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INVESTIGATION OF THE REASONS FOR THE EMPLOYEE TURNOVER OF PARKINSON'S PATIENTS

ORIGINAL ARTICLE

ABSTRACT

Purpose: It is known that early retirement has been increasing for patients with Parkinson's disease. The data on the factors that cause early retirement in this patient population is limited. The objective of this study is to analyze the effects of Parkinson's disease that cause early retirement.

Methods: Seventy-five patients with Parkinson's disease (mean age: 59.10 ± 9.20 years) participated in this study. Data were collected through face-to-face interviews with patients within the framework of 29 questions determined by the researchers by examining the literature and similar studies.

Results: Participants have been analyzed into groups: Retirement types and reasons for retirement. Patients that quit their jobs because of Parkinson's disease stated that bradykinesia in motor symptoms, somnipathy, and depression in non-motor symptoms came first in their reasons for retirement. It has been determined that 90% of participants that quit their jobs because of Parkinson's disease were not supported by the institutions they worked for, 77.55% couldn't receive physiotherapy treatment and 61.22% couldn't receive psychological therapy. In addition, it has been determined that 55.1% of the participants would like to work if they find a suitable job.

Conclusion: For patients to stay in the workforce longer, patients with Parkinson's disease, their caregivers, and employers should be informed about the health problems associated with Parkinson's disease, their possible consequences, as well as strategies and treatment techniques developed for motor and non-motor symptoms.

Keywords: Early-Retirement, Employee Turnover, Motor Symptoms, Non-Motor Symptoms, Parkinson's Disease

PARKİNSON HASTALARININ İŞ BIRAKMA NEDENLERİNİN İNCELENMESİ

ARAŞTIRMA MAKALESİ

ÖΖ

Amaç: Parkinson hastalarındaki erken emeklilik oranının giderek arttığı bilinmektedir. Bu hasta popülasyonunda erken emekliliğe neden olan faktörler arasında kısıtlı sayıda veri vardır. Çalışmadaki amacımız Parkinson hastalığının erken emekliliğe neden olan etkilerini incelemektir.

Yöntem: Çalışmaya 75 Parkinson hastası (ortalama yaş: 59,10±9,20 yıl) dâhil edildi. Literatür ve benzer çalışmalar incelenerek araştırmacılar tarafından belirlenen 29 soru çerçevesinde hastalar ile yüz yüze görüşülerek veri toplandı.

Sonuçlar: Katılımcılar emeklilik türlerine ve emekli olma nedenlerine göre iki farklı şekilde gruplanarak incelendi. Parkinson hastalığı nedeniyle işten ayrılan hastalar tarafından motor semptomlar içinde bradikinezi, non-motor semptomlar içerisinde ise uyku bozukluğu ve depresyon emeklilik nedeni olarak ilk sırada gösterildi. Parkinson hastalığı nedeniyle işten ayrılan katılımcıların %90'ının çalıştıkları kurum tarafından desteklenmediği; %77,55'inin fizyoterapi tedavisi, %61,22'sinin ise psikolojik tedavi almadığı belirlendi. Ayrıca katılımcıların %55,10'inin uygun bir iş bulması halinde çalışmak istediği belirlendi.

Tartışma: Hastaların iş hayatını daha uzun süre devam ettirebilmeleri için Parkinson hastalarının, bakım verenlerinin ve işverenlerinin Parkinson hastalığı ile ilgili sağlık sorunları, bunların olası sonuçları, ayrıca motor ve non-motor semptomlara yönelik geliştirilen stratejiler ve tedavi teknikleri hakkında bilgilendirilmeleri gerekmektedir.

Anahtar Kelimeler: Erken Emeklilik, İşten Ayrılma, Motor Semptomlar, Non-Motor Semptomlar, Parkinson Hastalığı.

INTRODUCTION

Parkinson's disease (PD) is a progressive neurodegenerative disease characterized pathologically by the degeneration of dopaminergic neurons in the substantia nigra and the development of Lewy bodies in the remaining dopaminergic neurons (1). Characterized by both motor and non-motor symptoms, patients with PD typically display rest tremor, rigidity, and bradykinesia as motor symptoms (2). Among the motor problems such as breathing, speech, swallowing, walking, and balance problems occur over time (3). Non-motor symptoms of PD include neurobehavioral disorders, cognitive impairment, and autonomic dysfunction.

