817 James Parkinson, a medical doctor, for the first time described the disease as *"involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forwards, and to pass from a walking to a running pace: the senses and intellects being uninjured"* [3].

### *Prevalence/Incidence*

**Parkinson's** disease is the second most common neurological disorder affecting disability after stroke [4,5]. The disease occurs more frequently in men than in women in every decade of life, which is explained by the neuroprotective effects of estrogens [6-8].

Prevalence and incidence of PD in European countries was estimated at approximately 108 to 257/100,000 and 11 to 19/100,000 per year, respectively, but it varied from country to country. The prevalence in Asia countries is slightly lower, all-age prevalence varied from 51.3 to 176.9/100,000 persons and the incidence from 6.7 to 8.7 per 100 000 persons per year [9]. Prevalence and incidence rates are the lowest in African countries – the crude prevalence varied from 7 to 31.4/100,000 persons and the crude incidence rate of PD was 4.5/100,000 persons per year [10]. When only older age groups ( $\geq 60$  years) were included, rates of prevalence and incidence in Europe varied from 1280 to 1500/100,000

persons and 346/100,000 persons per year, respectively [11]. Baldareschi and colleagues estimated an average annual incidence rate of 346/100,000, but only persons aged 65–84 years were included in their study population [12].

*Criteria for diagnosis*

Parkinson’s disease (PD) is an age-related neurodegenerative disease, characterized by relatively selective nigrostriatal dopaminergic degeneration. First symptoms of PD appear, when the remaining production of dopamine has been fallen below 20% of its original production or when 50% of the cells of the substantia nigra have been destroyed [2]. The criteria for diagnosis are including physical and mental symptoms which have an impact on quality of life (QoL) of patients with PD [14,13]. There are four main clinical symptoms of the disease: tremor, rigidity, slowness and problems with walking and posture [2]. The important physical symptoms of PD are also a blank stare (the so-called “Parkinson’s mask”) and troubles with manual dexterity [15]. Non-motor symptoms of the disease may include depression, sleep disorders, hallucinations and delirium, some of which may be related to treatment by dopaminergic drugs [16-18]. Table 1.1 is showing the main motor and non-motor symptoms.

**Table 1.1** Motor and non-motor symptoms of Parkinson’s disease

Motor	Non-motor symptoms
Tremor	Mood disorders: Depression, anxiety and apathy
Rigidity	Cognition: Bradyphrenia, dementia
Bradykinesia	Sleep disorders: Sleep fragmentation, REM sleep disorders, excessive daytime sleepiness, altered sleep–wake cycle
Postural instability	Autonomic disorders: Hypotension, constipation, detrusor dyssynergia, sexual dysfunction, seborrhea, sweating

*Treatment and healthcare services*

Although, over past three decades cell-based therapies, based on replacement of the lost dopamine neurons by transplantation, are developing, PD is still considered as an illness that cannot be cured [2,19]. There are several approaches to its treatment, from a “wait and see” policy to starting with drug treatment immediately after identifying the diagnosis, but so far neurologists did not reach consensus regarding treatment [20]. However, although curing PD is not yet possible, symptomatic treatment has improved in recent years. The most used symptomatic therapy for

PD is levodopa, introduced more than forty years ago, which efficacy is evident mostly in the beginning of the treatment [18,21]. However, after long using the levodopa the levodopa-induced side effects could appear: dyskinesias, motor fluctuations or neuropsychiatric disorders [18]. Another possibility, which has been used for treatment of PD symptoms since the 1970s, are the dopamine agonists which are associated with a lower incidence of dyskinesias, but they have less benefit on the motor function than dopamine itself, and there are increasing concerns about their side-effect profile [22]. Next possibilities are Catechol-O-Methyl-Transferase (COMT) inhibitors in conjunction with levodopa for longer-lasting treatment and selective MAO-B inhibitors for adjunctive therapy and from 2006 also in monotherapy. An algorithm suggests to start with dopamine agonists in younger patients and only later to combine it with other antiparkinsonian drugs. In patients over eighty it is recommended to start with levodopa. In Slovakia patients use antiparkinsonian therapy according international guidelines [23,24].

