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Investigation of the Treatment and Living Assistance Needed by Patients with Young-Onset Parkinson's Disease

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Purpose: This study assessed the symptoms, treatment, social systems use, and perception of living conditions of patients with young-onset Parkinson's disease (YOPD), and investigated the support needed by them. Method: Among the 252 people who completed our questionnaire, we defined YOPD patients as those diagnosed as young onset or those with onset at ≤40 years. The data were compared with others. Results: There were 24 patients with YOPD (9.5%) (average age: 61.7 years), with an average disease duration 6.4 years longer ($p < 0.01$) and time until diagnosis 0.7 years longer ($p < 0.1$) than those of other patients. This group took 1.6 times more types of medicines, and time to their next appointment was 8.6 days shorter than that of other patients ($p < 0.05$). Patients with YOPD had more pulsive walking and more sweating ($p < 0.05$), and more motor fluctuation ($p < 0.1$). More patients with YOPD had a physical disability certificate but felt they were not obtaining the required services ($p < 0.05$). 45.0% of the YOPD group wanted to work more, more used information and communication equipment ($p < 0.05$), and more felt their medications were adequate ($p < 0.1$). Conclusions: Increased awareness of YOPD is needed. YOPD patients have motor fluctuation because of the longer disease duration. Thus, the support of doctors and nurses, and frequent examination visits, are indispensable for controlling symptoms to achieve middle age developmental tasks. Increased support for care-giving, leisure-time activities, and work is also necessary and may help maintain the desire to work in this group.

INTRODUCTION

Parkinson's disease (PD) is often unpredictable, and usually starts after 60 years of age; however, it is known that in 5–10% of cases it starts during youth (6). PD is partially familial, and the elucidation of genetic abnormalities in the various PARK gene loci is improving (15). There is no accepted definition for age, but often "young onset PD" (YOPD) means onset at ages 21–40, while onset before age 21 is called "juvenile Parkinsonism" (7; 10). In recent clinical studies there has been little differentiation of YOPD from other forms of PD, but it is known that, compared to other patients with PD, patients with YOPD have a longer disease duration, experience muscular stiffness and walking difficulty more often, and levodopa (L-dopa) has a higher efficacy in this group, although with an increase in dyskinesia, while there is less occurrence of dementia (3; 5; 10). It has also been found that there is a higher rate of loss of work or early retirement when the disease occurs in middle age, and patient's "calmness," as measured by the Parkinson's Disease Questionnaire 39 (PDQ-39), their marriage satisfaction score, and their quality of life is significantly lower than that of patients for whom the occurrence of PD occurred at a more advanced age (13; 14).

The educator Havighurst refers to the ages from 30 to 55 as "middle age," and discusses items such as the establishment and maintenance of an economic standard of living, the development of adult leisure-time activities, relating oneself to one's spouse as a person, and adjusting to aging parents for this period. According to Havighurst, successful achievement of a task leads to happiness and to success with later tasks (4). Patients with YOPD have a disease in which they not only have physical difficulties but also difficulties in achieving developmental tasks, and that may be why their disease interferes with their happiness and lowers their quality of life.

In 2014, laws were established in Japan concerning the medical treatment of patients with intractable diseases. This guarantees opportunities for patients with intractable diseases, such as PD, to participate in society, so that they can maintain respect in society while obtaining assistance in living with others. For patients with intractable diseases, appropriate support to stabilize one's livelihood and to maintain a calm attitude is also indispensable in stabilizing the symptoms of the disease. However, the kind of support needed by young patients

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with intractable diseases is not sufficiently understood, and there has been little research into the living conditions of patients with YOPD in Japan. Therefore, the purpose of this research is to understand the symptoms, treatment, use of social systems, as well as the perception of their actual living conditions in patients with young-onset Parkinson's disease (YOPD), and to investigate the support they need.

METHOD

Study Method

In September 2017, with the co-operation of the Japan Parkinson's Disease Association, we provided a paper questionnaire to 436 members of the Hyogo prefecture branch of the Association. Three months prior to sending the questionnaire we asked for co-operation with the questionnaire through the association's publications, and we sent the questionnaire by mail to the address where the association was registered. The responses were anonymous and multiple-choice, and were answered either by the patients themselves or by co-operating persons who knew the patients well. If the patient consented to co-operate in the research then they responded using the envelope provided. The study was approved by the research ethics committee of Aino University (Aino 2017-007). Of the 259 persons who responded (response rate 59.4%), we used the 252 persons where no information was missing concerning age, sex, severity classification on the Hoehn and Yahr (hereinafter, "Yahr") scale, and age of occurrence (effective response rate 57.8%) for our analysis.