Although PD is generally associated with an older patient population, 5% of patients are diagnosed before age 50 and 30% before age 65 (4). Based on this information, we can say that many Parkinson's patients are diagnosed while they are still active in the workplace. It still takes a long time for these individuals to obtain the right to retirement. Psychological (non-motor) symptoms such as depression, anxiety, and sleep disorders observed in the early stages of PD may reduce the working capacity of the patients. In the later stages when progression is observed, the motor effects in addition to the existing symptoms can further increase the negativity in the work-life of the people. Cognitive problems and fatigue also gain importance in this period (5). Although levodopa and dopamine agonists used in the treatment of PD successfully reduce symptoms, their effectiveness decreases over time, and their effect on axial motor symptoms (such as postural instability, dysarthria, palilalia, dysphagia, flexor posture, freezing) and tremor is limited, and unfortunately, it is also associated with undesirable side effects such as motor fluctuations and dyskinesias. Although levodopa and dopamine agonists, as a gold standard, used in the treatment of PD successfully reduce symptoms, their effectiveness decreases over time, and their effect on axial motor symptoms and tremors is limited. In addition, levodopa has side effects such as dizziness, somnolence, headache, dyskinesia, dystonia, etc. Such side effects of pharmacological treatment can also cause a decrease in the working ability of patients, as well as Parkinson's symptoms (6).

Only a few studies have been conducted on the working ability of patients with PD. These few studies have shown that unemployment and early retirement rates in Parkinson's patients are gradually increasing (5, 7). In these individuals, turnover occurs 0-25 years after PD is diagnosed (7, 8). It was observed that the full-time working capacity of the patients decreased by up to 80%, and they quit work earlier than the general population (5). Disability such as bradykinesia, rigidity, tremor, sleep disturbances, cognitive impairment, and sensory disturbances associated with PD is thought to be a factor in the turnover of these employees (9). However, the reasons for early retirement are not fully known, and more information is needed about the specific problems of PD for patients to continue their professional life and stay in the workforce for longer. There are a few studies on this topic that have not been conducted in Turkey. Turkey has an industrial capacity shaped by its unique cultural and economic characteristics. Therefore, we thought that the reasons for the early retirement of patients with PD in Turkey should be investigated. Our aim in this study is to examine the factors that cause the early retirement of individuals with PD and to contribute to occupational health and human resources data about this situation in Turkey.

METHOD

This study was conducted in Istanbul University – Cerrahpaşa, Cerrahpaşa Medical Faculty, Neurology Department, Movement Disorders Unit, Parkinson's Disease Clinic, between May and October 2018. Approval for the study was obtained from Marmara University Institute of Health Sciences Ethics Committee with protocol number 132, dated 07.05.2018, and the study was carried out following the Declaration of Helsinki. All participants were made to sign a written informed consent form before the study. The clinical trial number is NCT03779880.

Participants

Seventy-five volunteer patients with PD participated in the study. Inclusion criteria in the study were to be diagnosed with PD according to the United Kingdom Brain Bank criteria [10] to be in the 30-85 years old range, and to have ongoing PD treatment; the exclusion criteria from the study were determined as dementia and the presence of severe cognitive impairment.

The sample size was calculated using single group proportional data (population was 150000, the incidence was 5% [7], and the confidence interval was 95%) and the minimum required sample size is 73 participants. Therefore, 75 participants were included in the study.

Outcome Measures

The demographic information of the participants was recorded, the Hoehn & Yahr Staging Scale (H&Y) was applied, and an interview was conducted with the participants. H&Y is used to measure how Parkinson's symptoms progress and the level of disability and classifies the disease into five stages. Stage 1 refers to a patient with unilateral involvement, and stage 5 refers to a wheelchair or bed-bound patient [11]. In our study, the H&Y stage of the participants was assessed by a neurologist.

