

Daily Living and Quality of Life in Parkinson's Disease

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Abstract. Parkinson's disease is a chronic-progressive and disabling neurological disorder which is clinically manifested by a broad spectrum of motor and non-motor symptoms which affect patients' life. The main objective of this study was to describe the life of patients with Parkinson's disease (PD) in the light of daily activities, general levels of cohabitation and well-being in a sample of patients with PD correlated with stage and duration of disease, right or left-sided Parkinsonism and cognitive status. The study highlights the early stage of affection of these patients' life quality via their individual activities negatively affected by motor disorders, their emotional reactivity caused by their illness as well as the prognosis, and also the stigmatization felt by these patients.

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***I*ntroduction**

A disease is an abnormal condition which in humans is often used more broadly to refer to any condition that causes a wide range of symptoms, first of all, pain. However, diseases affect people not only physically, but they also involve difficulties in normal cohabitation, distress for the person who suffers and for those in contact with the person afflicted, social problems, and last but not least, there is an emotional impairment because the disease can alter one's perspective on life. For the complex interaction of biological, psychological and social factors in medical conditions, the term *disorder* is used.

But what can we say about lethargy, sleepiness, anorexia, depression, inability to concentrate? These terms refer specifically to the patient's personal experience, without any objective injury. Can we conclude that it is possible for a person to be diseased without being ill and to be ill without being diseased?

Symptoms of some disease may lead to other medical, social or psychological problems which increase mortality, morbidity, financial cost etc. The impact of a health problem measured by different indicators is called disease burden. This burden is felt in many cases by the person who suffers, but when we discuss neurodegenerative diseases such as Parkinson's or Alzheimer's disease we have to take into account the caregiver burden as well. One of the several measures used to quantify the burden imposed by disease is the years of potential life loss, which is a simple estimate of the number of years that a person's life was shortened due to a disease, by death or by total dependence on others. Persons with young onset PD live for many years with a disorder associated

with old age, these patients having different treatment needs than older counterparts and a team approach (including neurologist, nurse, social worker, occupational therapist, physiotherapist) can be very effective in improving quality of life.¹

Burden in PD is due to especially motor symptoms such as hypokinesia, tremor, rigidity, painful dystonia, postural abnormalities, gait disturbances which progressively lead to falls, social embarrassment and increasing dependence on others for everyday activities. Sleep disturbances, affective symptoms, psychotic symptoms are psychological variables which as well as physical impairments affect the quality of life of patients with a chronic disease like PD.

In many cases the diagnosis is followed by anxiety or depression. In PD patients appears to be a special relationship between anxiety and depression. Risk factors for anxiety combined with depression include onset before the age of 55 and inherited disease.² There is a variety of results regarding the cause: some authors believe that anxiety and depression are related to the underlying neurochemical changes in the brain,^{3,4} while others talk about a psychological reaction to the stress of the illness, to the diagnosis.⁵ Psychological interventions often help patients with secondary psychological symptoms of Parkinson's disease, the strategies including relaxation and cognitive restructuring, together with situational behavioural analysis and training in social skills specifically adapted to the disease.⁶

Daily routines are reduced and endangered to their elimination not only by the disease itself, by its motor symptoms, but also by the additional symptoms that very frequently exist in this disease.

When we speak of the well-being of a person, we equally mean his/her physical, mental, as well as social and professional well-being. How could we speak of the physical well-being of PD patients when they feel stuck, they experience pain or tremor which obstruct them in performing certain activities? How could we speak of mental well-being when there is at all times a possibility of depression or anxiety, especially with the aggravation of the disease or the non-response to some specific medicine, or the appearance of psychotic phenomena (hallucinations, delusions). Whereas the symptoms listed above allow the patient to lead a satisfactory life either individually or only with short-time dependence, when we speak of PD dementia, such modes of existence or functioning no longer exist, since they are completely eliminated, while caregivers take over the main role in supporting the patients. Speaking of caregivers, we mean either the family, or a person with expertise employed by the family, or asylums in cases when the family does not have the means to support the patient.