Study Content

The patients were asked questions about their background, such as sex, age, age at diagnosis, number of people they were living with, and Yahr classification, as well as their symptoms, frequency of examination visits, treatment details, number of medications, use of social systems, existence and frequency of rehabilitation and going outside, place of treatment, and also about people providing assistance to them. The patients were also asked about subjective feelings, such as whether their livelihoods were stable and whether the person wanted to work more or wanted to go outside more.

Analysis Method

Among those who returned the questionnaire, we refer to patients with YOPD as those who responded that they were "diagnosed as young onset" or whose disease onset was at an age no greater than 40 years, and we compared them against the patients who did not have YOPD (hereinafter "PD patients"). For age classification we followed the system used by the Japan Intractable Diseases Information Center (9). To analyze background information, such as age, number of years of disease duration, and number of people the patient was living with, we performed a Mann-Whitney U-test. To assess differences in symptoms, treatment, societal services, and subjective feelings we used a Fisher's exact test. For items related to work, we divided the patients into groups based on their desire to work and then performed a Fisher's exact test. We used SPSS Statistics, version 24 (Windows 8.1) for all statistical analyses. We set the statistical significance level to 5%.

RESULTS

Subject Backgrounds

Of the 252 persons who participated in this study, there were 24 patients with YOPD (9.5%). The differences in the backgrounds among the total group of patients, patients with PD, and patients with YOPD are presented in Table I. The average age of the patients with YOPD was 61.7 ± 10.4 years, and the average disease duration was 18.1 ± 7.2 years. Compared to the patients with PD, the average age of patients with YOPD was 11.6 years younger, and the average disease duration was 6.4 years longer, both of which were statistically significantly different ($p < 0.01$). The average age at disease onset was 43.6 ± 10.7 years, which was 16.0 years younger than for other patients with PD patients ($p < 0.01$). The minimum and maximum age of onset for patients with YOPD was 21 and 66 years, respectively. The average number of years until diagnosis was 2.8 ± 4.1 years, which was 0.7 years more than for other patients with PD, and this showed a trend towards significance ($p < 0.1$). The average number of hospitals that the patients with YOPD attended prior to being diagnosed was 0.4 times greater than for other patients with PD. The current Yahr stages of the patients with YOPD averaged 3.4 ± 1.1, which was not significantly different from other patients with PD. There was also no significant difference in the sex ratio between the groups. The patient images for each Yahr stage are presented in Table II, and, in general, for most of the Yahr stages the average age was younger and the average disease duration was longer for patients with YOPD than for other patients with PD.

Status of Symptoms, Treatment, and Examination Visits

The differences in symptoms and the treatments received among all patients, the other group of patients with PD, and patients with YOPD are presented in Table III. The number of people who answered that they had pulsive walking or easy sweating was significantly higher in the YOPD group than in the other group of patients with PD ($p < 0.05$). There was a trend towards significance ($p < 0.1$) for people to answer that they had more difficulty speaking, a mask-like expression, a decrease in sexual desire, and motor fluctuation in the YOPD group. The percentage of people who said they had tremors or dementia was larger and the percentage who said they salivated was fewer in the YOPD group than in the other group of patients with PD.

Table Ⅰ. Respondent Characteristics N＝252

	total		PD		YOPD		p	
	N	breakdown, %	n	breakdown, %	n	breakdown, %		
total	252		228	(90.5%)	24	(9.5%)		
male		118 (46.8%)		105 (46.1%)		13 (54.2%)	0.521	(ⅰ)
female		134 (53.2%)		123 (53.9%)		11 (45.8%)		
Patient Responded on Their Own	243	175 (72.0%)	219	158 (72.1%)	24	17 (70.8%)	1.000	(ⅰ)
	N	(average±SD)	n	(average±SD)	n	(average±SD)		
age	252	72.2±7.9	228	73.3±6.7	24	61.7±10.4	0.000 **	(ⅱ)
male	118	71.9±8.1	105	73.1±6.7	13	61.9±11.4		
female	134	72.4±7.7	123	73.4±6.7	11	61.6±9.5		
Age of onset	252	59.9±10.6	228	61.6±9.0	24	43.6±10.8	0.000 **	(ⅱ)
Disease Duration (Years)	252	12.3±7.5	228	11.7±7.3	24	18.1±7.2	0.000 **	(ⅱ)
Age at Diagnosis	250	61.7±9.9	227	63.2±8.5	23	47.0±11.4	0.000 **	(ⅱ)
Years until Diagnosis	239	2.1±4.7	216	2.1±4.7	23	2.8±4.1	0.073 †	(ⅱ)
Number of Hospitals Visited until Diagnosis	245	2.2±1.7	224	2.2±1.7	21	2.6±1.3	0.362	(ⅲ)
Hoehn&Yahr Stage	252	3.21±1.0	228	3.19±1.0	24	3.38±1.1	0.473	(ⅱ)
		(breakdown, %)		(breakdown, %)		(breakdown, %)		
stage1		17 (6.7%)		16 (7.0%)		1 (4.2%)		
stage2		34 (13.5%)		31 (13.6%)		3 (12.5%)		
stage3		106 (42.1%)		96 (42.1%)		10 (41.7%)		
stage4		69 (27.4%)		63 (27.6%)		6 (25.0%)		
stage5		26 (10.3%)		22 (9.6%)		4 (16.7%)		
Required Caregiving Degree (※)	247	1.6±1.6	223	1.57±1.6	24	1.65±1.8	0.982	(ⅱ)
Number of People the Patient Lives with	231	2.4±1.1	210	2.3±1.1	21	2.8±1.3	0.082 †	(ⅱ)
Number of Types of Medicines (for PD)	238	4.2±2.3	216	4.1±2.1	22	5.8±3.6	0.034 *	(ⅱ)
Number of Days to Next Appointment	239	47.9±23.5	217	48.8±23.1	22	39.3±25.6	0.030 *	(ⅱ)