The interviews with the patients were conducted face to face by a physiotherapist. The 29 questions asked to the patients during the interview were determined by the researchers in advance by examining similar studies in the literature (Appendix).

Twenty-three of the questions are retrospective and are about the conditions of the patients during their retirement or when they leave the workforce. It includes questions about why the participants were retired, how and to what extent they felt the effects of the disease in the work environment, and how they perceived employer support. The last question of the questionnaire requires that the effect of PD on retirement or leaving the workforce is scored between 0-10 points by the patient. 10 points given indicate that PD has the highest effect on leaving the workforce and retirement. 6 prospective questions assess the participants' current desire to work, their working status, and what type of job they continue to work.

Statistical Analysis

Statistical Package for Social Sciences (SPSS), version 25 (Chicago, IL, USA) was used for statistical

analysis. After evaluating the normal distribution of the obtained data, Mann Whitney U test was used to compare differences between groups, and the Pearson correlation coefficient was used for correlation analysis. Cohen correlation classification was used for correlation severity. A p-value less than 0.05 is set as statistically significant.

RESULTS

Seventy-five patients with PD (mean age: 59.10±9.20 years) were evaluated. Bradykinesia in 23 patients, tremor in 45 patients, and both tremor and bradykinesia in 7 patients have been observed as initial symptoms. The average retirement age of participants is 49.75±6.30 years; the average age of starting working life is 19.46±4.58 years. Demographic information of participants with PD is shown in Table 1.

Table 1. Demographic Information of the Participants (n=75)

Data	n (%)
Gender	
Female	9 (12%)
Male	66 (88%)
Education	
Uneducated (n, %)	1 (1.33%)
Primary School (n, %)	25 (33.33%)
Secondary School (n, %)	13 (17.33%)
High School	19 (25.33%)
University	17 (22.67%)
Duration of Disease (in years)	
0-5	26 (34.67%)
6-10	22 (29.33%)
10+	27 (36%)
H & Y Stage	
1	28 (37.33%)
2	20 (26.67%)
3	21 (28%)
4	6 (8%)
Retirement Type	
Disability pension	23 (30.66%)
Standard (old age) pension	52 (69.37%)

H & Y: Hoehn & Yahr

The reasons for leaving the work the patients were asked by giving 3 options: "reasons due to illness", "reasons related to the workplace but not related to the health problem" and "different personal reasons apart from disease". Participants were allowed to select more than one option. According to the answers given, the participants have grouped into two; a total of 49 patients (65.33%) (Group 1) whose reasons are due to disease and a total of 26 patients (34.67%) (Group 2) whose diseases did not affect their retirement. 15 patients in Group 1 reported both disease-related and institutional reasons as reasons for retirement (Table 2).

Identification of Groups

H&Y stage of the participants in Group 1 was 2.50 ± 0.89 ; the average age was 57.34 ± 9.38 years; the duration to quit work was 6.02 ± 4.52 years after diagnosis. The rate of quitting work was calculated in the first 5 years as 57.17%; between 5-10 years as 28.57%; after 10 years as 14.28%. H&Y stage of the participants in Group 2 was 1.40 ± 0.57 ; the average age was 60.08 ± 5.95 years. Since 26 of our participants did not consider PD as a reason for quitting work, the analysis of the results was continued with Group 1, consisting of 49 patients.

Table 2. Grouping of Patients Based on Their RetirementType

Group 1 (n=49)	Group 2 (n=26)
Those who retired on disability due to PD diagnosis (n=23) Those who wanted to work after retirement but had to quit due to PD (n=26)	Those who normally retired (of old age) and do not want to continue working of their own accord (n=21) Those who continue to work of their own accord after retirement (n=5)

PD: Parkinson's disease

Evaluation of Motor and Non-Motor Symptoms (n=49)

When examining which of the motor and non-motor symptoms of PD is/are mentioned in retirement tests, bradykinesia among the motor symptoms with a rate of 34.75%; sleep disorder and pessimistic mood among non-motor symptoms with a rate of 20.65% take the first place that causes retirement the most (Figure 1 a-b). In addition, in the correlation analysis conducted to evaluate the relationship between disease progression and duration of work, a moderate negative correlation (p= 0.010, r= -0.377) was reached between the H&Y stage and the duration of work after PD.



