

ORIGINAL ARTICLE

PROBLEMS WITH DAILY LIVING AND PERFORMING HOME EXERCISE IN JAPANESE HOME-CARE PATIENTS WITH PARKINSON'S DISEASE

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Abstract Background/Aims: We investigated the relationship between problems in daily living such as falls and the practice of home exercises in patients with Parkinson's disease (PD) in Japan, to show the requirements for their effective and sustainable home exercises.

Methods: An anonymous questionnaire was sent by mail to 159 PD patients who were members of the Miyagi Prefecture Branch of the Japan Parkinson's Disease Association. The questionnaire included questions on PD symptoms, chief complaints, history of falls, use of the nursing care insurance program, and performance of exercise therapy.

Findings: The questionnaire response rate was 62.3%. Falls had been experienced by 38 subjects (44.2%) during the month before the survey and by 52 (60.5%) during the 6 months before the survey. More than half (52.3%) of subjects had never undergone exercise therapy at a medical institution, and those who continued to undergo exercise therapy accounted for only 12.8% of all subjects. Thirty-three subjects (38.4%) did not undergo exercise therapy on a regular basis in any setting.

Conclusion: To prevent a decrease in activity due to disuse muscular atrophy, it is important to establish more effective home exercises for home-care PD patients so that they can do these exercises on a regular basis.

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Key words: exercise therapy; home care; Parkinson's disease; questionnaire survey by mail.

原 著

在宅パーキンソン病患者の日常生活の課題とホームエクササイズの実施状況

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抄録 背景・目的：在宅パーキンソン病患者(PD)の生活場面における転倒などの問題と、効果的で持続可能な家庭での運動療法の実施状況について調査を行った。

方法：全国PD友の会宮城県支部会員159名に対し、症状や日常動作における主訴、転倒歴、介護保険の利用状況、運動療法の実施状況などの無記名式アンケート調査を郵送法で行った。

結果：アンケート回収率は62.3%であった。転倒状況は、調査時点から過去1ヶ月間で38名(44.2%)が転倒を経験しており、過去半年間では52名(60.5%)が経験していた。医療機関における運動療法の実施状況では、半数以上の52.3%が医療機関で運動療法を実施した経験が無く、現在も継続・実施しているのは全回答者の僅か12.1%であった。また、医療機関以外でも定期的に運動療法を実施していない者が33名(38.4%)であった。

結語：活動量の現象による廃用による筋力低下を防止するため、定期的に遂行でき、効果的な在宅PDに対するホームエクササイズを確立することが重要である。

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Introduction

Parkinson's disease (PD) is a progressive neurological disorder that generally begins between the ages of 50 and 60 years and increases in prevalence with age. It is one of the most common neurological disorders, with a prevalence rate in Japan of approximately 100 per 100,000 people aged 40–64 years and approximately 200 per 100,000 people aged 65 years or older ¹⁾. Because its prevalence increases with age, PD may become even more common in the future in this aging society ²⁾ and may become a serious issue ³⁾. The number of PD patients in Miyagi Prefecture who received a medical allowance as a part of the Ministry of Health, Labour, and Welfare Research Project for the Treatment of Special Chronic Diseases increased by approximately 2.3 times from 971 in 2001 to 2302 in 2011 ⁴⁾. Since the Special Chronic Disease Treatment Guidelines were enacted in 1972, various support measures, such as the model project for medical consultation for patients with intractable disease, have been applied to PD patients in Japan who receive home-care services. The Long-Term Care Insurance System started in 2000, and medical insurance and the Long-Term Care Insurance System were revised simultaneously in 2006. These reforms led to the use of Nursing Care Insurance Services by many patients with intractable diseases, creating an opportunity to offer these patients exercise therapy. However, a number of issues remain to be resolved, such as the inability of some patients to receive any nursing care services ⁵⁾ and the existence of services that fail to meet the needs of users ⁶⁾. Adequate education and exercise therapy are effective in improving activities of daily living in PD patients ⁷⁾. Indeed, a home exercise is important for home-cared PD patients ⁸⁾. In reality, however, these patients have had difficulty performing home exercises on a long-

term basis ⁹⁾.