(ⅰ) Fisher exact test（every side） (ⅱ) Mann-WhitneyU test *p＜0.05、**p＜0.01、†p＜0.1

(※) Calculated Nursing Care Level: 0 = No Long-term Care Insurance, 0.3 = Need for Support Type 1, and 0.6 = Need for Support Type 2

Table Ⅱ. Patient Image for Each Hoehn & Yahr Stage N=252

		Yahr stage 1		Yahr stage 2		Yahr stage 3		Yahr stage 4		Yahr stage 5	
		n	average±SD	n	average±SD	n	average±SD	n	average±SD	n	average±SD
age	PD	16	71.5±4.9	31	70.5±6.3	96	72.4±6.6	63	74.5±6.0	22	78.9±6.9
	YOPD	1	81.0±0.0	3	63.0±7.9	10	61.9±10.6	6	59.0±10.5	4	59.5±10.7
Disease Duration (Years)	PD	16	6.0±3.3	31	7.7±4.4	93	11.1±6.0	62	15.5±11.6	22	19.1±13.8
	YOPD	1	16.0±0.0	3	10.3±4.0	10	21.7±8.7	6	19.0±3.9	4	14.3±2.2
Number of Types of Medicines (for PD)	PD	16	2.4±1.1	30	3.1±1.5	90	4.2±1.7	59	4.8±2.5	21	4.0±2.7
	YOPD	1	2.0±0.0	3	7.7±5.0	9	6.0±3.4	5	6.0±4.2	4	4.8±2.8
Number of Days to Next Appointment	PD	16	42.1±14.0	29	55.1±24.7	94	48.6±22.1	61	46.2±24.2	17	55.1±27.3
	YOPD	1	30.0±0.0	3	27.0±5.2	10	40.6±29.7	6	38.0±22.5	2	60.0±42.4
			(breakdown, %)		(breakdown, %)		(breakdown, %)		(breakdown, %)		(breakdown, %)
People with motor fluctuation	PD	16	2 (12.5%)	31	9 (29.0%)	96	43 (44.8%)	63	32 (50.8%)	22	10 (45.5%)
	YOPD	1	0 (0.0%)	3	1 (33.3%)	10	6 (60.0%)	6	5 (83.3%)	4	3 (75.0%)
Off Time Per Day (Only People with motor fluctuation)	PD	5	2.4±0.9	12	3.6±1.4	51	4.1±3.1	39	4.4±3.2	9	5.0±2.4
	YOPD	0	-	2	8.0±2.8	6	3.8±2.0	4	6.3±5.9	1	20.0±0.0