Figure 1: a: Motor symptoms that are among the causes of retirement (%) **b:** Non-motor symptoms that are among the causes of retirement (%)

Opinions of the participants about the effect of the workplace of employment on early retirement (n=49)

All the participants in Group 1 were working in the private sector. 73.46% only because of the symptoms of PD; 26.54% of them stated that they had to quit working life due to the institution they worked for in addition to PD symptoms. While 13 (26.53%) of the participants in Group 1 stated that the institution they work for supported them to continue their working life after the diagnosis, 32 (65.31%) stated that they could not find any support. Only 4 (8.16%) of 49 patients reported that they received a sufficient level of support from the institution they were working at.

The status of individuals receiving physiotherapy and rehabilitation and psychological support (n=49)

All the participants in Group 1 reported both motor and non-motor symptoms as the reason for leaving/retiring from the workforce. Despite this, it was determined that 77.55% (n=38) of the participants did not receive physiotherapy treatment and 61.22% (n=30) did not receive any psychological treatment in the period just before quitting the job. The longest regular treatment period was determined as only 1 year in patients who stated that they received physiotherapy treatment.

Expectations of individuals for the continuation of working life (n = 49)

When asked if participants in group 1 would like to work again in the future, 55.1% stated that they

would like to work if there is a suitable job, and 55.1% stated that they would like to work if there is a suitable job. When questioned about the suitable job description the most common responses are "work that is desk jobs, less tiring/less stressful and has shorter working hours". After these participants were grouped by their educational backgrounds and when their will to work was compared, it was observed that the will to work of the participants with 8+ years of education was statistically significantly higher (p=0.010).

DISCUSSION

It is known that PD has a negative effect on working capacity, and patients with PD leave the workforce at an earlier age than normal employees (6). The objective of our study is to determine the factors that cause the patients with PD to retire early, detect specific problems of patients with PD regarding their working life, and generate data specifically for Turkey.

According to the results of our study, we determined that approximately 65% of the participants had difficulty in continuing their working life after being diagnosed with PD, and 30% retired with a disability report. These rates were considered higher when compared with the results of studies conducted in various countries. While it was detected that an early retirement rate of 20-27% in the conducted studies (12,13), the higher early retirement rate in our study might have various reasons. Differences in the number of participants in the studies, the age and educational background of the participants, the H&Y stages of the patients, the differences in the occupations and working conditions between countries, the employers' perspective on diseases, and the policies of the health-related units may also affect these results.

Martikainen et al. stated that according to the data received from 529 patients who knew the exact date of their retirement says that retirement rate is the highest in the first three years of PD (5), on the other hand, for Murphy et al., it is the highest in the fifth year (14). In our study, we determined that, in line with the literature, the participants quit their jobs on average in the sixth year after the diagnosis of PD. While the rate of quitting the job was approximately 57.17% in the first five years after diagnosis, 14.28% of the participants continued to work for ten years or more. At the same time, as the H&Y stages of the participants increased, it was expected that the duration of work after diagnosis would decrease and there would be a higher degree of correlation between the two data while a negative moderate correlation was found according to our results. These results show that the differences between individuals also play a role in retirement. Martikainen et al. interpreted this in a way that while some patients prefer to continue working despite their symptoms, some patients prefer to quit their job notwithstanding their low stage of H&Y (5). The fact that only motor symptoms are considered in H&Y staging may also be one of the reasons for the negative correlation. Because the non-motor symptoms of PD starting many years ago may cause the person to be affected more emotionally over the years, even if the H&Y stage is in the early stage. The tolerance level of patients may have decreased against situations such as stress management, workload, and hierarchy in work life. Although motor symptoms were mentioned more frequently by study participants as a reason for early retirement, considering the variety of non-motor symptoms, they probably have a higher impact on early retirement.

