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Predictors of Health Care Use in Patients With Parkinson's Disease: A Longitudinal Study

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Summary

PURPOSE: To predict health care use in patients with Parkinson's disease.

METHODS: The health care use of 235 patients with Parkinson's disease was studied twice over the course of 1 year. Use consisted of visits to the neurologist and general practitioner (GP) and use of a physiotherapist, a psychotherapist, or home care nurse. The effects of both prior and concurrent sociodemographic, disease-related, and psychosocial characteristics on health care use were examined.

RESULTS: Patients who were living with others and patients with private health insurance paid significantly ($p < 0.01$) more visits to their neurologists. For visits to the general practitioner, disease severity and poor quality of life, as measured by the Parkinson's Disease Quality of Life questionnaire (PDQL), were the most important predictors. Other sociodemographic and disease-related characteristics, such as age, gender, and disease duration, were not related to doctor visits. Physiotherapy was associated with disease severity and poor quality of life. Lack of social support, depression, and poor quality of life were correlated with psychotherapy, whereas age, female gender, living alone, disease severity, and disease duration were related to use of a home care nurse.

CONCLUSIONS: The number of visits to a neurologist by patients with PD is not associated with disease severity or quality of life impairment, but only with sociodemographic characteristics. Nonmedical care is predicted by disease severity and psychosocial characteristics. The consequences for care and costs are discussed.

Key Words: Parkinson's disease—Health care utilization—Quality of life—Neurologist visits—GP visits.

Parkinson's disease (PD) is a relatively common disease among the elderly of all ethnic groups and socioeconomic classes in many countries throughout the world.[1]

The European age-adjusted prevalence is estimated at 160 of 100,000.[2] The prevalence of PD increases with age, with a prevalence ratio of 60 of 100,000 for the age group 65–69 years rising to a prevalence ratio of 360 of 100,000 for those 80–84 years old.[2] On the basis of the predicted demographic changes, these prevalence rates are expected to rise in the next decades. Patients with PD regularly visit their neurologists and general practitioners (GPs),[3,4] and also seek nonmedical care from physiotherapists,[5] psychotherapists,[6] and home care nurses.[4] Because PD is a chronic disease with an average disease duration of approximately 15 years,[7] the health care use of patients with PD is substantial. Therefore, the expected rise in prevalence rates will result in an increasing impact of those health care services.

Health care use is not exclusively a function of prevalence, but is also affected by other factors. Identification of those factors that determine and predict health care use is important for physicians, other caregivers, and policymakers. Understanding these factors may enhance present care and predict future patterns. This insight may enable a more appropriate allocation of resources or indicate the need for interventions. Thus, the quality of life of patients with PD may be improved, while the costs of care could simultaneously decrease.

Research among patients with other chronic illnesses has shown that several factors are important in the use of health care. Disease-related factors, such as disease severity,[8–10] disease duration,[11] and comorbidity,[12] were found to influence health care use. In addition, psycho-

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social characteristics such as quality of life,[8,9,11,12] depression,[9,13] and lack of social support[14] were also shown to be important predictors. The number of physician visits and hospitalizations of chronically ill patients does not seem to be influenced by sociodemographic characteristics such as age,[11] gender,[10,11,13,15] living situation,[9] education,[10,11,13] or insurance.[10,13,15]

Few studies have examined the influence of these characteristics on nonmedical health care services.[16] The use of these services may be equally determined by disease-related and psychosocial characteristics, but may also be influenced by factors such as income and insurance.

Earlier studies have focused on associations between characteristics measured at the same time. There is no insight into the effects of these factors in the long term. Disease-related and psychosocial characteristics might predict future health care use, but so far longitudinal studies among patients with PD have not been performed.

The objective of this study is to identify factors that influence health care use in patients with PD. We examine which prior and concurrent sociodemographic, disease-related, and psychosocial characteristics are associated with medical and nonmedical health care use.