¹ S. M. Calne, S. C. Lidstone, and A. Kumar, "Psychosocial Issues in Young-Onset Parkinson's Disease: Current Research and Challenges," *Parkinsonism Relat Disord* 14, no. 2 (2008).

² J. Santamaria, E. Tolosa, and A. Valles, "Parkinson's Disease with Depression: A Possible Subgroup of Idiopathic Parkinsonism," *Neurology* August 36:1130 (1986).

³ I. H. Richard, "Anxiety Disorders in Parkinson's Disease," *Adv Neurol* 96 (2005).

⁴ Matthew A.; Robertson-Hoffman Menza, Doreen E.; Bonapace, Arlene S. , "Parkinson's Disease and Anxiety: Comorbidity with Depression," 34(7)(1993) DOI: 10.1016/0006-3223(93)90237-8

⁵ K Walsh and G Bennett, "Parkinson's Disease and Anxiety," *Postgrad Med J* 77(2001) DOI: 10.1136/pmj.77.904.89

⁶ Walsh and Bennett, "Parkinson's disease...", 92.

Certainly, the patient's age at the onset of the illness, the manner in which it starts, as well as the body part involved have a very important role to play in the patient's daily routine and implicitly for the quality of his/her life. A person of old age at the onset of his disease, presenting tremor at his left hand will definitely cope better with his daily routine and adapt much better to his disease than a young adult in full professional ascent, having family duties, and experiencing beginning tremor on the right side, which will affect his motor abilities and determine his future withdrawal from professional life, and even social life due to social embarrassment felt because of his "handicap". So we can ask ourselves: how well can these people feel on a social level? Are they stigmatized? How well can they function professionally because of their symptoms? What is the affective resonance of their condition?

The purpose of this paper is to document the impact of PD on functioning and well-being.

Methods

The study was conducted on a sample of 16 outpatients with diagnosis of Parkinson's disease. Taking into account the number of patients diagnosed or kept under observation with a diagnosis of PD, which is around 72000 in Romania and around 2900 in Cluj County,¹ I have chosen **sampling** as patient selection method. A sample – and not simply a "group" – allows for formulating conclusions about the characteristics of a whole population by interrogating only some of its members. I have used probability or random sampling since in this case each member of the population has equal chance of being included into the sample, and the sample obtained is **representative**, an essential feature which means that the sample is capable of reproducing as faithfully as possible the characteristics of the population it is chosen from.²

The patients of the sample, with a definite diagnosis of PD, were chosen randomly from the medical files of also randomly selected general practitioners' offices from Cluj County. They were then contacted by telephone either by the general practitioner or directly by the interviewer for setting the date of the interview.

After this step, patients with clinically significant cognitive impairment at disease onset, other neurological diagnoses, or drugs which could cause Parkinsonism, or the presence of brain abnormalities compatible with other diseases than PD were excluded. In the end, 16 patients remained in the sample, information was gathered from them regarding age, gender, age at disease onset, marital and living status, working status, information related to Hoehn and Yahr stage, and side affected; other diagnoses and treatment status were taken from medical files. The interview was taken either in the GP's office (in case of patients from a rural environment) or at the patient's home (for those from an urban environment). An informed consent was obtained from each patient.

The diagnosis of Parkinson's disease was based on the United Kingdom Parkinson's disease Society Brain Bank Clinical Diagnostic Criteria.³ Parkinsonian

¹ 26.04.2012 <http://www.asociatia-antiparkinson.ro/Boala-Parkinson-HTML/Despre-boala-Parkinson.html#statistici-boala-Parkinson> (Accessed: march 2012)

² There is also a possibility of doing nonprobability sampling, when the sample is not chosen randomly, therefore it is not representative.