In the examined sample of PD patients, 12% used only L-dopa, and 24% used only dopamine agonists. L-dopa in combination with Catechol-O-Methyl-Transferase (COMT) inhibitors was used by 25.3% of the patients, and L-dopa with dopamine agonists was used by 20% of the patients. The combination of L-dopa, a COMT inhibitor and dopamine agonists was used by 16% of the patients from our sample [25].

Rehabilitation and physical exercises are used for slowing down the secondary damaging of motor functions [2]. However, physical therapists and trainers should take into account neurophysiologic aspects of motor impairment in PD, e.g., akinesia, the inability to perform sequential movements, impairments in the pacing of rhythmic movements, and impairments in the predictability of movements [26]. A quite novel kind of treatment of motor functions in PD patients is the combination of motor imagery and real practice, which seems to be effective, especially for reducing bradykinesia [27].

Information about quality of life in patients with PD is important for a neurologist, as it can help him to make appropriate decisions. Hence, it is important to pay attention to study findings in this group of patients and to continue exploring the variables which can indicate changes in their quality of life. To improve the overall health status of the patients and to maintain their independence and active life is one of the challenges in neurology.

## **1.2 Impact of Parkinson's disease on their quality of life**

PD is not a fatal diagnosis by itself, but in people seriously disabled, suffering from the disease several years, it will influence their general

physical and mental conditions as well as their social functioning, which could decrease the patient's quality of life and also reduce the length of his/her life [4,28]. After 2–5 years from the onset of disease, up to 50% of PD patients develop motor complications which include regular visits of neurologist and intensive rehabilitation [29]. The progressive nature of PD and its increasing prevalence have resulted in a substantial economic burden to society, health care providers, individual patients and their families [29,30].

#### *Physical domain*

The poorer quality of life of PD patients is mainly associated with functional status and disease severity [25,31,32], a fact confirmed by several studies. In a 4-year follow-up study, disease severity was significantly the most important factor for a lower QoL [33]. Altered gait and postural instability also contributed to the worsened QoL of these patients [32,34].

#### *Psychological domain*

There are several psychological aspects associated with PD decreasing QoL in patients. The presence of fatigue in PD patients predicts the worsening of all QoL domains measured by the Parkinson's Disease Questionnaire-long form (PDQ-39), a disease specific measurement; that is, primarily bodily discomfort, mobility and emotional well-being [35]. Depression is the major contributor to the explanation of the variance in QoL scores [2,36–38]. The rate of depression in community-based samples of patients with PD is approximately 30–40%, ranging from 20 to 70%, but only a minority of these patients (approximately 2.7 to 7.7%) fulfills the criteria of DSM IV for depression [39]. Physical impairment due to disease, such as increased disease severity, recent disease deterioration and the occurrence of falls, is a condition for higher levels of depression in PD patients. It was also found that depression is more strongly associated with patients' perception of being handicapped than by actual disability and can reflect a pessimistic outlook on the future [36,37]. Worse overall mental condition and patients' memory complaints are also significant factors associated with lower QoL [2,32,37]. Personality traits, such as extroversion, neuroticism or Type D personality, were till now not examined in the context of Parkinson's disease.

#### *Social domain*

The social aspect of PD most negatively influencing the social domain of QoL of patients is isolation, which is due to the embarrassment caused by the symptoms and problems with communication [40]. Patients mentioned that major social problems associated with the *disease* were the loss of social contact, behavioral problems, family members under strain and communication problems within the family [41].

### **1.3 Measuring quality of life in patients with Parkinson's disease**

For measuring QoL in patients with PD, disease specific instruments and generic instruments can be used. The use of this variety of instruments is resulting into difficulties in comparing QoL of PD patients from different studies on the one hand and with other groups of chronically ill patients on the other hand.

#### *Disease specific measurements*

Disease-specific instruments widely used are the Parkinson's Disease Questionnaire (PDQ-39) designed by Peto et al. (1995) and the Parkinson's Disease Quality of Life questionnaire (PDQL) developed by De Boer et al. (1996) [42,43]. In several studies also the Parkinson's Impact Scale (PIMS) was used, useful in identifying potential problems areas, and the Parkinson LebensQualität (Parkinson QoL questionnaire) (PLQ) used mostly in German studies [44].