Table Ⅲ. Symptoms and Treatment N=252

	Total			PD			YOPD			p	
	N	breakdown, %		n	breakdown, %		n	breakdown, %			
Main Symptoms;											
Number of Persons Who Said They Had Them											
Tremors	252	139	(55.2%)	228	122	(53.5%)	24	17	(70.8%)	0.132	(i)
Muscle Stiffness and Contraction	252	196	(77.8%)	228	176	(77.2%)	24	20	(83.3%)	0.612	(i)
Posture Maintenance Disability	252	190	(75.4%)	228	172	(75.4%)	24	18	(75.0%)	1.000	(i)
Immobility	252	202	(80.2%)	228	183	(80.3%)	24	19	(79.2%)	1.000	(i)
Frozen Gait	252	184	(73.0%)	228	160	(70.2%)	24	24	(100.0%)	0.236	(i)
Pulsive Walking	252	66	(26.2%)	228	55	(24.1%)	24	11	(45.8%)	0.028 *	(i)
Difficulty Speaking	252	156	(61.9%)	228	137	(60.1%)	24	19	(79.2%)	0.079 †	(i)
Difficulty Swallowing	252	117	(46.4%)	228	105	(46.1%)	24	12	(50.0%)	0.831	(i)
Salivation	252	146	(57.9%)	228	136	(59.6%)	24	10	(41.7%)	0.127	(i)
Constipation	252	171	(67.9%)	228	156	(68.4%)	24	15	(62.5%)	0.646	(i)
Difficulty Urinating	252	80	(31.7%)	228	70	(30.7%)	24	10	(41.7%)	0.356	(i)
Sweating	252	115	(45.6%)	228	99	(43.4%)	24	16	(66.7%)	0.033 *	(i)
Lack of Sweat	252	22	(8.7%)	228	20	(8.8%)	24	2	(8.3%)	1.000	(i)
Hallucinations	252	83	(32.9%)	228	75	(32.9%)	24	8	(33.3%)	1.000	(i)
Mask-Like Expression	252	94	(37.3%)	228	81	(35.5%)	24	13	(54.2%)	0.080 †	(i)
Depression	252	67	(26.6%)	228	58	(25.4%)	24	9	(37.5%)	0.227	(i)
Tiring Easily	252	146	(57.9%)	228	134	(58.8%)	24	12	(50.0%)	0.515	(i)
Enhanced Sexual Desire	252	22	(8.7%)	228	20	(8.8%)	24	2	(8.3%)	1.000	(i)
Reduced Sexual Desire	252	39	(15.5%)	228	32	(14.0%)	24	7	(29.2%)	0.071 †	(i)
Cognitive Symptoms	252	59	(23.4%)	228	50	(21.9%)	24	9	(37.5%)	0.125	(i)
Motor fluctuation	252	111	(44.0%)	228	96	(42.1%)	24	15	(62.5%)	0.082 †	(i)
		average±SD			average±SD			average±SD			
Off Time Per Day※	129	4.4±3.3		116	4.2±2.9		13	6.4±5.5		0.140	(ii)
Number of Years Until Off Appeared※	134	6.8±4.9		119	6.6±4.4		15	8.6±7.8		0.597	(ii)
Treatment:											
People Who Said Yes											
Being Treated with Medicine	252	249	(98.8%)	228	226	(99.1%)	24	23	(95.8%)	0.260	(i)
Had Surgery	252	18	(7.1%)	228	17	(7.5%)	24	1	(4.2%)	1.000	(i)
Getting Rehabilitation	243	181	(74.5%)	222	169	(76.1%)	21	12	(57.1%)	0.068 †	(i)
Doing Well on Medicine	232	144	(62.1%)	210	130	(61.9%)	22	14	(63.6%)	1.000	(i)
Have Adjusted the Medicine Themselves	248	75	(30.2%)	225	67	(29.8%)	23	8	(34.8%)	0.637	(i)

(i) Fisher exact test（every side） (ii) Mann-WhitneyU test *p＜0.05、**p＜0.01、†p＜0.1

※Only Those Who Have Them

With regard to treatment, 95.8% of patients with YOPD took medication, and 4.2% had had surgery. This was not significantly different from other patients with PD. 57.1% of patients with YOPD had received rehabilitation, but the percentage was less than for other patients with PD, and this showed a trend towards significance ($p < 0.1$). The percentage of people who had rehabilitation on their own was low. As shown in Table I, the average number of medicines taken by patients with YOPD was 5.8 ± 3.6, which was 1.7 more than for other patients with PD ($p < 0.05$). The average time to the next examination visit of patients with YOPD was 39.3 ± 25.6 days, which was 8.6 days less than for other patients with PD, and this difference showed a trend towards significance ($p < 0.1$). As shown in Table II, for any severity stage, patients with YOPD had a higher average number of medicines, and the average number of days to the next hospital visit was less than for the other group of patients with PD. The percentage of people with motor fluctuation due to their medicine showed a trend towards being significantly larger ($p < 0.1$), and the average off time per day was longer in this group.