METHODS

Patient Recruitment

In November 1994, we sent self-report questionnaires to members of the Dutch Parkinson's Disease Society. The society has approximately 4200 members, including patients with PD, relatives, and professionals such as neurologists and physiotherapists. From the organization's mailing list, we identified 529 members by systematic sampling of zip codes (every eighth member on the list). In all, 450 questionnaires were returned (85% of 529) of which 384 (73% of 529) were completed. Sixty-six questionnaires (12% of 529) were not completed because the patient had died or the member was either a relative or a professional.

In November 1995, we conducted a repeated measurement with 298 patients. The addresses of 86 patients could not be traced because of privacy regulations. Questionnaires of 235 patients with PD were returned at follow up (79% of 298). Seventeen patients (6% of 298) had died. The patients lost to follow up were older, had been ill for a longer period of time, had higher disease severity scores and a worse quality of life, but gender distributions were found to be comparable.

Data is presented of the 235 patients who completed the questionnaire both times. Prior assessment refers to the data obtained in 1994. Concurrent characteristics were assessed in 1995.

The study design was approved by the ethics committee and all patients provided written informed consent before participation.

Measurements

All characteristics were measured by self-report questionnaires.

Medical health care use was measured by the number of visits to the neurologist and to the GP in the preceding 6 months, because this period is usually short enough to be adequately remembered. *Nonmedical health care use* was measured by use of a physiotherapist (including Caesar and Mensendieck therapist), a psychotherapist, or a home care nurse. Nonmedical health care use was measured dichotomously (yes or no).

Sociodemographic characteristics included gender, age, education (1 = primary school to 7 = university), insurance (private or national), and living situation (alone or with others).

Disease-related characteristics included: (1) disease duration (years since diagnosis); (2) comorbidity, measured using a standard list provided by the Dutch Central Bureau of Statistics[17]; (3) disease severity measured by the Schwab and England Activities of Daily living Scale (0–100%)[18]; and the Hoehn and Yahr Scale (five categories).[19] For the Schwab and England scale, lower scores indicate worse disease severity. For the Hoehn and Yahr scale, higher scores indicate worse disease severity. Psychosocial characteristics included quality of life, depression, and social support. Quality of life was assessed with the Parkinson's Disease Quality of Life Questionnaire (PDQL) which consists of 37 items. These items are combined to form four subscales: Parkinson-related symptoms and functioning (for example, stiffness, shaking; 14 items), systemic symptoms (for example, fatigue, obstipation; seven items), emotional functioning (for example, difficulty accepting illness, feeling embarrassed; nine items), and social functioning (for example, need to cancel social activities; seven items). The items are scored on five-point Likert scales. The PDQL has established levels of reliability and validity.[20] Scores range from 37–185 and higher scores indicate better quality of life. Depression was assessed by the Center for Epidemiologic Studies Depression scale (CES-D).[21] The scale includes 20 items and was found to be reliable and valid.[22] Scores range from 0–60, while the cut-off score for depression is 16. Higher scores indicate more depressive symptoms. Social support was measured with the MOS Social Support Survey (20 items), which yields adequate levels of reliability and validity.[23] Scores range from 20–80 and higher scores indicate more social support.

TABLE 1. *Disease-related and psychosocial characteristics of 235 cases*

	Prior* (mean [SD])	Concurrent (mean [SD])
Disease-related characteristics (range)		
Disease duration (2–43)	7.8 (6.5)	8.8 (6.6)
Hoehn (1–5)	2.8 (0.9)	2.9 (0.9)
Schwab (0–100)	72 (18)	68 (20)
Comorbidity (No., %)	117 (50)	105 (45)
Psychosocial characteristics (range)		
Quality of life: PDQL		
Parkinson symptoms (14–70)	45.6 (9.7)	43.8 (10.2)
Systemic symptoms (7–35)	23.7 (5.7)	23.2 (5.8)
Emotional functioning (9–45)	32.8 (7.0)	31.8 (7.3)
Social functioning (7–35)	25.0 (6.5)	24.0 (6.4)
Total score (37–185)	127.1 (24.3)	122.8 (25.2)
Depression (0–60)	16.5 (9.5)	17.4 (9.4)
Social support (20–100)	70.8 (19.8)	69.0 (20.2)

PDQL, Parkinson's Disease Quality of Life questionnaire.