It is known that both motor and non-motor symptoms have a negative effect on the ability to work. According to our results, bradykinesia is the most common motor symptom that causes retirement. Since various problems such as hypometria, hypophonia, aprosodia, micrography, hypomimia, and shortened stride length are sub-headings of bradykinesia, these complaints were classified as bradykinesia in our study. Because of these sub-headings, bradykinesia may be shown more prominent as a reason for early retirement by the participants compared to other cardinal symptoms (15), as it will lead to a more comprehensive disability in daily life activities and working life. Among the non-motor symptoms, insomnia and depressive mood were the most common causes of early retirement cited by our participants. Depression can increase people's sense of pain and make it difficult for them to cope with chronic illnesses (16). In addition, the loss of motivation and decrease in energy level caused by depression can affect working life and decrease working capacity. Cognitive impairment, which is one of the consequences of depression, can also impact patients' perception levels, business management processes, and adaptations. Sleep problems, which are common in patients with PD, are likely to cause difficulties in adapting to the job because of not being able to maintain regular sleep during the night, fatigue, and sleepiness at work caused by insomnia. Therefore, working patients may experience a decrease in their working efficiency during the day. There are many studies in the literature reporting a relationship between sleep disorder and depression (14,16,17). This may help explain why our participants cited both depression and sleep disturbance at the same rates as the cause of early retirement. At the same time, as the deterioration of one of the symptoms will affect the other, the negative effects in working life may also be parallel to each other.

According to the results of our study, it was observed that employers and institutions also play an important role in early retirement besides PD symptoms. Only 10% (n=4) of the participants who retired early due to PD reported that they received sufficient support from their institution. Studies have shown that workplace regulations have a positive effect on the working processes of patients with PD (5). It has been reported that it would be beneficial for working patients to be freer in determining the regulation to be made in the type of work and working hours (8). Similarly, our participants defined fewer working hours or part-time work, and positions that require less responsibility as opportunities to work for them. Though there is no specific research on the problems encountered by patients with PD in Turkey, studies point out that people with disability generally face their employers' negative attitudes. Reasons such as unsuitability of workplace physical conditions, transportation difficulties, slowing down work, inefficient work, capriciousness, and being aggressive are among the reasons that prevent disabled employment by employers (18).

The severity of PD should be evaluated not only according to motor problems but also complete well-being by considering the psychological and social conditions of the patients. Therefore, it is of great importance that patients receive both physiotherapy and rehabilitation treatment and psychological treatment during PD. Considering the results of our study, although each of the 49 participants who left their jobs due to PD stated the presence of both motor and non-motor symptoms at the time they decided to guit, 77.55% did not receive physiotherapy treatment and 61.22% did not receive psychological treatment. After their work will to work was questioned, it is seen that 55.1% of them want to work if they find a suitable job. In the light of this data, we think that if the participants are regularly supported with physiotherapy and psychological treatment after they are diagnosed with PD, their work capacity and productivity may increase, and they may be working actively in the current situation. It might be suggested that if treatment methods such as physiotherapy, and psychotherapy, which have a high level of evidence, are applied intensively and programmatically from the early stage of the disease, symptoms of the patients will be controlled, so early retirement will be prevented.

Both motor and non-motor symptoms may cause early retirement in patients with PD. While early retirement is associated with high costs at the social level, it is also associated with a loss of income at a young age at the individual level. Loss of income often requires additional costs, such as treatment costs and daily living expenses, which must be borne by the patient's family or relatives. This situation may cause psychological stress in patients by causing patients to feel more responsible toward their families.

The inability of patients to continue their work-life may cause a loss of income, as well as cause them to be disconnected from social life and to be alone with the disease for a longer period. Financial inadequacy brings with it a decrease in the patient's sense of self and self-worth. Since PD is also directly related to non-motor symptoms such as depression and stress, such feelings can negatively affect the quality of life of patients, and lead to severe mental problems and even suicide. For this reason, it is important for patients to stay as long as they can in working life in terms of both their financial and mental well-being. Our study has some limitations: (1) Findings were not collected prospectively but through the recall of patients. This situation may cause changes in data such as date, age, and term of employment due to remembering wrong. (2) Since there is no objective measurement method that can evaluate the effect of PD on working life, the data were collected through an interview done by the researchers (3) the number of participants was limited, and the data were collected from a single center.

