

Evaluation of health related quality of life in patients with Parkinson's disease

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ABSTRACT

الأهداف: تقييم السمات الاجتماعية، السكانية، والسريية للمرضى المصابين بمرض باركنسون. وصحتهم ذات الصلة بجودة الحياة (HRQoL) والعلاقة بينها.

الطريقة: أجريت هذه الدراسة المقطعية في جامعة سطنبول – مستشفى تشيرابسا، ووزارة الصحة – مستشفى تقسيم وحسيكي – اسطنبول – تركيا. أدرج في هذه الدراسة عينة مكونة من 80 مريضاً مصاباً بمرض باركنسون، والذين حضروا إلى العيادات الخارجية من أجل السيطرة على مرض باركنسون والاعتلال الحركي، خلال الفترة ما بين مارس 2006م وحتى يوليو 2006م. تم جمع البيانات باستعمال (نموذج الاستبيانات) والذي شمل الصفات السكانية، الاجتماعية، السريية، وطريقة هوهن وياهر لقياس الدرجة السريية ونقاط معدل مرض باركنسون (UPDRS)، وملف نوتنقهام الصحي (NHP).

النتائج: بلغ متوسط عمر المرضى 67.5 ± 8.76 عاماً، 62.5% كانوا من الذكور، 47.5% في المرحلة الأولى من المرض. كانت أعلى نقاط من (UPDRS) «للجهاز الحركي» (11.62 ± 7.45)، وجودة قياس الحياة بالتحديد، «الطاقة» (69.79 ± 21.17)، «الحركات البدنية» (44.95 ± 24.23)، «النوم» (± 36.36)، و«ردود الفعل العاطفية» (31.55 ± 35.01) كانت متأثرة.

خاتمة: تشير هذه الدراسة إلى أن المرضى المصابين بمرض باركنسون والذين تكون أكثر المشاكل التي يعانون منها هي الحركة، كان لديهم زيادة في نقاطهم لفحص (UPDRS) مع مراحل متقدمة من المرض، كما أن صحتهم المتعلقة بجودة الحياة (HRQoL) أيضاً متأثرة بشكل سلبي. إن القيام بمثل هذه الدراسة جوهر أساسي لتطوير نوعية رعاية الفرد.

Objectives: To evaluate the socio-demographic and clinical feature of patients with Parkinson's disease, their health-related quality of life (HRQoL), and the relationship between these.

Methods: This cross-sectional study was conducted in Istanbul University Cerrahpasa Medical Faculty Hospital, and Ministry of Health, Taksim and Haseki

Education and Research Hospitals in Istanbul, Turkey. The sample consisted of 80 Parkinson's disease patients who attended the Parkinson's and Movement Disorders Outpatient Clinics between March and July 2006. Data were collected using the questionnaire form, which included socio-demographic and clinical characteristics, the Hoehn and Yahr clinical staging scale, the Unified Parkinson's Disease Rating Scale (UPDRS), and the Nottingham Health Profile.

Results: The mean age of the patients was 67.5 ± 8.76 years, 62.5% were males, and approximately 47.5% were in stage one of Parkinson's disease. The highest mean score on the UPDRS was for the "motor function" part (11.62 ± 7.45); the quality of life dimensions of, in particular, "energy" (69.79 ± 21.17), "physical movement" (44.95 ± 24.23), "sleep" (36.36 ± 31.96), and "emotional reactions" (35.01 ± 31.55) were affected.

Conclusion: This study indicates that patients with Parkinson's disease who experienced the most problems in mobilizing, had an increase in their scores on the UPDRS with the advancing stage of the disease, and their HRQoL was also negatively affected. Studies such as this one have the potential to improve the quality of individualized care.

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Parkinson's disease (PD) is a chronic progressive neurodegenerative disease of the central nervous system and is characterized by motor, cognitive, and behavioral disturbances. Its onset generally occurs between the ages of 50 and 65, and it is a leading cause