Use of Social Systems, Family Life, and Leisure-Time Activities

The use of social systems and the types of activities for all patients, the other group of patients with PD, and the patients with YOPD are shown in Table IV. 66.7% of the patients with YOPD used long-term care insurance, 86.4% used the intractable disease treatment system (specific disease treatment certificates), and 75.0% had a physical disability certificate. The use of the physical disability certificate was significantly higher in the YOPD group than for other patients with PD ($p < 0.05$). In addition, the percentage that had problems with caregiving was higher in patients with YOPD than for other patients with PD, and the percentage that used long-term care insurance was lower, but the differences were not significant. The percentage of patients with YOPD who felt they received the necessary assistance was 47.1%, significantly lower than the 72.7% observed for other patients with PD ($p < 0.05$). As shown in Table I, the average number of people that the patient was living with was 2.8 ± 1.3, which was 0.5 people more than for other patients with PD, and this showed a trend towards significance ($p < 0.1$). As shown in Table IV, for both patients with YOPD and the other patients with PD the person giving assistance was usually the spouse. There were no significant differences in the percentages of the spouses or the

children (or the children's spouses) providing assistance, but for patients with YOPD the percentage of parents providing assistance was significantly larger ($p < 0.01$). In terms of activities, the percentages of patients with YOPD who said they had a place to exercise, or a place for hobbies, were both less than for other patients with PD. The percentage of patients with YOPD who felt that they wanted to go out more was larger than for the other group of patients with PD. 40.9% of patients with YOPD felt that their livelihoods were stable, which was less than for other patients with PD.

Table Ⅳ. Usage of Social Systems and Livelihood N=252

	Total			PD			YOPD			p	
	N	breakdown, %		n	breakdown, %		n	breakdown, %			
Use: Number of Persons Who Said Yes											
Long-term Care Insurance	246	191	(77.6%)	222	175	(78.8%)	24	16	(66.7%)	0.198	(ⅰ)
Medical Beneficiary Certificate of Intractable Disease	242	203	(83.9%)	220	184	(83.6%)	22	19	(86.4%)	1.000	(ⅰ)
Physical Disability Certificate	248	131	(52.8%)	224	113	(50.4%)	24	18	(75.0%)	0.030 *	(ⅰ)
Internet	242	88	(36.4%)	219	80	(36.5%)	23	8	(34.8%)	1.000	(ⅰ)
Smart Phone	243	62	(25.5%)	220	55	(25.0%)	23	7	(30.4%)	0.616	(ⅰ)
Activities: Persons Who Said Yes											
Problems with Caregiving	204	84	(41.2%)	184	73	(39.7%)	20	11	(55.0%)	0.233	(ⅰ)
Being Treated at Home	226	186	(82.3%)	202	168	(83.2%)	24	18	(75.0%)	0.393	(ⅰ)
Obtaining Required Services	211	149	(70.6%)	194	141	(72.7%)	17	8	(47.1%)	0.048 *	(ⅰ)
Feel That Their Livelihood is Stable	233	129	(55.4%)	211	120	(56.9%)	22	9	(40.9%)	0.179	(ⅰ)
Feel That They Want to Work More	222	50	(22.5%)	202	41	(20.3%)	20	9	(45.0%)	0.021 *	(ⅰ)
Want to Receive Work Services	218	53	(24.3%)	199	44	(22.1%)	19	9	(47.4%)	0.023 *	(ⅰ)
Can Perform Rehabilitation on Their Own	240	189	(78.8%)	220	176	(80.0%)	20	13	(65.0%)	0.150	(ⅰ)
Have a Place to Work	252	18	(7.1%)	228	15	(6.6%)	24	3	(12.5%)	0.393	(ⅰ)
Have a Place to Exercise	252	99	(39.3%)	228	92	(40.4%)	24	7	(29.2%)	0.381	(ⅰ)
Have a Place for Hobbies	252	80	(31.7%)	228	75	(32.9%)	24	5	(20.8%)	0.259	(ⅰ)
Have a Place to Meet People	252	68	(27.0%)	228	62	(27.2%)	24	6	(25.0%)	1.000	(ⅰ)
Have a Place to Be Calm	252	68	(27.0%)	228	60	(26.3%)	24	8	(33.3%)	0.473	(ⅰ)
Have a Place for Consultation	252	69	(27.4%)	228	62	(27.2%)	24	7	(29.2%)	0.813	(ⅰ)
Want to Go Out More	237	165	(69.6%)	217	149	(68.7%)	20	16	(80.0%)	0.446	(ⅰ)
Persons Giving Assistance (Multiple Answers)											(ⅰ)
Spouse	252	174	(69.0%)	228	158	(69.3%)	24	16	(66.7%)	0.818	(ⅰ)
Children and Their Spouses	252	118	(46.8%)	228	107	(46.9%)	24	11	(45.8%)	1.000	(ⅰ)
Parents	252	5	(2.0%)	228	2	(0.9%)	24	3	(12.5%)	0.007 **	(ⅰ)
		average±SD			average±SD			average±SD			
Number of Times Going Out per Week (※)	249	2.9±2.7		226	2.9±2.6		23	3.5±2.9		0.346	(ⅱ)
Number of Days of Rehabilitation per Week (Only Persons Who Do It)	186	4.5±2.5		172	4.5±2.5		14	4.8±2.7		0.825	(ⅱ)