From this perspective, we performed a home-visit survey ¹⁰⁾ of 15 home-care PD patients who were members of the Miyagi Prefecture Branch of the Japan Parkinson's Disease Association (JPDA). Of the responses collected in the survey, the most common complaints related to daily physical activities were problems with walking or standing up. The results of the survey showed that those who were certified as needing long-term nursing care or support (hereinafter referred to as "long-term care") accounted for 53.3% of all patients, but that only 26.7% of such patients actually used nursing care service programs. Those who had undergone exercise therapy at medical institutions during the period from the diagnosis of PD to the date of the survey accounted for only 20%, and those who performed home exercises (such as those in the common Parkinson's disease exercise program) accounted for 46.7%. These results demonstrated that fewer than half of the patients surveyed had tried home exercise, although as members of the JPDA they had all been advised of the benefits of exercise therapy. Because these results reflected the data from only about 10% of patients who were members of the Miyagi Prefecture Branch of the JPDA, we thought it necessary to perform a wider survey. We mailed questionnaires on exercise therapy to all patients who were members of the Miyagi Prefecture Branch of the JPDA, comparing the results of the questionnaire survey with those of preceding studies in Japan with the aim of shedding light on the actual situation of home-care PD patients in regard to exercise; the process and results of this undertaking are presented in this article.

Methods

1. Subjects

The 174 PD patients who were members of

the Miyagi Prefecture Branch of the JPDA as of 1 November 2012 were considered eligible to participate in the study. As 15 of these people were hospitalized at the time the survey was sent out, 159 home-cared patients were selected as study subjects.

2. Survey Methods and Details

The survey was performed by using anonymous questionnaires sent by mail. The deadline for the return was approximately 1 month, from 14 November to 11 December 2012. The questionnaire consisted predominantly of questions on PD symptoms, chief complaints related to activities of daily living, history of falls, status of certification for long-term care, use of nursing care services, and performance of home exercise. The question item about chief complaints related to activities of daily living was designed to allow subjects to choose multiple answers from a list of options for chief complaints related to daily physical activities on the basis of the results of preceding studies¹¹⁻¹²⁾.

3. Analysis Methods

The results of the survey were summarized in terms of chief complaints related to daily physical activities, number of falls, and other factors, and descriptive statistics were calculated and plotted. Patients were classified into 2 groups according to whether or not they were certified as needing long-term care and whether or not they performed home exercise. The SPSS 18.0 software for Windows was used for the analysis. Comparisons between the groups were made by using the chi-squared or t-test. The statistical significance level was set at 5%.

4. Ethical Considerations

All patients were provided with written information on the objectives of the study and were informed that the data obtained from them would be used exclusively for this study. Patients who responded to the questionnaire and returned it to us were regarded as

consenting to participate in the study. Before the start of the study, approval was obtained from the Ethics Committee of Hirosaki University Graduate School of Medicine.

Results

1. Questionnaire Response Rate and Subject Characteristics

Of the 159 subjects who were mailed the questionnaire, 99 returned it after responding—a response rate of 62.3%. Of these 99 subjects, 86 (54.1%) were included in the analyses; we excluded that 8 whose responses were either insufficient or illegible. 5 subjects with severe condition PD (Hoehn and Yahr stage V) who could not perform home exercise were also excluded. These 86 subjects consisted of 31 men and 55 women, with a mean age of 71.9 (*standard-deviation*7.3) years and mean time from PD onset of 11.0 (*standard-deviation*6.2) years. In terms of severity of PD according to the Hoehn and Yahr staging scale¹³⁾, 3 subjects were assessed as stage I, 24 as stage II, 39 as stage III, and 20 as stage IV by their each personal doctor.

2. Chief Complaints Related to Daily Physical Activities

The most commonly chosen answers were “slowness of movement,” “difficulty with activities requiring fast physical reactions,” “loss of muscle strength,” “walking with small steps,” “soft, weak voice,” and “acceleration of steps,” each of which was listed by more than 60% of respondents (Figure 1). In contrast, chief complaints such as “difficulty using an escalator,” “difficulty with holding things owing to tremor,” “difficulty getting into or out of the bathtub,” “problems using chopsticks or a spoon,” and “difficulty with face washing or teeth brushing” were each listed by fewer than 40% of respondents.