³ S. E. Daniel and A. J. Lees, "Parkinson's Disease Society Brain Bank, London: Overview and Research," *J Neural Transm Suppl* 39 (1993).

disability and stage was assessed by Hoehn and Yahr stage.¹ The test characterizes patients according to a scale of five stages of severity, from stage 1, which is mild, to stage 5, which is incapacitated.

Parkinson's Disease Questionnaire (PDQ-39)² is a tool for assessment of the quality of life in PD patients. The instrument was developed on the basis of interviews with people diagnosed with PD, being designed to address aspects of functioning and well-being. It is relatively brief and has been designed and validated to be self-completed by patients.

There are 39 questions covering eight aspects of quality of life (8 discrete scales): mobility (10 items), activities of daily living (6 items), emotional well-being (6 items), stigma (4 items), social support (3 items), cognitions (3 items), communication (3 items), bodily discomfort (3 items). Subjects are asked to think about their general well-being and to consider how often in the last month they have experienced those listed events.

Patients respond to each question on a 5-point scale: never=0, occasionally=1, sometimes=2, often=3, and always or cannot do at all=4. Scores on the PDQ range from 0 to 100, with higher scores reflecting greater problems.

In addition, Instrumental Activities of Daily Living (IADL)³ was administrated in order to evaluate the activities often performed by a person who is living independently in a community setting during the course of a normal day. The IADL assessment scale allows a health professional to establish the levels at which an elderly individual functions in caring for himself or herself and performing the more sophisticated tasks of everyday life. Increasing inability to perform IADLs may result in the need for care facility placement. IADL assessment scale comprises 8 items: using the telephone, getting to places beyond walking distance, grocery shopping, preparing meals, doing housework, doing laundry, taking medications and managing money. To each item there is possibility to answer: needs no help, needs some help (for each area in which he/she can function without/some help, means that subject is independent, 1 point) or unable to do at all (subject is dependent, 0 points). Total score is 8 points, and it gets lower with the patient's increasing inability to manage his life on his own.

Results and Discussions

The subject group is made up of patients with average age of 74.6 years (SD 8.35), lowest age of 58 years and highest of 87 years. Regarding the environment, the distribution is equal, 8 subjects coming from an urban, and 8 from a rural environment; however, women are slightly predominant: F/M=10/6.

We are speaking about an aged population, all pensioners, in various stages of evolution of the disease, from Hoehn&Yahr stage 1 (2 patients) to stage 4 (2 patients), and another 11 in intermediary stages, 7 subjects in stage 3 and 4 subjects in stage 2.

¹ M. M. Hoehn and M. D. Yahr, "Parkinsonism: Onset, Progression and Mortality," *Neurology* 17, no. 5 (1967).

² Jenkinson C. Peto V., Fitzpatrick R. et al, "The Development and Validation of a Short Measure of Functioning and Well Being for Individuals with Parkinson's Disease," *Quality of life research* 4 (1995).

³ M. P. Lawton and E. M. Brody, "Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living," *Gerontologist* 9, no. 3 (1969). www.ncbi.nlm.nih.gov/pubmed/5349366

There were also intermediary stages 1.5; 2.5; 3.5; 4.5. There was one single patient in the group in stage 2.5. The average duration of the disease was 10.7 (8.7) years.

In what regards the initial symptoms of the disease, 14 of the 16 subjects experienced tremor at the outset, therefore they visited a specialist sooner. They are all under medication (levodopa, dopa decarboxylase inhibitor, dopamine agonists, amantadine, or combinations of these).

The analysis of the sample on the basis of *gender* and considering the total scores for questionnaires of daily routine (IADL), the quality of life (PDQ-39), and cognitive screening, the total score obtained for men was 4.83 (SD=1.7) for IADL, 26.5 (4.3) for MMSE and 53.6 (14.8) for PDQ-39, while the total score for women was 5.4 (4.6) for IADL, 23.8 (4.8) for MMSE and 57.7 (13.6) for PDQ-39. Next, the patients were sampled according to the duration of the disease: under 10 years of disease – this group included 9 patients with average age of 72.6 (8.8) years, and over 10 years of disease – this group included 7 patients with average age of 77.1 (7.5) years. The IADL, MMSE, and PDQ-39 total scores were identified for each group.