#### *Generic measurements*

There are also generic (disease non-specific) instruments used to compare PD patients to the general population, or to other disease groups. Predominantly the Medical Outcome Study Short Form (SF-36) and the EuroQoL 5D (EQ-5D) are used, mostly successfully used in many studies where different groups of patients were compared.

### **1.4 Conceptual framework**

QoL is a complex and multidimensional construct that has been defined as *"a concept encompassing a broad range of physical and psychological characteristics and limitations which describe an individual's ability to function and to derive satisfaction from doing so"* [45]. It includes the following domains: the physical, encompassing the ability to conduct activities of daily living; the psychological or emotional; and the social, encompassing interactions with family, friends, and community [46].

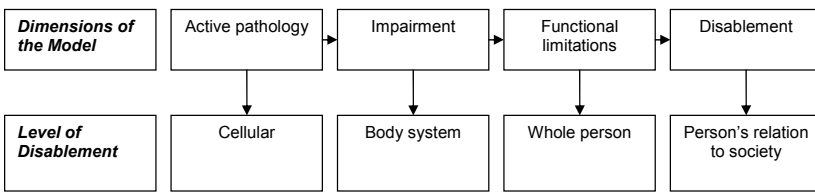
Various factors are influencing QoL in chronically ill patients. Clinical and socio-demographical factors, which are most frequently examined, are not the only factors predicting QoL. In practice, individual differences between patients were observed – patients with the same level of symptoms (objectively with the same score in neurological scales) informed the neurologist about different satisfaction with their lives.

There were several models in previous decades, which tried to explain the disablement process. Saad Nagi, a sociologist from Egyptian origin, started in the sixties of the twentieth century with this type of modeling, by introducing a dynamic view on disablement [47-49]. His

model describes the disablement process through concepts as are shown in Figure 1.1. Main terms are:

- *active pathology* – a state of the body’s defences and coping mechanisms caused by infections, traumas or other pathologies
- *impairment* – a loss of or abnormality of the tissue, organ and body system level
- *functional limitations* - limitations in an individual’s ability to perform the tasks and obligations of his usual roles and daily activities
- *disablement* - limitations in performing socially defined roles, e.g. employment or self-care

**Figure 1.1** Nagi’s model of disablement and functional consequences of a pathological process in the body [48]



In 1976 the WHO published an upgraded model which analyzed, described and classified the consequences of disease and which distinguish between impairment, disability and handicap. It was named International Classification of Impairments, Disabilities and Handicaps (ICIDH) [50]. It sees impairment, disability and handicap as three different levels of pathology consequences of pathological processes, which are related to different levels of experience and individual awareness [49].

The conceptual framework of this study follows the ICF model – the International Classification of Functioning, Disability and Health (ICF). The ICF is the WHO’s model for measuring health and disability at both individual and population levels. This widely used model was translated into several languages and it was used in studies from 191 countries and defines disablement as the result of the interaction among the domains of body, individual, and environment [51].

The ICF model is composed from 2 parts, each with 2 components (see Figure 1.2):

- part I: – Functioning and Disability
  - a) Body functions and Structures – physiological and anatomical changes
  - b) Activities and Participations – the capacity to executing tasks in a standard environment and the performance to executing tasks in the current environment