In regard to these chief complaints related

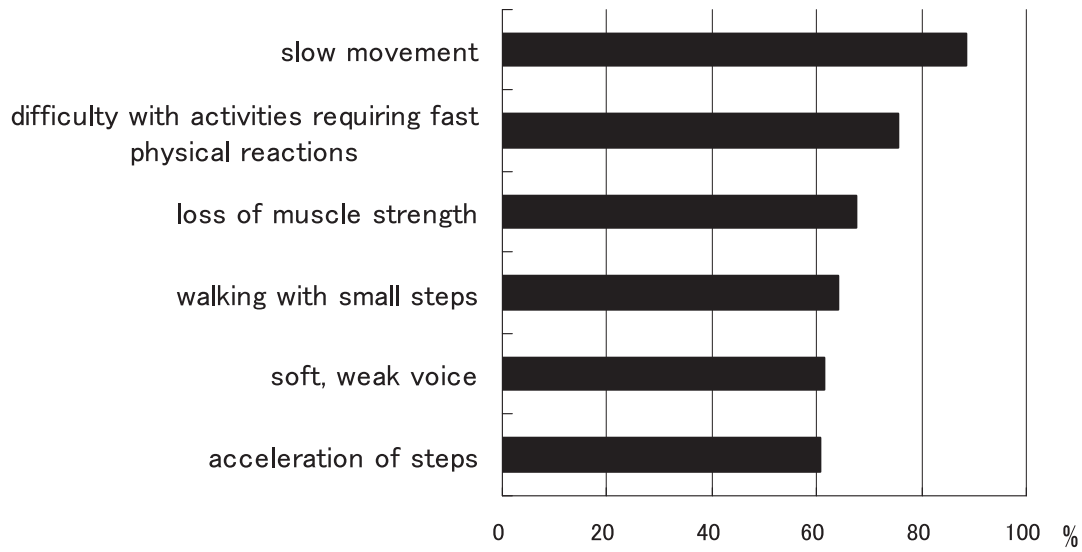


Figure 1. Percentages of chief complaints among the subjects surveyed (multiple answers allowed, n = 86)

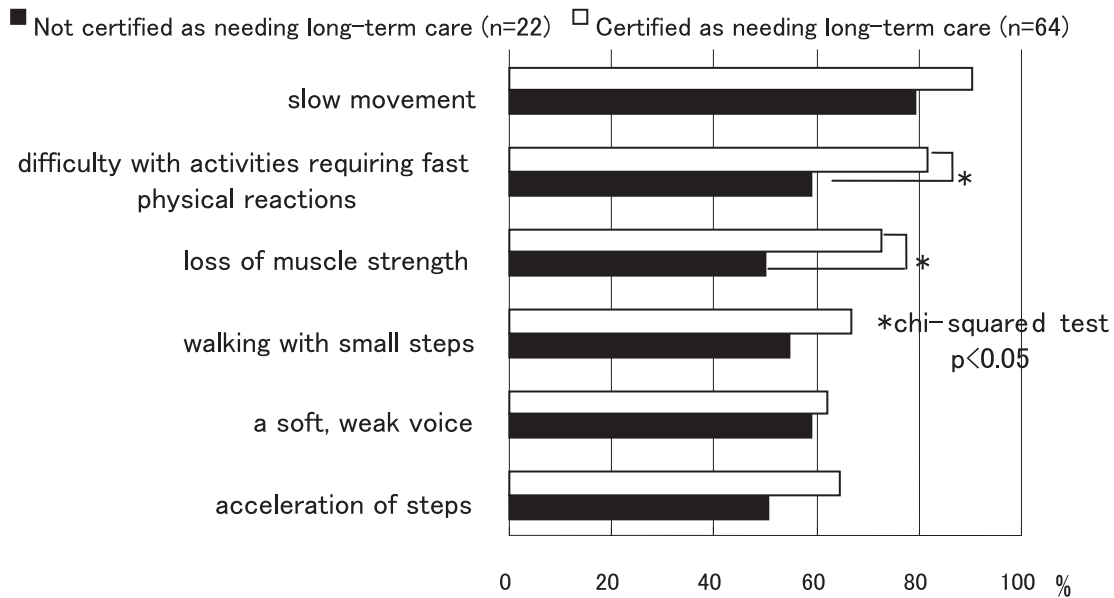


Figure 2. Percentages of subjects reporting each chief complaint, with respect to certification of long-term care need

to daily physical activities, we performed a between-group comparison after classifying subjects into 2 groups according to whether or not they had been certified as needing long-term care. Subjects who had been certified as needing this care were significantly more likely to report “loss of muscle strength” and “difficulty with activities requiring fast physical reactions” than were those who had not received such

certification ($P < 0.05$, chi-squared test) (Figure 2).