of neurological disability in individuals older than 60 years.¹ The disease affect males and females equally in all races.² Parkinson's disease include many symptoms that can result in a reduction in the quality of life (QoL). They have major adverse impact on patients' lives. Patients' symptom such as tremor, hypokinesia, rigidity, hypophonic voice, painful dystonia, postural abnormalities, gait disorders, sleep disturbances, depression, and drug related problems may progressively lead to falls, social embarrassment, loneliness, and increasing dependence on others for activities of daily living (ADLs).³ The symptoms associated with PD and its management affect an individuals' usual or expected physical, social, and mental well-being, referred to here, as health-related quality of life (HRQoL).^{3,4} The concept of QoL goes beyond the dimensions of health functioning to performance of social roles, mental acuity, emotional states, subjective well-being, and interrelationships. Life satisfaction, self-esteem, and physical health have also been identified as key elements of QoL.^{5,6} Health-related quality of life refers to a diverse range of the patients' own perceptions and experiences of their disease, and could be considered as the ultimate outcome measure of health care, beyond single symptoms.⁶ Health care professionals are learning to recognize and accept QoL as a major criterion in the evaluation of health interventions. Also, QoL has been reported to be the primary concern of patients with PD and their family members.⁵ Quality of life of patients with a chronic disease like PD includes the patient's symptoms and physical functioning, as well as, psychosocial variables. A few studies have estimated that QoL in PD is influenced by depression, motor disability, and cognitive impairment.⁷⁻⁹ A study published by Slawek et al¹⁰ shows not only QoL in relation to clinical parameters, but also the impact of certain psychosocial and demographic factors included in the analysis. Current literature has focused on the management of mobility in PD, and little attention has been devoted to psychosocial issues. This paucity of literature is attributed to the belief that if motor symptoms are treated, psychosocial aspects of the disease will spontaneously improve.⁵ Behari et al³ emphasized that health care professionals today not only give treatment and care to increase their patients' lifespan, they also have the goal of increasing their HRQoL. To improve QoL in patients with PD, health care professionals must have information about the factors affecting patients' physical and emotional well-being. Understanding the factors that weigh most on the patient's own perception of themselves and their disease, will lead to appropriate care interventions that would improve patient's well-being, and help modify HRQoL deficits. Thus, individualized care will be assisted in facilitating the

development of goals with the patient and family, which are congruent with achieving maximum QoL.^{4,5,11,12} Several researchers stress the contribution that nurses can make to the fulfilment of QoL, life satisfaction, self-esteem and physical health, as well as, the importance of setting goals with the patient and their family.^{5,11,12} The overall goal of care in PD patients is to improve the prognosis, and reduce the impact of the disease in both patients and their caregivers, with skilled medical and nursing intervention, to maintain functional ability, and retain independence. Medical treatment with drugs and surgical techniques is effective in PD, but there is also a major role for nurses in helping the patient come to terms with the disease, providing information, and managing care. The provision of timely and appropriate care for patients can do much to enhance QoL.^{5,7,12-14} This study aimed to determine the socio-demographic and clinical features of patients with PD, their HRQoL, and the relationship between these.

Methods. This cross-sectional study was undertaken in one university and 2 state hospitals in Istanbul, Turkey between March and July 2006. Eighty patients with Parkinson's disease, who attended the Parkinson's and Movement Disorders Outpatient Clinics of Istanbul University Cerrahpasa Medical Faculty Hospital, and Ministry of Health, Taksim and Haseki Education and Research Hospitals, were included in this study. The inclusion criteria for these patients were having the ability to communicate, being cooperative in an interview, and willingness to participate in the research. The permission to undertake this study was received from the ethical committee of the hospitals. Prior to the study, the patients were informed of the purpose of the research, and what would be expected of them. Informed consent was obtained from each participant, and they were assured of their right of refusal to participate, or to withdraw from the study at any stage. The anonymity and confidentiality of participants were guaranteed. In the data collection questionnaire form, the unified Parkinson's disease rating scale (UPDRS), the Hoehn and Yahr clinical staging scale, and the Nottingham health profile (NHP) were used. The questionnaire form was based on the literature review,^{2,3,7,14,15} including questions on socio-demographical characteristics and diseases of the patients, as well as, details such as age, gender, marital status, duration of illness, working status, type of first PD symptoms, and treatment. Parkinsonian disability was assessed by the UPDRS. This scale is frequently used in PD-focused research. In this study, the first of the 2 dimensions of full UPDRS was used. The second UPDRS dimension, which query complications of dopaminergic therapy, was not included. The first dimension of the UPDRS is divided