SD, standard deviation; higher scores denote higher quality of life, more depression, or more social support.

* 1 year before assessment of health care utilization.

ANALYSIS

All data were checked for accuracy and analyzed using the Statistical Package for the Social Sciences (SPSSPC, 5.0, SPSS Inc., Chicago, IL, U.S.A.).[24] Quality of life, psychosocial, and health care use data were checked for violations of normality assumptions. Results of the Kolmogorov-Smirnov test for normality and inspection of the normality plots indicated normality within an acceptable range for the quality of life and psychosocial characteristics, but the health care use data were skewed toward low use. Correlations were calculated to examine the relationships between medical and nonmedical health care use measures and both prior and concurrent sociodemographic, disease-related, and psychosocial characteristics.

Because the health care use data were not normally distributed, we used Spearman correlation coefficients. The significance level was set at $p < 0.01$ because of the large number of tests performed. Following the recommendations of Cohen, correlations will be considered low ($r < 0.20$), moderate ($0.20 < r < 0.50$), or high ($r > 0.50$).[25]

The effects of patient characteristics on health care use were additionally analyzed with multivariate analysis, because it was expected that sociodemographic, disease-related, and psychosocial characteristics were interrelated. Stepwise multiple regression and logistic regression were performed to determine the best predictors of medical and nonmedical health care use, respectively. Based on earlier studies,[8,13] variance explained will be considered low if less than 10%, moderate if 10–30%, or high if more than 30%.

RESULTS

Patient Characteristics and Health Care Use Rates

Women comprised 46% of the sample. The mean age of the patients in the study was 67 years (range, 30–86 yrs). All patients indicated that their diagnosis of PD was confirmed by a neurologist. Eighty percent of the patients were living with others, whereas 20% was living alone at home. Forty-three percent had private health insurance. Prior and concurrent disease-related and psychosocial characteristics are reported in Table 1.

The average disease duration was 8 years (range, 1–42 yrs). Average disease severity on both measurements was approximately 3 on the Hoehn and Yahr and approximately 70 on the Schwab and England scale, indicating moderate impairment. Comorbidity was present in 50% of the patients at the first survey and 45% of the patients at the second survey, mainly because of chronic back problems (12% of all patients in both years), rheumatoid arthritis (7% prior and 10% concurrent), asthma (3% and 4%), and cancer (3% and 4%). Quality of life as measured by the PDQL had a mean score of 127 at the prior measurement and 123 at the concurrent measurement, indicating mild impairment in quality of life on average. Mean depression scores were 16.5 on the first measurement and 17.4 on the second, which are both above the cut-off score for depression.

The number of visits patients with PD paid to their neurologists and GPs is represented in Figure 1.

The figure shows that most patients (132) did not visit their GP in the past 6 months. Some paid one (33 patients) or two (39 patients) visits to their GPs. A different pattern is shown for visits to the neurologist. Most patients (96) paid two visits to their neurologist, whereas some paid one visit (66 patients) or three visits (26 patients). The average medical and nonmedical care use is shown in Table 2.

The average number of visits to the neurologist in the past 6 months was 1.9 (range, 0–13) and the average number of GP visits was 1.1 (range, 0–15). Many patients used physiotherapy (48%) and home care (20%). Only a small percentage of patients visited a psychotherapist (8%).

Explaining Medical Health Care Use

Table 3 shows matrices of correlations between medical care use and prior as well as concurrent sociodemographic, disease-related, and psychosocial characteristics.