As regards *daily routines*, it was observed that, regardless of the years of disease, shopping is equally deficient, the average IADL score is the same for both groups (both under and over 10 years of disease): 0.4 (0.5). This is therefore one of the most rapidly affected daily routines, the patients are either only able to do their daily shopping (bread and milk), or need to be accompanied, or are completely incapable of shopping on their own. Preparing meals (IADL=0.3 for <10 years of disease and 0.5 for >10 years of disease) is another item that deserves attention since the patients are also incapacitated in preparing their meals, needing help for this activity as well as for having their meals served to them. It can be observed that IADL score is lower for the group with less years of disease. In this respect the men/women difference must also be taken into account. The difference derives from the double number of men in the first group compared to the second (group I: 4 men, 5 women; group II: 2 men, 5 women). For the “doing laundry” item (IADL=0.5/0.2), although there are modern methods for washing clothes, patients cannot cope with sorting out the clothes or setting a certain program. For those who have no modern means for doing their laundry, the intervention of caregivers is necessary. The scores prove that it is a daily routine which is affected at an early stage of the disease.

There is a substantial difference in using transportation means, as long as patients with under 10 years of disease are able to use their own car or city transportation, either independently, or with someone’s help (average IADL=1 for the whole sample), while those with over 10 years of disease use taxi or car for short distances, but always with someone’s help (average IADL=0.5).

The patients are only able to use the telephone for dialling some familiar numbers, or answering the phone, but they cannot use it spontaneously or in a regular way. For both categories of the interviewed, the average total score was 0.8 (0.3) for this item, close to the highest possible score. As regards housework and money management, the average score of daily routines is 0.8 and 0.7 respectively, for both sub-groups. This means that they either need help for doing housework, or only do some easy things (making the bed, washing the dishes); in case of money management, they either manage their money independently, or need help for banking and important shopping, but manage their money for daily shopping.

However, neither of the groups can be seen to be responsible for their treatment. The reasons vary from memory disorders due to the disease as long as it is a known fact that cognitive impairment to dementia has high frequency in PD, or to old age, or to a mixture of these two factors. Average total IADL score for this item is 0.5 (0.5) for both group of patients (longer or shorter duration of illness), which means they only take their medication if the dosage has been prepared beforehand, or they are incapable of taking their medication even if it has been prepared beforehand, making it the caregiver's duty to administer the treatment.

Taking into consideration the average score for cognitive screening, there is no significant difference between the two sub-groups: the group with shorter duration of disease (<10 years) obtained a score of 25.3 (SD 3.8), the other group (>10 years) obtained a score of 24.1 (SD 4.8). The scores are high as related to the average duration of the disease: 4.2 years (SD 3.0) for the first sub-group, and 19.1 years (SD 5.7) for the second sub-group. It could be expected that the second group suffered much more significantly of cognitive impairment, considering that the difference in number of years of disease is almost five times higher in the second than in the first group; however, there is contradictory evidence regarding the relationship between duration of disease and cognitive impairment. Some authors think that duration of disease is an important determinant of the presence of cognitive deficits in PD patients,¹ while others had not found any correlation between cognitive disorders in Parkinson's disease and duration of disease.²

In terms of quality of life according to PDQ-39, it can be said that it is the same for the two sub-groups of patients depending on the duration of their disease, since although the group of <10 years of disease has a higher score (57.2) it is the case because the sampling resulted in a higher number of subjects (9) for this group comparatively with the other group (>10 years) of 7 patients, with an average PDQ score of 54.7. Possibly, if there were the same number of patients in both sub-groups, the average score would be approximately the same, which means that practically the life impairment of these patients starts with the onset of the first motor symptoms, that is, the first months of the disease, being preserved or accentuated later on, and being directly responsible of the individual's quality of life.