(ⅰ) Fisher exact test (every side) (ⅱ) Mann-WhitneyU test *p＜0.05、**p＜0.01、†p＜0.1

(※)Number of Days Going Out per Week, 7 = "every day," 2.5 = "two or thee times per week," 1 = "once per week," 0 = "almost none"

Factors Related to the Desire to Work

As shown in Table IV, 12.5% of patients with YOPD felt that they had a place to work, which was a larger percentage than for other patients with PD, and 45.0% of patients with YOPD felt that they wanted to work more, which was a significantly larger percentage than for other patients with PD ($p < 0.05$). The results of the comparison of the "desire" group of people, who felt that they wanted to work more, to the "non-desire" group of people who did not feel that way, are shown in Table V. The average ages of the two groups were about the same, but the averages with regard to the number of years of disease duration, the Yahr stage, and the degree of need for caregiving were lower for the "desire" group than for the "non-desire" group. These differences were not significant. The percentage of men in the "desire" group was higher than in the "non-desire" group, but the difference was non-significant. 66.7% of the people in the "desire" group said that they were doing well on their medicine, which was a significantly higher trend than in the "non-desire" group ($p < 0.1$). In addition, the people who answered that they adjusted their medication themselves was significantly higher ($p < 0.05$). The percentage of people who felt that their livelihood was not stable was higher in the "desire" group, and this showed a trend towards significance ($p < 0.1$). In the "desire" group, the average number of days that the patient went outside was higher, and the people who said that they had a place to exercise was higher compared to the "non-desire" group, and these differences showed trends towards significance ($p < 0.05$). Compared to the "non-desire" group, the "desire" group used the internet and smart phones more often, and this was statistically significantly different ($p < 0.05$).

Table Ⅴ. Factors Related to Wanting to Work More N=20

	"Desire" group		"Non-desire" group		p	
	n	average±SD	n	average±SD		
age	11	61.4±11.7	9	61.3±9.1	0.941	(ii)
Disease Duration (Years)	11	20.4±8.7	9	17.3±5.7	0.456	(ii)
Hoehn&YahrStage	11	3.6±1.0	9	3.3±0.7	0.603	(ii)
Number of Times Going Out per Week	11	2.7±2.9	9	4.7±2.8	0.131	(ii)
Number of Days to Next Appointment	9	48.2±29.6	9	27.9±15.8	0.297	(ii)
People Who Said Yes	n	breakdown, %	n	breakdown, %		
Is Male	11	5 (45.5%)	9	6 (66.7%)	0.406	(i)
Doing Well	10	4 (40.0%)	8	7 (87.5%)	0.066 †	(i)
Have Adjusted the Medicine Themselves	10	1 (10.0%)	9	6 (66.7%)	0.020 *	(i)
Feel That Their Livelihood is Stable	10	6 (60.0%)	9	1 (11.1%)	0.057 †	(i)
Have a Place to Work	11	1 (9.1%)	9	1 (11.1%)	1.000	(i)
Have a Place to Exercise	11	1 (9.1%)	9	5 (55.6%)	0.049 *	(i)
Have a Place for Hobbies	11	3 (27.3%)	9	2 (22.2%)	0.854	(i)
Have a Place to Meet People	11	3 (27.3%)	9	3 (33.3%)	1.000	(i)
Have a Place to Be Calm	11	5 (45.5%)	9	1 (11.1%)	0.157	(i)
Have a Place for Consultation	11	4 (36.4%)	9	3 (33.3%)	1.000	(i)
Want to Go Out More	10	8 (80.0%)	8	6 (75.0%)	1.000	(i)
Have an Internet Use	11	1 (9.1%)	9	6 (66.7%)	0.017 *	(i)
Have a Smart Phone Use	11	1 (9.1%)	9	5 (55.6%)	0.049 *	(i)

(i) Fisher exact test (every side) (ii) Mann-WhitneyU test *p＜0.05、**p＜0.01、†p＜0.1

DISCUSSION

Patient Image

The average age of all of the subjects in this study was 72.2 ± 7.9 years (men: 71.9 ± 8.1 years; women: 72.4 ± 7.7 years), which is somewhat older than in Fujimoto's large-scale study of Japan (men: 71.10 ± 8.58 years; women: 70.35 ± 8.66 years). The average disease duration was 11.7 ± 7.3 years, which was longer than in the Fujimoto study (9.31 ± 5.08 years). The patients with YOPD were 9.5% of the total, which was about the same or greater than the numbers in the studies of Yokochi and others (Yokochi, 10.6% (20); Mehanna, age less than 49, 10% (7); Wickremaratchi, age less than 50, 5.4% (19)). The sex ratio agrees with the report by Yokochi, which was the same or had somewhat more men (20). The subjects included in this study are generally believed to match patients both within Japan and elsewhere, but it is possible that the older ages and longer disease durations show regionality for the Hyogo prefecture.