The significant correlations between medical care use and predictor factors were of low to moderate magnitude. Patients with private health insurance and patients who were living with others were more likely to visit their

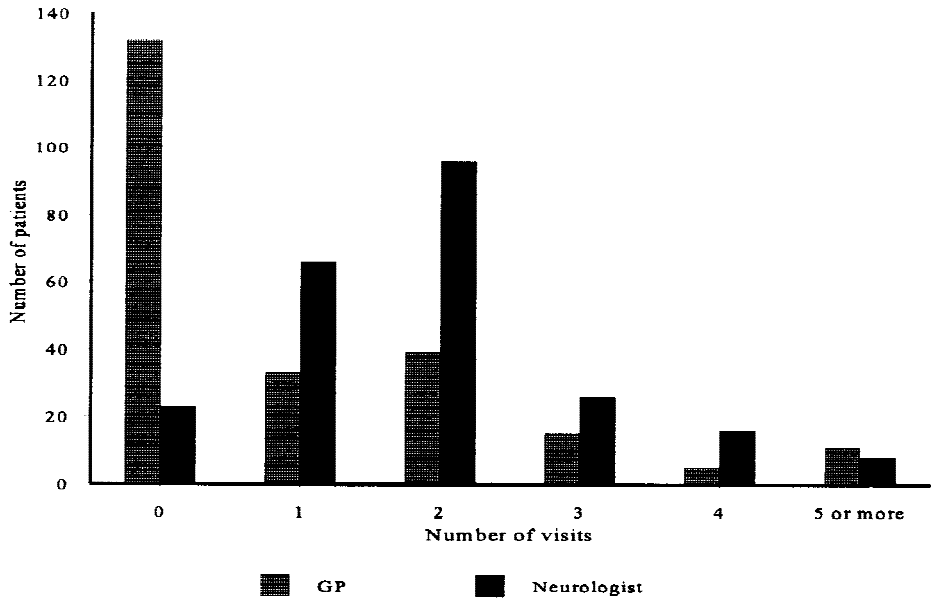

FIG. 1. Visits to the neurologist and GP in six months.

neurologists. The number of visits to the GP was associated with disease severity as measured by the Schwab scale, with poor quality of life scores on all PDQL scales, and with depression. Age, gender, education, comorbidity, disease duration, and social support were not correlated with physician visits.

Almost no significant associations between prior characteristics and subsequent medical care was found, only prior private health insurance explained neurologist visits, and prior Parkinson symptoms explained GP visits.

To determine the best prediction of medical health care use, multiple regression was performed. Results are summarized in Table 4.

For both the neurologist and GP visits, the prior characteristics explained 4% of the observed variance of use data whereas the concurrent predictors explained 7%. Regarding neurologist visits, a significant contribution was found for having private health insurance, living with others, and concurrent poor social functioning. The best predictors for GP visits in the multivariate model were both prior and concurrent poor quality of life.

Explaining Nonmedical Health Care Use

Matrices of correlations between nonmedical health care use and prior and concurrent sociodemographic, disease-related, and psychosocial characteristics are reported in Table 5.

The significant correlations between the predictor characteristics and nonmedical care use proved to be low to moderate. Sociodemographic characteristics were not significantly associated with physiotherapy or psychotherapy. However, older patients, women, and patients living alone tended to receive more help from a home care nurse. Prior and concurrent disease severity and concurrent disease duration showed moderate correlations with both physiotherapy and home care help, whereas disease duration was only significantly associated with receiving home care. Concurrent comorbidity was correlated with receiving psychotherapy. Psychosocial characteristics, such as prior and concurrent poor quality of life, lack of social support, and depression were related to receiving psychotherapy. Poor quality of life was also correlated with physiotherapy and home care, whereas lack of social support was weakly associated with receiving home care.

The effects of patient characteristics on nonmedical health care use were additionally analyzed with logistic regression. These results are presented in Table 6.