3. Falls

Falls had been experienced by 38 subjects (44.2%) during the month before the survey and by 52 (60.5%) during the 6 months before the survey. The mean number of falls experienced was 3.1 (standard-deviation 9.9) during the month before the survey and 14.4 (standard-

Table 1 Long-term care-need certification status and use of care services by respondents (n = 86)

Number of people certified as needing support or long-term nursing care (n = 64)		
Grade	Criteria	Number
Support level 1	Those who need no continuous care but need some support in the instrumental activities of daily living, such as support for cooking, shopping, washing and cleaning.	11
Support level 2	Those who have lower ability in the instrumental activities of daily living than grade of class1, and need the social support or prevention of care-need.	14
Care level 1	Those who need a watching or assistance in part of daily life, such as support for walking or transfer.	6
Care level 2	Those who need a watching or assistance in the entirety of daily life because of becoming difficult in eating and toileting.	14
Care level 3	Those who need full assistance because of disabilities of toileting, bathing and dressing.	11
Care level 4	Those who need overall care in the entirety of daily life because of disabilities in activities of daily living, and because of dementia or problem behavior.	7
Care level 5	Those who need continuous care because of being helpless and bedridden.	1
Users of elderly-care services (n = 56, 88.8% of certified persons and 65.1% of all subjects)		
Services used (multiple answers allowed)		
	Day care services for seniors	25
	Day care rehabilitation at facilities	21
	Home-visit care services	13
	Home-visit bathing services	8

deviation 56.2) during the 6 months before the survey. The sites of falls varied widely and included both inside and outside the house. The most common fall sites reported (multiple answers allowed) were the living room in 27 subjects, corridor in 23, and bedroom in 19. Twenty-nine subjects had fallen while walking or engaging in activities and 27 had fallen while turning around. The most common injuries caused by falls were abrasions in 26 subjects and bruising in 26. Twenty subjects who had fallen reported sustaining no injuries. Fractures from falls had occurred in 4 subjects.

4. Status of Long-term Care-need Certification and Use of Nursing Care Services

Of the 86 subjects, 64 (74.4%) had been certified as needing long-term care. Of these 64 subjects, 56 (88.8% of subjects certified as needing long-term care and 65.1% of all subjects surveyed) responded that they were using certain types of nursing care services. Day care for seniors, ambulatory rehabilitation, and

home-visit care were the most commonly used services, in that order. In terms of domiciliary services, the home-visit bathing service was used by fewer subjects than were other services. (Table 1)

5. Rehabilitation

Of the 86 subjects surveyed, 41 subjects (47.7%) had experienced exercise therapy at a medical institution. However, only 11 subjects (12.8% of all subjects) continued to receive exercise therapy at a medical institution at the time of the survey (Table 2). Exercise therapy at non-medical institutions, which was defined as exercise therapy performed at such institutions on a regular basis, was performed by 53 (61.6%) of the 86 subjects. The environments in which these 53 subjects underwent exercise therapy included day-care centers for seniors, day-care rehabilitation facilities, short-stay services, and classes organized by neighborhood community associations, as well as private gyms and exercise classes.

Table 2 Experience of exercise therapy at institutions (n = 86)

At medical institutions	
Subjects who had experienced exercise therapy	41 (47.7%)
[on admission for examination 13]	
[after a doctor's referral 21]	
[at patient's own request 7]	
Subjects who had never experienced exercise therapy	45 (52.3%)
Subjects who were regularly performing exercise therapy	11 (12.8%)
In non-medical-institution environments	
Subjects regularly performing exercise therapy	53 (61.6%)
Subjects not regularly performing exercise therapy	33 (38.4%)
Facilities used	
Day-care service for seniors	26
Day-care rehabilitation	17
Short-stay services	3
Others	8
(Classes held by neighborhood community Associations, as well as private gyms and exercise classes)	

Table 3 Associations between performance of home exercise and chief complaints.