Some adjustments may be required in the workplace so that patients with PD can stay working for a longer period. We believe that patients could work in workplaces with a part-time or shift system more comfortably. In addition, the patients we interviewed reported that night shifts were challenging frequently, therefore, working hours should include daylight hours. In patients with PD, work that takes a lot of effort and concentration can lead to injuries, exhaustion, and stress. It is important for the patients' health that the work was chosen to be desk jobs that do not entail a lot of responsibility. Furthermore, longer, and adequate rest intervals and more rights to paid vacation might benefit provide an advantage for these patients.

As a result, to enable patients to stay in the workforce for a longer period, patients with PD, their caregivers, and employers (1) need to be informed about the health problems associated with PD and their possible consequences, and (2) the strategies and techniques developed to counter motor and non-motor symptoms. This field needs to be studied further in detail to identify occupational challenges, necessary regulations, and support for patients with PD.

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Conflict of Interest: There is no conflict of interest.

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Appendix: Interview Guide

- When were you first diagnosed with Parkinson's disease? 1
- 2. What was your first symptom of Parkinson's disease, and where did this symptom first appear in your body?
- When did you start your working life? 3.
- 4. When did you retire?
- 5. Select the type of retirement: a. Standard pension b. Disability pension
- 6. Whom did you live with when you retired?
- Did you have any dependents when you retired? If yes, what was your degree of affinity? 7.
- 8. Why did you retire?
- 9. Which of the following is/are among the reasons for your retirement?
 - a. Disease-related causes
 - b. Reasons based on the institution I work for
 - c. No reason, of my own accord
- 10. Did you decide to leave after learning about the disease when there was no problem in keeping your job? b. No a. Yes
- 11. Had you lost your commitment to your job before you were diagnosed with the disease? a. Yes b. No
- 12. Which of the following motor symptoms were among the reasons for your retirement? (You can tick more than one option.)
 - a. Hand tremor
 - b. Difficulty starting or transitioning between movements, slowing of movements
 - The resistance felt during movement or the stiffness felt in the muscles C
 - d. Freezing during gait, loss of balance
- 13. Which of the following non-motor symptoms were among the reasons for your retirement? (You can tick more than one option.)
 - a. Loss of interest in events around you
 - b. Difficulty falling asleep and staying asleep at night
 - c. Feeling sad, moody
 - d. Forgetfulness
 - e. Loss of motivation
 - Unexplained pain f.
 - g. Seeing or hearing things that you know are not or have been told that they are not h. Incontinence or difficulty defecating
- 14. Did the institution you work for the support you to continue your job after you were diagnosed with Parkinson's disease? a. Yes
 - b. No (If "no", go to question 16.)
- 15. Do you think the support provided by the institution you work for was sufficient?
 - a. Yes b. No
- 16. Are you still working? (If "no", go to question 20.)
 - a. Yes b. No
- 17. What job are you doing now?
- 18. Specify the type of your work (desk job, in the field, etc.)
- 19. Is your current job different from your previous job? Please explain.
- 20. Would you like to continue working with your current health condition?
- a. Yes b. No
- 21. What kind of job would you like to work in if given the opportunity?
- 22. Did you have any other illnesses when you retired? (If "no", go to question 24.)
- a. Yes b. No
- 23. Which are illnesses?
- 24. Did you receive physical therapy for Parkinson's treatment when you retired? (If "no", go to question 27). a. Yes b. No
- 25. How long / how many sessions of physical therapy did you receive?
- 26. Do you continue your exercises?
- a. Yes b. No
- 27. Did you receive psychiatric therapy for Parkinson's treatment when you retired? a. Yes b. No
- 28. If you were to describe your psychological state in a few sentences when you retired, which sentences would you use?
- 29. What do you think Parkinson's part is in your retirement? (0: none at all, 10: All due to Parkinson's)
 - 4 5 6 7 8 9 10 2 3 0 1