For physiotherapy use, the significant predictors were both prior and concurrent disease severity as indicated by Schwab scores and concurrent Parkinson symptoms as

TABLE 2. *Medical and non-medical care use in past 6 months*

Utilization measure	No. of visits (SD)
Medical care use	
Neurologist	1.9 (1.4)
General practitioner	1.1 (1.7)
	No. of patients (%)
Non-medical care use	
Physiotherapist	112 (48%)
Psychotherapist	18 (8%)
Home care nurse	48 (20%)

TABLE 3. *Medical health care use: prior and concurrent predictors*

Predictors	Neurologist		General practitioner	
	Prior	Concurrent	Prior	Concurrent
Sociodemographic				
Age	—	—	—	—
Gender (Female)	—	—	—	—
Insurance (private)	0.17*	0.17*	—	—
Education	—	—	—	—
Living with others	—	0.17*	—	—
Disease-related				
Comorbidity	—	—	—	—
Disease severity (Schwab)	—	—	—	−0.21*
Disease severity (Hoehn)	—	—	—	—
Disease duration	—	—	—	—
Psychosocial				
Quality of life: PDQL				
PDQL-total	—	—	—	−0.21*
Parkinson symptoms	—	—	−0.17*	−0.17*
Systemic symptoms	—	—	—	−0.23†
Emotional functioning	—	—	—	−0.23†
Social functioning	—	—	—	−0.17*
Social support	—	—	—	—
Depression CES-D	—	—	—	0.22*

PDQL, Parkinson's Disease Quality of Life questionnaire; CES-D, Center for Epidemiologic Studies Depression Scale.
Spearman correlation coefficients; *<0.01; †<0.001.

measured by the PDQL. For psychotherapy, best prediction was achieved by prior systemic symptoms and lack of social support and by concurrent comorbidity, Parkinson symptoms, and lack of social support. Best prediction of use of home care help included age, prior disease severity, and prior lack of social support, as well as concurrent disease severity, disease duration, and having private health insurance.

DISCUSSION

The objective of this study was to identify factors that influence medical and nonmedical health care use in patients with Parkinson's disease. With regard to medical care use, some surprising results were found. The number of visits paid to a neurologist appeared not to be influenced by disease severity or quality of life as experienced by the patient. Instead, neurologist visits proved only to be influenced by sociodemographic characteristics: patients with private health insurance and patients who were living with others paid more visits to a neurologist than patients with national health insurance and patients living alone. On the other hand, visits to the GP did correlate with disease severity and psychosocial factors: more visits were paid by patients with higher Schwab scores, poorer quality of life as measured by the PDQL, and higher depression. These findings were confirmed by the results of the multivariate regression analyses. It is possible that these findings are evoked by the differences in the invitation of check-up or follow-up visits. In The Netherlands, most neurologist visits are scheduled by the neurologist as check-up visits at regular intervals. Only a minor proportion of the visits is

TABLE 4. *Prior and concurrent characteristics predicting visits to the neurologist and general practitioner (GP): regression analysis*

Prior predictors	Beta	R^2	Concurrent predictors	Beta	R^2
Neurologist visits			Neurologist visits		
Private insurance	0.14*	0.02	Living with others	0.15*	0.03
Living with others	0.13*	0.04	PDQL-social functioning	−0.15*	0.05
			Private insurance	0.15*	0.07
GP visits			GP visits		
PDQL-total	−0.19†	0.04	PDQL-total	−0.27‡	0.07

PDQL, Parkinson's Disease Quality of Life questionnaire.
Beta, standardized regression coefficient; R^2: cumulative variance explained.
* p >0.05; †p <0.01; ‡p <0.001; only significant coefficients are reported.