Diagnosis and Treatment

The average age of onset for patients with YOPD in this study was more than 40 years old, but even if they were in their 50s or 60s there were still cases that were diagnosed as young onset; therefore, it appears that YOPD is diagnosed for a wide age range, compared to the common diagnostic criteria. The time until diagnosis of the patients with YOPD was 0.7 years longer than that of the other patients with PD, which is less than that indicated in the report of Rana in which it was 15 months longer (11). However, in our study time was still required until diagnosis, and the number of hospitals visited was greater. It is possible that examination was delayed because the patients were young and busy, or that awareness of YOPD is low, so that time was required until the patient was examined by a specialist. It is possible that, since the start of appropriate treatment and the use of social systems was delayed, physical and psychological difficulties were more likely. In the future, it will be necessary that both doctors and nurses who have the opportunity to witness patient symptoms understand YOPD better in order to aid in early diagnosis, and it will also be necessary to increase the awareness of the disease in general.

There is no previous research showing that the number of medicines taken or the frequency of examination visits were greater for patients with YOPD, but a relationship with a greater disease duration (2) and treatment need was possible to predict. It is necessary to control in detail the symptoms of patients with YOPD, together with their family life and social activities, as described below. Moreover, due to the frequent examination visits there are large burdens of time and expense on these patients. Thus, generous treatment assistance may be needed for this group.

Because only a small number of patients with YOPD underwent rehabilitation, it was thought that there were difficulties in the use of a long-term care insurance system described below and that the need for rehabilitation of patients with YOPD might be different from those of other patients, from the perspective of the developmental task.

Symptoms and Difficulty

According to the review by Marras, adverse prognostic factors of motor decline are the absence of tremors at the time of disease onset and advanced age (8). In addition, in our study patients with YOPD showed slower disease progression. However, at the times when similar severities were reached, the frequency of motor fluctuation and length of off time was larger in the YOPD group, suggesting difficulty with daily activities. This may be related to the disease duration and the length of time on medication (2).

In previous research, it was reported that patients with YOPD had difficulty walking (3), dyskinesis (3; 10), and depression (7) more often compared to other patients with PD, but there are also reports in which there are no such differences (13). The fact that more of the patients with YOPD who were subjects in our study had pulsive walking agrees with studies reporting greater difficulty walking in this group, though on the other hand frozen gait was rare. Cognitive symptoms, which were rare in prior studies (10), or were the same as for other patients with PD (3), had a high frequency of 37.5% in our study, which was a larger percentage than for other patients with PD. Neurological manifestations (hallucinations) were also 33% higher than the 18.4% shown by Taniguchi (18). This may be due to the longer disease duration, though the exact reason is unclear. There are few previous studies on nonmotor symptoms in patients with YOPD, and there was no data regarding sweating that was common in patients with YOPD in this study. In the future, it seems necessary to focus on the effects of such nonmotor symptoms on social life, similar to motor symptoms. This study was performed by using a questionnaire, and the existence of symptoms could have been affected by the subjectivity of the respondents. However, symptoms that are felt strongly by patients are a factor that interferes with the achievement of developmental tasks. Doctors and nurses must provide assistance so that patients can control their symptoms when issues occur in daily life.

Usage of Social Systems, Family, and Leisure Activities

With regard to the use of social systems, PD is a specified disease for the long-term care insurance system, and even type 2 insurance recipients between the ages of 40 to 64 years can receive services. In this study, it is possible that there were several patients with YOPD who had difficulty with caregiving because the services cannot be used by patients with YOPD who are under 40 years of age. In addition, it was thought that a prolonged duration of disease might result in a feeling of burden. Conversely, although there was a high percentage of those with a physical disability certificate in the study, the majority of patients with YOPD did not feel that they were receiving the services they needed, suggesting that the required support is both large and wide ranging. This study suggests that support is needed for patients with regard to family life, leisure-time activities, and work.