into 3 parts, all scored on a quantitative 5-point scale (0-4), measuring the severity of signs and symptoms of PD: UPDRS-mental (mental symptoms, behavior, or mood), UPDRS-activities of daily living (ADLs), and UPDRS-motor (based on a motor examination). These parts in the UPDRS were used to evaluate illness severity and sickness influences on ADLs performance and mobility; each item representing a certain sign or symptom of Parkinsonism, is rated according to severity from 0 (normal) - 4 (most severe). The UPDRS score can range from 0 - 124, and is calculated from the sum of the scores of 31 items. A higher score indicates more severe PD. The validity and the reliability of the Turkish version of the UPDRS was established by Memis,¹² the UPDRS was used along with Hoehn and Yahr clinical staging scale.^{3,8,11,16} The Hoehn and Yahr clinical staging scale is a standard way to classify the stages of PD. The Hoehn and Yahr scale give scores for severity of the disease from 0 (no sign of disease) - 5 (wheelchair-bound, or walking only with assistance). The stages are classified as mild (stage 1-2), moderate (stage 3), and severe (stage 4-5).^{1,8,11,16} The NHP is a widely used British-designed instrument for the assessment of health status, to determine perceived health-related problems in the physical, emotional, and social domains. The NHP is a 2-part-self-administered questionnaire. It is common for NHP-1 to be used alone, and this approach was adopted in this study, omitting the optional part 2, that is supposed to give a rough guide to how far such distress is affecting the ADLs. In this study, HRQoL was evaluated with the first part of the NHP (NHP-1), which contains 38 statements covering 6 health dimensions: pain (8 items), social isolation (5 items), emotional reactions (9 items), physical mobility (8 items), sleep (5 items), and energy (3 items). Respondents answered "yes" or "no" to a total of 38 questions. Each item carries a specific weight, so that within each dimension the weighted scores range from 0 (indicating good health) - 100 (indicating poor health). A higher score indicates poorer HRQoL. The NHP-1's usefulness in PD research has been reported elsewhere. The NHP is short, easy to complete, generic, valid, and reliable.^{8,15-19} In this study, the Turkish version was used; the reliability and the validity of the Turkish version of NHP has established by Küçükdeveci et al.¹⁷ Data collection instruments were administered by a researcher to all patients in a face-to-face interview. Most of the patients needed assistance in filling the questionnaire. During data collection, each question was read to the patients, and their responses were entered into the questionnaires, as most of the subjects were poor at basic reading, and writing skills.

The statistical analysis of the data was conducted using the Statistical Package for Social Sciences version

10.0 for Windows licensed to Istanbul University. Descriptive statistics were used to determine patients' socio-demographic and disease characteristics. The relationship between UPDRS and NHP dimensions was examined using Spearman's rank correlation procedure. Finally, the Kruskal-Wallis test was used to compare the differences between the NHP dimensions and the Hoehn and Yahr stages. A $p < 0.05$ was considered statistically significant.

Results. A total of 47.5% of the patients were in the 61-70 year old age group, and their mean age was 67.5 ± 8.76 years. Most of them were male, and married. For the majority, the duration of PD was between 5 and 9 years, with an average of 7.41 ± 4.02 years. Most of them were not working for reasons other than PD (for example, retirement). The beginning symptoms of PD most frequently experienced were hand tremors, and slowness in movement. The most common medication patients used in the treatment of PD were levodopa (L-dopa), and dopamine agonists. It was determined that 47.5% of patients were in stage-1. Due to problems with communication and advanced functional deficits, no patients in stage-5 were included in the study (Table 1). The mean UPDRS score was 25.09 ± 15.85 . The highest mean from the UPDRS parts was for "motor examination", followed by "ADLs" and "behavior, mental, and mood". In the examination of the UPDRS item score means, the highest (1.38 ± 1.23) was for an item (turning in bed and adjusting bedclothes) in part II; the next highest (1.26 ± 0.56) was for an item (body bradykinesia and hypokinesia) in part III. The lowest mean (0.98 ± 1.01) was for an item (motivation/initiative) in UPDRS part I. Regarding NHP dimensions, "energy" was affected the most, and "pain" the least (Table 2). The relationship between NHP and UPDRS is shown in Table 3. There was a significant positive correlation between NHP's "physical mobility" dimension and the "behavior, mental, and mood", "ADLs", and "motor examination" parts of UPDRS, as well as, with the UPDRS total score. As the parts and total scores of UPDRS increased, the NHP "physical mobility" score also increased. Also, we found a significant positive correlation between NHP's "energy" dimension and the "behavior, mental, and mood", and "ADLs" parts, and the total score of UPDRS; the positive correlation with the "motor examination" part score was also significant, but at a $p < 0.05$ level (Table 3). There was a significant positive correlation between the "pain" dimension of NHP and the UPDRS "behavior, mental, and mood", "ADLs", and "motor examination" parts, as well as, UPDRS total score (Table 3). We found a positive correlation between the "sleep" dimension of NHP and the "behavior, mental, and mood" part

Table 1 - Socio-demographic and clinical features of patients (N=80).