Home exercise	Needing long-term care		Chief complaints											
			Slow movement		Difficulty with activities requiring fast physical reactions		Loss of muscle strength		Walking with small steps		A soft, weak voice		Acceleration of steps	
			yes	no	yes	no	yes	no	yes	no	yes	no	yes	no
Performed (57)	43	14	52	5	42	15	38	19	36	21	33	24	37	20
Not performed (29)	19	10	24	1	23	6	20	9	19	10	20	9	15	14
n = 86	$\chi^2 = 1.258$ p = 0.2621		$\chi^2 = 1.568$ p = 0.2105		$\chi^2 = 0.007$ p = 0.9316		$\chi^2 = 0.011$ p = 0.9173		$\chi^2 = 0.002$ p = 0.9644		$\chi^2 = 0.681$ p = 0.4092		$\chi^2 = 1.902$ p = 0.1678	

6. Home Exercise

Home exercise, which was defined as exercise therapy done at home on a regular basis, was performed by 57 subjects (66.3%). Subjects were classified into 2 groups according to whether or not they performed home exercise, and these 2 groups were compared by using the chi-squared test in terms of certification as needing long-term care and chief complaints related to daily physical activities. No significant difference was detected in either of these parameters (Table 3).

The common types of exercise therapy performed at home were stretching, walking, lower extremity muscle strengthening, and radio calisthenics. The mean duration of a home exercise session was 27.1 (*standard-deviation*19.1) min. However, because of the low

weekly frequency of exercise therapy practice, the mean duration of home exercise was 14.5 (*standard-deviation*12.5) min/day.

Discussion

A previous survey of 16 Japanese home-care PD patients assessed as Hoehn and Yahr stage III or IV reported that the common complaints were "slow movement," being "too weak to hold anything," "difficulty with standing," "difficulty with sit-to-stand and stand-to-sit movements," "difficulty with walking," and "low-back pain"¹¹⁾. Similarly, the most common complaints in our patients were "slow movement," "loss of muscle strength," and gait disturbance reflected in "walking with small steps" and "acceleration of steps," each of which was listed by more than

60% of respondents. Yuasa et al.¹⁴⁾ stated that approximately 40% of PD patients had low-back pain; this was similar to the proportion of our subjects reporting low-back pain. Our results showed that a relatively small proportion of subjects had chief complaints such as "difficulty with using an escalator," "difficulty with holding things owing to tremor," and "difficulty getting into or out of the bathtub." This may have been attributable to the fact that approximately 30% of all subjects in our study had only mild PD (i.e. Hoehn and Yahr stage I or II). In terms of the chief complaints related to daily physical activities, a between-group comparison showed that subjects who were certified as needing long-term care were significantly more likely to report "loss of muscle strength" and "difficulty with activities requiring fast physical reactions" than those without this certification. Hence, the results of our mail-based study of PD patients who were members of the JPDA suggested that chief complaints such as "loss of muscle strength" and "difficulty with quick physical reactions" might have led PD patients to apply for certification as needing long-term care.

In previous studies of falls in PD patients, the fall rate (proportion of patients who had experienced falls) has ranged from 38%–68%¹⁵⁾. Our fall rate was within this range. Previous studies in outpatients^{3, 12)} have reported that common sites of falls are the living room, hallway, and bedroom, and that most falls occur when patients are walking or standing up. Our results were similar, suggesting that falls occur mainly in places where people spend most of their time and during walking or standing up. Fracture as an outcome of a fall had occurred in 10.3% of our falling subjects during the month before the survey. Koura et al.¹²⁾ reported similarly that 9.5% of patients had experienced a fracture caused by a fall. These facts suggest that strategies for falls prevention are essential for ambulatory PD patients who were assessed

as high-risk faller.

A survey conducted relatively soon after the start of the nursing care insurance program in 2000 reported that a low percentage of PD patients had been certified as needing long-term care^{16, 17)}. A 2008 survey of 52 outpatients with PD-related disease (assessed as Hoehn and Yahr stage III or greater) found that 75% of patients possessed such certification¹⁸⁾. Our study, although it was performed in patients who were members of the JPDA, found that the proportion of patients certified as needing long-term care was similar to that in the 2008 study. Twenty-two of our subjects were not certified as needing long-term care, and 7 did not use nursing care services despite being certified to do so. This study included 3 subjects with mild PD who were assessed as Hoehn and Yahr stage I. Researchers have pointed out that although home-care PD patients have high needs for nursing care services¹⁸⁾, the services provided do not meet their needs⁶⁾ and some PD patients have little interest in, or insufficient information on, the nursing care service system¹⁶⁾. These factors may explain why 22 subjects in this study were not certified as needing long-term nursing care and why 7 subjects did not use nursing care services despite being certified to do so. Day care for seniors, rehabilitation, and home-visit services were the facilities most commonly used by our subjects, in that order, being used by 10%–20% of subjects, a similar proportion to that reported by a previous study of home-care PD patients¹⁸⁾. The rate of use of services or ambulatory rehabilitation varies depending on the level of need for care¹⁹⁾. Because fewer of our PD subjects were assessed as stage I or V compared with other stages, however, the relationships between the level of need for care and the rate of use of care services should be further investigated in future studies.