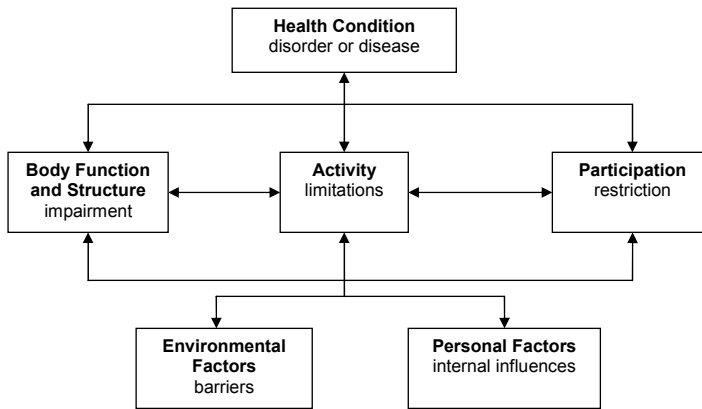
- part II: – Contextual factors

a) Environmental Factors – external influences on functioning and disability

b) Personal Factors – internal influences on functioning and disability

**Figure 1.2** The WHO model of the International Classification of Functioning, Disability and Health [51]

The ICF could be applied in a wide range of scientific and also practical areas, e.g. social security, management of health care, prevention and health promotion on a national, but also on an international level [51].

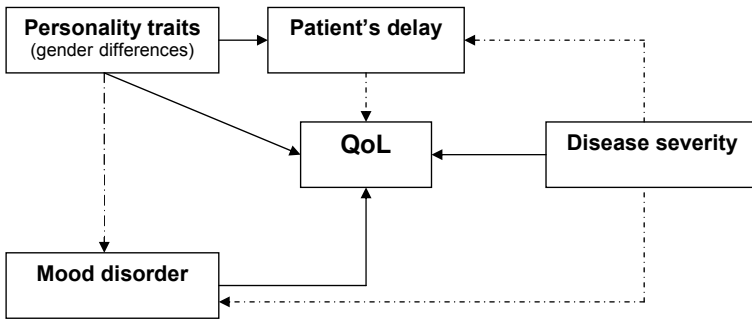


## 1.5 Aims of the study and research questions

The main aim of this cross-sectional study was to explore psychological factors (which are included in the *personal factors* of the ICF model) associated with quality of life – neuroticism, extroversion, negative affectivity, social inhibition, Type D personality and mood disorders (anxiety, depression). Associations explored in the study were derived from the theoretical background from theories dealing with the concept of QoL (Figure 1.3).



**Figure 1.3** Design of the variables used in the thesis



The main objectives of the thesis therefore include:

- 1) to explore whether psychological factors were associated with the perception of quality of life in patients with Parkinson's disease;
- 2) to investigate whether psychological factors of patient's help-seeking behavior may be associated with quality of life of patients with Parkinson's disease.

The objectives led to the following general research questions (RQ):

- 1) to explore the associations between various personality traits, neuroticism, extroversion, negative affectivity, social inhibition and Type D personality and quality of life in Parkinson's disease patients. In addition, gender differences were examined as well (*Chapter 2 and Chapter 3*);
- 2) to explore differences between delayers and non-delayers regarding psychological factors associated with quality of life in patients with Parkinson's disease and the impact of life in patients with Parkinson's disease and the impact of fear and anxiety on help-seeking behavior in non-parkinsonian diseases (*Chapter 4 and Chapter 5*);
- 3) to compare the role of the association of psychological factors – Type D personality, anxiety and depression – with quality of life in patients with Parkinson's disease and multiple sclerosis (MS) (*Chapter 6*).

## **1.6 Structure of the thesis and summary of contents**

In *Chapter 1* a General Introduction on Parkinson's disease and the patient's quality of life was presented.

In *Chapter 2* the associations between extraversion, neuroticism and quality of life were presented. In this chapter personality traits for women and for men will be analyzed separately.

Chapter 3 is focused on Type D personality, negative affectivity and social inhibition as predictors of perceived quality of life. Gender differences in models for men and women will be presented as well.

Patient's delay is associated with decreasing of quality of life in many diagnoses. In Chapter 4 a systematic review was performed for to explore, how fear, and its intensity, was associated with patient's delay in chronic and also acute disease.

Personality traits could influence decision making in help seeking, as well. In Chapter 5 differences in personality traits between delayers and non-delayers in patients with PD were explored.

In Chapter 6 we are comparing patients with Parkinson's disease with patients with multiple sclerosis regarding personality and depression and anxiety.

In Chapter 7 we summarized the results of this study and discussed them. Furthermore we are trying to outline practical implication of the results of the research in neurological practice. Results of our research lead to the suggestions for further research of the quality of life in patients with Parkinson's disease.

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