Variables	n	(%)
<i>Age</i>		
40-50	6	(7.5)
51-60	9	(11.3)
61-70	38	(47.5)
71 and up	27	(33.7)
<i>Gender</i>		
Female	30	(37.0)
Male	50	(63.0)
<i>Marital status</i>		
Married	55	(68.8)
Unmarried	4	(5.0)
Widow	21	(26.2)
<i>Duration of diseases</i>		
1-4 years	20	(25.0)
5-9 years	33	(41.3)
10 years and up	27	(33.7)
<i>Working status</i>		
Working	7	(8.7)
Not working due to PD	8	(10.0)
Not working due to other reasons	65	(81.3)
<i>The symptoms present at the beginning of the diseases*</i>		
Bradykinesia	25	(31.2)
Rigidity	19	(23.8)
Pain	9	(11.3)
Gait disorders	8	(10.0)
Speech disorders	3	(3.8)
<i>Treatment*</i>		
L-Dopa	76	(95.0)
Dopamine agonists	42	(52.5)
Catechol-O-Metil Transferaz (COMT)	10	(12.5)
Amantadine	8	(10.0)
Anticholinergics	1	(1.3)
<i>Hoehn and Yahr Stages</i>		
Stage-1 (unilateral involvement only)	38	(47.5)
Stage-2 (bilateral involvement only)	22	(27.5)
Stage-3 (disability is mild to moderate)	17	(21.2)
Stage-4 (fully developed severe disease; disability marked)	3	(3.8)
Stage-5 (confinement to bed or wheelchair)	-	-

*Multiple choices have been selected

Table 2 - Mean scores and standard deviations of UPDRS and NHP.

Scale	Mean ± SD
<i>UPDRS parts</i>	
I- Behavior, mental and mood	2.59 ± 2.17
II- Activities of daily living (ADL)	11.02 ± 7.40
III- Motor examination	11.62 ± 7.45
<i>NHP dimensions</i>	
Physical mobility	44.95 ± 24.23
Energy	69.79 ± 21.17
Pain	20.41 ± 28.79
Sleep	36.36 ± 31.96
Social isolation	27.97 ± 31.29
Emotional reactions	35.01 ± 31.55

UPDRS - Unified Parkinson's Disease Rating Scale,
NHP - Nottingham Health Profile

of UPDRS, and a significant positive correlation with “ADLs” and “motor examination” parts (Table 3). There was a significant positive correlation between NHP’s “social isolation” dimension and UPDRS’s “behavior, mental, and mood”, “ADLs”, and “motor examination” parts, as well as, UPDRS total score (Table 3). In addition, we found a positive relationship direction between the “emotional reactions” dimension of NHP and the UPDRS “behavior, mental, and mood”, “ADLs”, motor examination” parts, and a total score. It was determined that the worsening of patients’ functional status had a negative effect on their QoL (Table 3). In comparing the patients’ disease stage with the dimensions of NHP, significant differences were found in NHP results, depending on the PD stage. The advancement of the PD stage had a negative effect on patients’ QoL (Table 4).

Discussion. Parkinson’s disease is an illness, which has a negative effect on the physical, emotional, and social aspects of ADLs, thereby decreasing QoL. The assessment of socio-demographic and clinical feature of patients with PD, their HRQoL, and the relationship between these, may assist in determining individualized care goals, and strategies. In this way, enhanced psychosocial adjustment to PD may improve HRQoL. The age demographic results obtained in our study are similar to those reported in the literature, that PD patients are between 40-75 years, and that, it is frequently seen in individuals over 60 years.^{2,3,15,20} Although a significant difference in prevalence based on gender was not found for PD, women are slightly more likely to have it.^{2,21} Our findings were supported by the literature, and by Behari et al,³ and Delil et al’s² studies, in which the majority of the patients were male.