With a total PDQ-39 score of 100, the maximum scores to be obtained for each scale are as follows: 26.4 for mobility, 15.7 both for activity sub-scale and the emotional element, 10.5 for the patient's feeling of being stigmatized, and 7.9 for each sub-scale of support, cognition, communication, and bodily discomfort.

¹ C. A. Biggins et al., "A Controlled, Longitudinal Study of Dementia in Parkinson's Disease," *J Neurol Neurosurg Psychiatry* 55, no. 7 (1992).

² D. Aarsland et al., "Risk of Dementia in Parkinson's Disease: A Community-Based, Prospective Study," *Neurology* 56, no. 6 (2001).



Teodora Cosman, *Over-exposures*,
acrylic on synthetic tissue, 60 x 60 cm, 2010

The table below shows the scores of the interviewed patients correlated with the maximum value of the sub-scale.

Table 1. Average scores for sub-scales of PDQ-39 depending on duration of disease

	Mobility (SD)	Activities	Emo-tions	Stigma	Support	Cognition	Communi- cation	Bodily dis- comfort
<10 years of disease	16,8 (SD 5.7)	9.4 (SD 3.7)	8.9 (2.8)	6.2 (2.3)	2.0 (0.7)	4.7 (1.5)	3.7 (0.9)	5.0 (1.1)
>10 years of disease	14.0 (7.1)	9.6 (4.8)	8.0 (1.1)	5.8 (2.4)	2.3 (0.8)	4.5 (0.9)	2.9 (1.4)	5.6 (1.0)

Cognitive impairment was determined with the Mini-Mental State Examination (MMSE)¹ using a total score of 24 (30 maximum) as cut-off, as usually chosen in clinical studies on PD patients.² The MMSE was used only for describing the sample, not for classification of dementia cases.

Considering that those with MMSE < 24 present cognitive impairment, statistical analysis shows significant difference in the ability to use the phone and money management between the groups with MMSE score ≥ 24 and MMSE score < 24 ($p < 0.001$). Other daily routines are also significantly influenced by MMSE scores, such as: housework, shopping, or using city transportation ($p < 0.05$).

Subjects with cognitive impairment have higher scores for 4 out of 8 sub-scales of PDQ-39: mobility, activities, communication, and physical discomfort; this means lower life quality for these from the point of view of their independence in doing necessary activities (housework, shopping) or other activities which imply mobility (walking for a certain distance). At the same time difficulties in expression, the feeling of inappropriate communication with others is more stressed in persons with cognitive impairment, with a possible subsequent appearance of the feeling of neglect and abandonment. The same difference appears in case of physical discomfort caused by muscular or bone pain, involuntary muscular contractions, pains at various places, or modified perception of body temperature, more common at patients with cognitive impairment, causing lower life quality.

As regards their emotions, they all experience feelings of sadness, anxiety, irritability, or concern for the evolution of their disease, regardless of their cognitive status.

The situation is different when speaking about stigmatization or social support (of the family or other close people). Stigmatization is felt primarily by patients who are not affected or only slightly affected in their cognitive abilities; they think they have to conceal their disease from people, avoid situations which imply socialization with unknown people (including eating or drinking in public) because they feel embarrassed or concerned by the reaction of others on seeing or being told about their disease. Therefore the support of family and close friends is much more frequent and significant in the case of younger patients, or they feel this support to be more significant. In order to shed light on the network of social support, the subjects answered questions about support from the family, spouse, or close friends in the difficult times when their help was needed. In the same respect, the possible problems in the subjects' close relationships caused by the disease were also taken into consideration.

In the next phase, the analysis focussed on the differences in quality of life for subjects in various stages of the disease.

¹ M. F. Folstein, S. E. Folstein, and P. R. McHugh, "Mini-Mental State". A Practical Method for Grading the Cognitive State of Patients for the Clinician," *J Psychiatr Res* 12, no. 3 (1975).

² M. Emre et al., "Rivastigmine for Dementia Associated with Parkinson's Disease," *N Engl J Med* 351, no. 24 (2004).