Our results showed that more than half (52.3%) of subjects had never undergone

exercise therapy at a medical institution, and that only 26.8% of subjects were continuing to undergo exercise therapy at the time of the survey. Those who did not undergo exercise therapy at any place on a regular basis accounted for 38.4% (33 subjects). Sasaki *et al.*¹⁷⁾ performed a questionnaire survey of home-care PD patients from Nagasaki Prefecture in Japan who were receiving care at a medical institution and reported that 36.4% of these patients had experienced exercise therapy at a medical institution, whereas 63.6% had never undergone exercise therapy. Although these results were similar to ours, the proportion of our subjects who had experienced exercise therapy at a medical institution was slightly higher than that in the aforementioned study. This is probably because our subjects were members of the JPDA and therefore likely had greater understanding and awareness of PD than other patients with PD. Our results demonstrated that some PD patients have little opportunity to undergo exercise therapy at medical institutions or any other places. As is clear from the previous studies^{20), 21)}, patients must develop muscular disuse atrophy under such circumstances. Even when practicing home exercise in their own way, patients may risk overuse or misuse of muscles owing to a lack of adequate guidance²²⁾.

Fifty-seven subjects (66.3%) performed home exercise on a regular basis. The common types of home exercise were stretching, walking, lower extremity muscle strengthening, and radio calisthenics. Only a limited number of subjects had learned specific exercise therapy strategies for PD²³⁻²⁵⁾, such as concentrating on an activity to be performed by avoiding dual-task performance, imagery rehearsal before the performance of exercise, and training for climbing stairs or stepping over a line. Exercise therapy, including home exercise, is effective for PD patients^{26), 27)}, and interruptions in exercise

therapy intervention can negate these effects²⁸⁾. Further investigations will be needed to clarify the reasons why patients are unable to continue home exercise, the ways in which they can be given more opportunities for rehabilitation treatment by specialists, and the types of exercise therapy intervention that should be provided by specialists.

This study had limitations that need to be considered in determining the general applicability of our findings. The sample size was small and consisted of a convenient sample of volunteers. In addition, the questionnaire response rate was not high (only 62.3% of 159 PD patients). Those people who responded to the questionnaire might have had different perceptions of, and experiences with, home exercise than those who did not respond. Furthermore, we were unable to explore the performance of exercise therapy in home-care patients who were not members of the Miyagi Prefecture Branch of the JPDA. It is likely that people who belong to the JPDA have perceptions of home exercise, and thus rates of exercise, different from those of patients who do not belong to the JPDA. Finally, because we could not confirm the medication status of each subject, it was not possible to take into account the effect of dosing schedule on our results. Future research needs to explore the medication status of home-care patients with PD and how it affects the performance of physical activity.

Conclusions

The results of our mail-based study were similar to those of our home-visit survey in that more than half of the home-care PD patients had not experienced exercise therapy at a medical institution. Only a limited number of subjects continued to undergo exercise therapy at a medical institution, and many subjects who

were undergoing exercise therapy were doing so at a day-care service site or rehabilitation service site. Approximately 60% of subjects participated in home exercise, which consisted mainly of stretching and lower extremity muscle strengthening. Even among the present members of the JPDA, who likely had a strong understanding and awareness of PD, we observed some patients who had no opportunity to undergo exercise therapy. To prevent muscle disuse atrophy or muscle overuse and misuse due to a lack of adequate guidance, it is important to devise effective rehabilitation programs and methods to instruct and intervene in home exercise. This would help all home-care PD patients to exercise on a regular basis. The future challenge is to establish effective rehabilitation programs and intervention methods for exercise therapy and to validate the efficacy of such programs in home-care PD patients.

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