In the beginning, PD patients reported that they experienced hand tremors and slowness in movement. Delil et al² reported. that the first beginning symptom of the disease in 456 patients was tremors, and in 174 patients it was bradykinesia. These research results are similar to ours, which are supported by some additional literature.^{2,15,20} The goal of the medical treatment and management of PD, is to keep to a minimum, limitations in movement, and to maintain hope for life.³ Levodopa is the most effective medication in relieving the symptoms of PD, and its use improves the QoL of most patients. Physicians prefer dopamine agonists because there are indications that they have long-term effects, and may slow the advance of the disease. The fact that the majority of patients in this study were taking L-dopa and dopamine agonists in the treatment of PD, is consistent with the literature.^{4,20,22}

According to Hoehn and Yahr’s clinical staging scale, the majority of the patients were in the first 2 stages,

Table 3 - Correlations of NHP dimensions with parts and total scores of UPDRS.

NHP	UPDRS							
	Behavior, mental, and mood (I)		Activities of daily living (II)		Motor examination (III)		Total score	
	r_s	p -value	r_s	p -value	r_s	p -value	r_s	p -value
Physical mobility	0.693	0.001**	0.559	0.001**	0.727	0.001**	0.615	0.001**
Energy	0.333	0.003**	0.369	0.001**	0.284	0.011*	0.299	0.007**
Pain	0.509	0.001**	0.410	0.001**	0.466	0.001**	0.512	0.001**
Sleep	0.281	0.011*	0.382	0.001**	0.346	0.001**	0.160	0.158
Social isolation	0.557	0.001**	0.523	0.001**	0.538	0.001**	0.522	0.001**
Emotional reactions	0.496	0.001**	0.567	0.001**	0.483	0.001**	0.411	0.001**

r_s - Spearman correlation co-efficient, UPDRS - Unified Parkinson's Disease Rating Scale, NHP - Nottingham Health Profile, * $p < 0.05$, ** $p < 0.01$

Table 4 - Comparison of NHP dimensions mean scores and Hoehn and Yahr stages.

NHP dimension	Hoehn and Yahr Stage			X_{kw}	P -value
	1	2	3-4		
	Mean ± SD	Mean ± SD	Mean ± SD		
Physical mobility	34.89 ± 22.13	44.29 ± 23.95	64.80 ± 15.3	22.58	0.001
Energy	62.92 ± 17.46	70.0 ± 20.40	82.60 ± 23.27	11.82	0.001
Pain	7.43 ± 16.51	18.17 ± 24.67	47.50 ± 33.58	27.61	0.001
Sleep	29.02 ± 26.31	32.60 ± 32.17	54.43 ± 35.88	7.59	0.022
Social isolation	14.45 ± 25.22	27.74 ± 25.13	53.88 ± 32.57	21.47	0.001
Emotional reactions	23.71 ± 23.01	26.96 ± 23.80	65.28 ± 34.45	18.93	0.001

X_{kw} - Kruskal Wallis, UPDRS - Unified Parkinson's Disease Rating Scale, NHP - Nottingham Health Profile

which suggests that they had not yet become dependent in their ADLs. The data from studies by Karlsen et al,⁸ Delil et al,² and Kul et al²³ are consistent with these findings. Parkinsonian disability was experienced the most in the motor examination (body bradykinesia and hypokinesia), and ADLs (turning in bed and adjusting bedclothes) parts. Bradykinesia is one of PD's 3 basic symptoms that causes the most significant disability, and can develop early or late. Bradykinesia causes a clear slowness in all ADLs.²⁰ In their study, Delil et al² determined that tremors and bradykinesia began at the same time, as the first symptom in patients. Kul et al²³ reported that PD patients have difficulty getting from a back-lying position in bed to sitting up. Our study findings are consistent with these studies, and the literature.^{2,20,22,23}

In all of the studies that evaluated QoL in PD, it was determined that there is a parallel increase in the negative effect of the disease on QoL as the PD stage increases.^{1,3,8,11,15} In research evaluating the QoL of individuals with PD using the NHP, as reported by Karlsen et al,¹⁵ Wasielewski and Koller,⁷ Karlsen et al,⁸ and Pechevis et al,⁹ it was determined that particularly the QoL dimensions of “energy”, “sleep” and “emotional reactions” were negatively affected by the progression of PD. In our study, the NHP dimension most affected was “energy”, and the dimension least affected was “pain”. In our study, a significant relation was found between the NHP “physical mobility” dimension and several UPDRS parts, as well as, the total UPDRS. Karlsen et al⁸ determined that as the diseases' clinical degree increased physical inability, UPDRS scores also increased. Low

energy is commonly seen together with depressive signs and symptoms, such as fatigue. Karlsen et al¹⁵ also determined low energy for 30% of the patients in their study. Rigidity and inability to move extremities in PD often causes muscle pain. Although rigidity is rarely seen in the spinal area, it can cause patients to have back pain. Rigidity in the muscles supporting the femur and feet can result in painful cramps.^{15,20,24} In this research, the significant correlation between NHP's "pain" dimension and UPDRS's parts is consistent with the literature.