Table 2. Average score of PDQ-39 sub-scales depending on the stage of disease

PDQ sub-scale	Stage 1 HY N=2 subjects	Stage 2 HY N=4 subjects	Stage 3 HY N=7 subjects	Stage 4 HY N=2 subjects
Mobility	10.5 (SD 5.9)	13.4 (SD 8.0)	17.6 (SD 5.2)	16.0 (SD 9.3)
Activities	8.9 (SD 2.9)	6.3 (SD 4.2)	11.0 (SD 3.5)	13.5 (SD 3.3)
Emotion	9.4 (SD 1.4)	8.6 (SD 2.9)	8.6 (SD 2.5)	8.6 (SD 0.3)
Stigma	4.7 (SD 1.4)	5.3 (SD 3.8)	6.8** (SD 1.1)	5.0** (SD 3.3)
Support	1.5* (SD 0.0)	2.6* (SD 1.2)	2.0 (SD 0.5)	2.1 (SD 0.7)
Cognition	5.2 (SD 1.4)	3.2 (SD 1.2)	5.0 (SD 1.0)	5.2 (SD 0.7)
Communication	4.2 (SD 0.7)	2.6 (SD 1.1)	3.0** (SD 1.1)	5.0** (SD 0.3)
Bodily discomfort	5.2 (SD 1.4)	5.0 (SD 1.3)	5.3 (SD 1.0)	6.3 (SD 0.7)
PDQ -39 total	50.0 (SD 11.1)	47.6 (SD 19.2)	59.9 (SD 11.5)	66.8 (SD 9.6)

* $p < 0.001$

** $p < 0.05$

Comparing the four groups, one may observe that the statistically significant differences between patients in stage 1 and stage 2 of the disease only exist on the level of social support, the lower score meaning that they have “never” or only “occasionally” had problems in their close relationships because of their disease. At the same time, they did not experience lack of support of their spouse when they needed it, and neither of their family and close friends.

However, there are differences for other items between patients in more advanced stages of disease; those in stage 3 HY experience a stronger feeling of embarrassment because of their condition, which they would want to conceal from other people since they are worried by the reaction of others on seeing or hearing about their suffering. Communication of patients in stage 4 is significantly more affected than those in stage 3, meaning that verbal expression is much more difficult, it is much harder for them to make themselves understood, their dialoguing is poor. In this stage we can speak about both qualitative and quantitative impairment (thematic pauperization).

Whereas many items score higher as the disease advances, not the same can be said about the emotional element. As the table shows, emotional disorder with feelings of sadness, anxiety, irritability to anger, tension, concern for the future are much higher in stage 1 than in any other stage, perhaps because patients in this stage do not yet know how they will cope with this disease, what the evolution of the disease will be, and many of them socially isolate themselves. In parallel with the evolution of the disease the emotional reaction is slightly reduced but is not eliminated, since the score for the emotional sub-scale is high in all stages. In other words, any passage to a different stage brings with it an emotional reactivation which is, in fact, completely normal. However, at the time of the survey not all patients have been recently diagnosed with a certain stage, therefore we cannot claim that emotional reactivation has been produced by passage to a superior stage of disease. Therefore one might think of the presence or absence of other symptoms of the disease that would determine emotional activation or, on the contrary, one might assume the persistent presence of feelings of anxiety, concern, subliminal sadness.

I have also proposed another characterization related to the stage of disease, regarding the ability to perform daily routines, and I observed that those in stages 1 and 2 had no problem in using the telephone, city transportation, managing money, or doing housework. Other activities or abilities, such as those connected to prepare one's own meals, shopping, clothing, and responsibility for one's own treatment begin falling under the "previous" level.

When speaking about stage 3 patients, one may observe that all daily routines are affected and cannot be optimally completed, but patients need help from other people (family member, caregiver) for completing that particular action.

Comparing the performance in daily routines of stage 2 and stage 3 patients, there are difference in what regards their ability of doing housework, using city transportation, or using-managing their financial resources in an adequate way ($p<0.05$).