TABLE 5. *Non-medical health care use and prior as well as concurrent predictors*

	Physiotherapist		Psychotherapist		Home care	
	Prior	Concurrent	Prior	Concurrent	Prior	Concurrent
Sociodemographic						
Age	—	—	—	—	0.24†	0.21*
Gender (female)	—	—	—	—	0.20*	0.21*
Insurance (private)	—	—	—	—	—	—
Education	—	—	—	—	—	—
Living alone	—	—	—	—	0.19*	0.24†
Disease-related						
Comorbidity	—	—	—	0.17*	—	—
Disease severity (Schwab)	−0.25†	−0.27†	—	—	−0.21*	−0.29†
Disease severity (Hoehn)	0.21*	0.25†	—	—	0.25†	0.30†
Disease duration	—	—	—	—	0.23†	0.23†
Psychosocial						
Quality of life:						
PDQL-total	−0.17*	−0.23†	−0.20*	−0.17*	—	−0.19*
Parkinson symptoms	—	−0.26†	−0.19*	—	—	—
Systemic symptoms	−0.19*	−0.17*	−0.20*	−0.19*	—	—
Emotional functioning	—	—	−0.17*	−0.17*	—	—
Social functioning	—	—	—	—	—	—
Social support	—	—	−0.17*	−0.24†	—	−0.17*
Depression CES-D	—	—	0.17*	0.21*	—	—

PDQL, Parkinson's Disease Quality of Life questionnaire; CES-D, Center for Epidemiologic Studies Depression Scale.
Spearman correlation coefficients; *<0.01; †<0.001.

planned at the patient's request in between the regular check-ups, for example, because of worsening of symptoms. Patients who initiate the visits themselves may be the ones who have private insurance or who live with others. The patients who have private health insurance might be more assertive in convincing the GP that they should be directed to a specialist. Furthermore, it might be that the patient's partner or other relatives notice disease progression well before the patient does and may encourage the patient to make an appointment. Thus, patients living with others might be more likely to pay a visit to their neurologist than patients who live alone.

An earlier study by Rybicki et al. found that patients with suspected PD who were referred to a neurologist were more likely to have private health insurance and to be married than patients who were not referred.[3] The present study showed that the insurance type and living situation do not only affect the first referral to a neurologist, but also the subsequent number of visits.

In contrast to what was found in the literature on other chronic diseases, predictor characteristics such as age, disease duration, disease severity, quality of life, and depression were not found to be associated with neurologist visits in our patients with PD. One possible explanation for this is that those diseases described in the literature were chronic diseases with acute episodes, such as inflammatory bowel disease,[8] HIV infection,[10] or respiratory episodes in chronic obstructive pulmonary disease.[9,11] Because PD is a slow progressive disease, visits to a specialist could be more rigidly scheduled. The results of an earlier study by Mercer[26] illustrate the possibility of rigidly scheduled check-up visits, which are not affected by interventions. In this study, a health management program (Propath) did assist patients with PD to deal with the psychologic aspects of their disease, and it

TABLE 6. *Prior and concurrent characteristics predicting non-medical care: logistic regression analysis*

Non-medical care	Prior predictors	B	Concurrent predictors	B
Physiotherapist	Disease severity (Schwab score)	.27†	Disease severity (Schwab score)	.18‡
			Parkinson symptoms	.03*
Psychotherapy	Systemic symptoms	−.12‡	Comorbidity	.58‡
	Social support	−.03*	Parkinson symptoms	.07*
			Social support	−.05*
Home care	Age	.07†	Disease severity (Schwab score)	.25‡
	Disease severity (Hoehn score)	.65†	Disease duration	.08‡
	Social support	−.02*	Private health insurance	1.07‡

B: regression coefficient; *p <0.05; †p <0.001; ‡p <0.01; only significant coefficients are reported.

improved their overall quality of life, but the program had no significant effect on the number of telephone encounters or visits the patients with PD paid to their neurologists.

Conversely, GP visits are usually initiated by the patient. This might explain why the number of GP visits is better predicted by patient characteristics such as disease severity, quality of life, and depression. Therefore, the explanation for the difference in predictors for the number of neurologist visits and GP visits might be the difference between physician-initiated and patient-initiated check-up visits. However, we could not test this hypothesis, because we lacked the information relating to whether neurologist and GP visits were patient- or physician-initiated. Further research is needed to test this hypothesis.