With regard to family life, based on the percentage of patients who have people who can help them and based on the number of people the patients live with, patients with YOPD are able to raise families in the same way as other patients with PD, but often the children are not independent or they live with their parents. It is easy for patients with YOPD to get assistance from those nearby, but when one is helped by one's parents it is difficult to achieve the developmental task of adjusting to aging parents. Also, as time goes by, children who were providing become independent, and parents age. There may be cases where the caregiver system needs to be recreated. With regard to the relationship with one's spouse, if one is receiving care from an early stage of the relationship then it is difficult to build an equal relationship, or it may be difficult to build intimacy due to a loss of sexual desire. The onset of the disease in middle age can lead to the loss of, or changes in, family roles (16; 17). It may be difficult to achieve the developmental task of relating oneself to one's spouse as a person (4), so it is necessary for medical teams to understand this and provide support.

With regard to leisure activities, it was indicated that patients with YOPD cannot maintain exercise or hobbies, and there are few contacts with organizations for the purpose of pleasure. When one has a disease from a young age it becomes difficult to build relationships with others, and one may lose the desire for leisure-time activities. It is possible that rehabilitation is often not performed due to issues with caregiver insurance, but the number of patients with YOPD who engage in rehabilitation on their own is also small. Havighurst indicates that adult leisure-time activities can be developed into central sources of interest and pleasure over the years to come (4). According to Tanigaki, patients with PD with a high quality of life score had more experience with social activities and leisure-time activities before the onset of the disease than did those with a low score, and they also acquired more information about hobbies, shopping, and travel (17). It has been indicated that patients with PD are introverted, but in our study the number of patients with YOPD who wanted to go out more was as high as

80.0%. As patients age, leisure-time activities are important, and assistance becomes necessary, not just for getting places and going out, but also to promote the desire for leisure-time activities and for accessing information, such as with information and communication equipment.

Factors Related to the Desire for Work, and Work Assistance

Among the patients with YOPD, 45.0% felt that they wanted to work more, which was significantly higher than for other patients with PD, and it is believed that early work assistance is necessary. 88.8% of the patients with YOPD who want to work more felt that their livelihoods were not stable, suggesting that one reason for working more is economic. According to Havighurst, during middle age, the developmental task of a person is to establish economic security for his family ahead of his desire to speculate and venture (4). It is necessary to provide substantial support, such as for the family's living expenses and educational expenses, and it is also believed that work is related to one's place in society. Among those patients who wanted to work more, few answered that they were able to relax, and that probably means that they are looking for a role and comfort in their workplace.

According to Fujii, patients with PD have a tendency for a low self-efficacy evaluation, but the evaluation is higher for those who try to understand the disease and feel that they can cope with it (1). From our study, we believe that among patients with YOPD, those who feel they want to work more also feel they are doing well on their medications and are active with regard to exercise and in collecting information by using information and communication equipment, and therefore have high self-efficacy. There is a risk when one adjusts one's own medications, but this is considered a sign of self-efficacy, i.e., that one is best at understanding one's own disease symptoms and managing them on one's own.

For patients with YOPD, the high rates of motor fluctuation, difficulty speaking, and mask-like expression could make it difficult to communicate with those around them and to be understood. Since patients engage in social activities while living with these symptoms, they can easily have difficulties in such activities. However, through better symptom control, by maintaining regular hospital visits even while working, and through the adjustment of environments, so that, as necessary, the workplace co-operates with their treatment and the surroundings assist with their symptoms, and also through improved social awareness of the disease, patients will be able to compensate for their difficulties and improve their self-efficacy. In order to improve the desire to work in patients it would be effective to support access to information and communication equipment. The long disease duration of a patient with YOPD may be an advantage in finding employment.

Limitations of This Research

This study was conducted on a limited number of patients in one location in the Hyogo prefecture. Examination visits, caregiving, family relationships, leisure time, and work activities are all affected by the residential location. More investigation is needed before generalizing the results of this study.

CONCLUSIONS

The patients with YOPD required on average 0.7 years more to be diagnosed than other patients with PD. Therefore, the awareness of treatment providers and social awareness need to be improved. With regard to symptoms, motor fluctuation in the symptoms can easily be caused by the disease duration as well as the duration of time taking medicines and the large quantity of medicines. Doctors and nurses must provide sufficient support by considering the developmental tasks of people of middle age, and it is believed that an environment is needed for receiving comfortable treatment, including examination visit time, methods, and expenses.

Many of the patients with YOPD had physical disability certificates, but the majority felt that support for life activities was insufficient. In particular, with regard to long-term care, it is necessary to establish a system that can provide equivalent long-term care services in some way, even for those under 40 years of age.

This research has highlighted the fact that there are problems with leisure-time activities and work for patients with YOPD. For leisure-time activities, patients need substantial support, such as for getting places and for ensuring the existence of places for exercise and hobbies. For work, it is necessary for patients to have better control of symptoms with their medication and to have an understanding of their environment in order to make it possible for them to continue working.

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