While stage 3 patients can be observed to perform all their daily routines with the help of others, the case is different for certain activities in stage 4: in case of shopping, preparing their meals, or eating alone, doing their laundry, or taking their medication, they are completely dependent on others. For the remaining items (using the phone, doing housework, using money or city transportation) they can handle these if they have someone to guide them. The survey shows that, whereas in stage 3 shopping, medication, feeding, and hygiene (laundry) could be handled by the patient with someone's help, in stage 4 there is a major difference as long as patients are completely dependent on another person in completing these activities ($p<0.001$).

Parkinson's disease is often associated with mild cognitive impairment and dementia, PD patients have an almost 6-fold increased risk of developing dementia compared to healthy controls.¹ It is important to predict which patients with PD will develop dementia for planning patient management and treatment.

In case of my patients, it can be seen that the differences in cognitive screening between patients under 10 years and over 10 years of disease are not very great (25.3 and 24.1), but there are differences between patients in Hoehn&Yahr stage 1 and 4, meaning that stage 1 patients have an MMSE score of 26.5 (SD 0.7), corresponding to a slight cognitive impairment, while stage 4 patients suffer from more serious cognitive impairment, supported also by their MMSE score of 22.0 (SD 4.4). Although we do not know the risk factors for cognitive impairments in PD, old age and severe Parkinsonism² are predictive factors for later dementia.

Performance in daily routines is strongly correlated with cognitive status; the better it is, the more independent patients are, and the less need they have for the help of their family members ($p<0.05$).

Whereas the tables above represent the average score of PDQ-39 depending on the duration and stage of the disease, in the table below one may follow the average score for the entire sample in comparison with the maximum score obtained in case the patients met no difficulties because of their disease, their affective state raised no problems and their social integration were satisfactory.

¹ Aarsland, Andersen et al, "Risk of dementia in Parkinson's disease...", 730–736.

² Ibid.

Table 3. Comparative scores for sample and maximums

	PDQ-39 subjects	Score	PDQ-39 maximum	Score
Mobility	15,6		26,4	
Activities	9,5		15,7	
Emotional	8,5		15,7	
Stigma	6,0		10,5	
Support	2,1		7,9	
Cognition	4,6		7,9	
Communication	3,3		7,9	
Bodily discomfort	5,3		7,9	

The average value of the total PDQ-39 index was 56.1 (SD=13.7), considering that the score 100 means the most serious impairment of the quality of life. The aspects most affected in what regards the quality of life for the sample studied are, in a descending order: physical discomfort, daily routine, and mobility. Stigma and emotional comfort follow close behind, while communication and support, although reduced as well, are not as affected as the motor element.

For the whole sample the PDQ-39 score is higher for women than men.

Final considerations

We can conclude that women are more affected compared with men regarding activities of daily living and quality of life perhaps because the number of women is higher or because demoralization at disability, loss of autonomy, the prospect of a chronic progressive neurological disorder, abandonment of life goals and long-term plans are more strongly felt for women.

We also saw that patients are emotionally affected in all stages, often only for a limited period and secondarily to adverse psychosocial circumstances such as stress and loss, or to disappointment for failing to live up to one's own expectations. Quality of life starts to be affected at the very beginning, initially due to the motor disturbances which cause impairments in daily activities or negative feelings. We should have in consideration that the diagnosis and the fact of having a progressive and disabling disease may be sufficient to cause deterioration in quality of life. Later in the course of the disease decreased communication skills, progressive deterioration of cognition, bodily discomfort and increasing dependency give a poorer quality of life for PD patients.

Regarding the Hoehn and Yahr stages, those with Parkinson's disease stage 1 or 2 have a better quality of life, a better capacity to perform in daily activities compared with those in the final stages. But, at any stage, a rapid deterioration from any level, or the development of treatment complication, or the worsening symptoms cause a lower quality of life.

Translated by Emese Czintos