Immobility and rigidity that continues all night have been reported in the literature along with repeated Parkinson's signs and symptoms, such as irregular respiration, and nocturia or psychiatric disorders, such as depression and anxiety. All of these can lead to changes in sleep pattern and sleep disorders, and can have a negative effect in both the patient and the spouse's QoL.^{11,20,25} In the study by Yüksel et al,²⁵ it was determined that as UPDRS scores increased, Parkinson's disease sleep scale (PDSS) scores decreased. As PDSS scores decreased, an individual's problem with sleep increased, as the patients' QoL and ADLs worsened. The results of this study are consistent with those found by Yüksel et al.²⁵

Within the scope of an individual's wholeness, it is inevitable that patients whose emotional and social aspects are good, will be better able to continue their ADLs, and maintain their QoL. The emotional reactions of anxiety and depression are important determinants of the QoL of an individual with PD.^{26,27} In a study by Onur et al,²⁷ the UPDRS mean score for Parkinson's patients with depression was found to be higher at a statistically significant level, than for those without depression. Similarly, we found significant correlations between NHP's "social isolation" and "emotional reactions" dimensions, and the UPDRS. According to our findings, as the disease stage advanced, all dimensions of NHP, and consequently the patients' QoL were negatively affected. Delil et al,² determined a clear relationship between advanced stages and bradykinesia; as the disease stage advanced, physical inability increased dependence, and the need for assistance with ADLs. Furthermore, Kul et al²³ examined the patients' ability to perform physical activities according to their illness stage, and a direct decrease was found from stage-1 to stage-4. Karlsen et al¹⁵ determined, as the illness stage increased, patients' energy level decreased. In the literature, it has also been reported that as the disease stage increases, there is an increase in the pain score due to the increased rigidity.^{15,28} Also, together with an advance in disease stage, there is a parallel increase in the difficulty of carrying out social roles and responsibilities. Patients who see themselves as a burden in social settings frequently feel lonely and inadequate, and may experience feelings of guilt, and social isolation.^{5,29} Emotional reactions are frequently

seen, in the form of anxiety and depression. Psychotic symptoms are seen as a major symptom or treatment complication of the advanced stages of PD.²⁹ In a study by Öztürk et al,²⁶ more than 40% of patients with PD were found to have anxiety disorders, including panic attacks and social phobias.

In conclusion, the results obtained from this study show that the socio-demographic characteristics, such as, age and gender of the PD patients participating in this study, reflected those of PD patients reported in the literature. In addition, a significant relationship was determined between illness characteristics, and HRQoL. As the stage of PD increased, the UPDRS scale and item scores increased, and had a negative effect on all dimensions of the NHP, and therefore on HRQoL. Patient problems can be determined by continually monitoring patients' behavior, their mental and emotional state, and their ADLs and motor examination findings, planning the appropriate care can increase the quality of individual care.

Educational programs, which will systematically give all information needed about the illness, diagnosis and treatment, and for maintaining ADLs, must be planned and continued for individuals who assist PD patients. In this way, the providers will be able to give care that is based on patients' needs, determined by individual interviews. Collaborating with other health disciplines in the health care facility is important. Counseling is needed for patients, their families, and others who care for the patients, as are support groups, and social organizations. In particular, for young patients, increasing the number of organizations and facilities that can assist them with relationships within their families, and also with finding financial assistance needed because of the possible early retirement, could decrease the individuals' concerns about their future, and help them with psychosocial adaptation to their illness.

This study has several limitations. First, the sample size was small. Second, a generic instrument for evaluation of HRQL was used in this study. Furthermore, there have been a few studies on this subject in Turkey. Therefore, this research could be repeated with larger samples using QoL questionnaires specific for PD. It is also recommended that studies be conducted, not just with the patients, but also with their life partners, and with those who provide their care.

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