Another explanation could be that those patients lost to follow up would have been the ones with the most neurologist visits. Because the patients lost to follow up were older, had been ill longer, had higher disease severity scores, and had poorer quality of life, they might have been the ones with the highest use rates. Thus, because we were not able to capture the entire range and variety in patients' quality of life and health care use, we might have underestimated both the use rates and the relationship between predictor characteristics and health care use.

On average, patients with PD paid 1.9 visits to their neurologist and 1.1 visits to their GP over 6 months. This number is lower than was reported in earlier American studies.[3,26] It is possible that patients in the United States have generally higher use rates than Dutch patients, because the groups were similar with regard to gender, age, and disease severity. Almost half of the patients used physiotherapy, whereas 20% received help from a home care nurse. Relatively few patients (8%) visited a psychotherapist, although CES-D depression scores were high compared with the general population.[21] Furthermore, the average depression score was above the cut-off limit, so we expected psychotherapy rates to be higher. On the other hand, the patients with PD in our study were 69 years old on average, and members of this generation might be less accustomed to seeking psychotherapy than younger patients.

More significant correlations were found for nonmedical health care use than for medical care use. Again, this could result from the patient initiating this type of care. Use of physiotherapy was mainly explained by measures of physical functioning: the service was primarily used by patients with higher disease severity and more Parkinson and systemic symptoms. As expected, depressed patients with lack of social support and poor quality of life tended to receive more psychotherapy. Older patients, women, patients living alone, or those with more advanced disease stages were more likely to receive home care. These factors were stable: correlations between nonmedical care use and either prior or present factors were similar, thus reflecting the chronic nature of PD.

Some limitations of the present study merit consideration. First, the patients surveyed were members of the Dutch Parkinson's Disease Society. This may have introduced selection bias. It could be that such members are more assertive or more sociable than nonmembers. For this reason, it is difficult to determine the extent to which these results are generalizable to the entire patient population with PD. However, sociodemographic characteristics of this patient sample, such as age and gender distribution, were comparable to the European epidemiology figures,[1] only the average age of onset (59 years) might be young. This could be the result of the fact that younger people are more likely to become members of a patient society than older people. Second, all patients indicated that their diagnosis of PD was confirmed by a neurologist. Because those data were generated from self-report questionnaires, diagnostic errors might have occurred. Therefore, we cannot rule out the possibility of the inclusion of parkinsonism and other non-PD diagnoses. Moreover, even for neurologists, it may be an uneasy task to assign an accurate grade of disease to a specific patient. Therefore, the self-assessment of disease stage could also be affecting the data.

Third, a potential source of bias is recall bias. Health care use was reported by the patients and not measured by automated data. Consequently, inaccurate recollection of the amount of care that was received in relation to PD might have occurred. The extent of this recall bias is unknown, although we assume that the period of 6 months is short enough to be adequately remembered by the patients.

We conclude that the number of visits to a neurologist by patients with PD is not associated with the majority of patient-related characteristics. On the other hand, the number of visits to a GP is associated with disease severity, quality of life, and depression. Our results imply that to give more effective care to patients with PD, neurologists might have to reconsider their check-up schemes by making it more flexible and tailored to the patients' individual needs. In scheduling check-up appointments, more emphasis could be put on the health status and living situation of the patients. Special attention is required for patients with poor quality of life and patients who live alone, because they might need more check-ups. At the same time, patients with better quality

of life and lower disease severity may require less visits to their neurologists. Special "Parkinson nurses" have been introduced in the health care system in Britain to visit patients at their homes and coordinate their care.[27] These nurses could play an important role in the allocation of care of patients with PD. Future research is needed to evaluate the effects of patient-, physician-, or nurse-initiated visits on both patients and the health care system.

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