

Group Education with Personal Rehabilitation for Idiopathic Parkinson's Disease

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ABSTRACT: Objective: To evaluate the effect of a group education program with personal rehabilitation for idiopathic Parkinson's disease (IPD). **Methods:** A single-blind, randomized, controlled clinical trial, with a pre-test/post-test quasi-experimental design. Forty-four stable, non-demented patients with IPD were randomly assigned to an intervention group (n=23) and control group (n=21). Three group lectures on health education specific to IPD were delivered to the intervention group. The theme of lectures was "Not a lonely journey, as your friend, we---experts specializing in IPD--- would love to join with you." Three domains of the management of IPD were mentioned: "How to manage your routine Meal, Moving and Mood after suffering from IPD" Each lecture was scheduled for 45 minutes (excluding breaks), and designed as an interactive dialogue rather than a traditional lecture. To strengthen the impact of the lectures, relevant information was published on a website: <http://www.parkinsonism.cn/>. Following the group lecture, individualized and tailored rehabilitation made up of 24 half-hour sessions over eight weeks were provided for the intervention group. **Results:** The program ran smoothly and IPD patients were satisfied with this program. After only eight weeks, the health-related quality of life (HR-QOL) in the intervention group improved significantly ($p < 0.001$). Patients and their caregivers in this group also reported their mood elevations following the program. **Conclusion:** Group education combined with personal rehabilitation program appears to be a beneficial and practical intervention, not only complementing the medical treatment for IPD patients but also meeting the growing demand for long-term care.

RÉSUMÉ: Enseignement de groupe avec réadaptation personnelle dans la maladie de Parkinson idiopathique. Objectif : Le but de cette étude était d'évaluer l'effet d'un programme d'enseignement de groupe avec réadaptation personnelle dans la maladie de Parkinson idiopathique (MPI). **Méthodes :** Il s'agit d'une étude clinique contrôlée, randomisée, à simple insu, avec un devis quasi expérimental prétest/posttest. Quarante-quatre patients atteints de MPI sans démence, dont la maladie était stable, ont été assignés au hasard au groupe intervention (n = 23) ou au groupe témoin (n = 21). L'intervention consistait en trois cours de groupe portant sur la santé, adaptés à la MPI, dont le thème était « Ce n'est pas un parcours solitaire, nous - les experts spécialistes de la MPI - aimerions nous joindre à vous en tant qu'amis ». Trois domaines de gestion de la MPI ont été abordés : « Comment gérer sa routine concernant les repas, les déplacements et l'humeur quand on est atteint de MPI ». Chaque cours devait durer 45 minutes (sans les pauses) et était conçu comme un dialogue interactif plutôt qu'un cours traditionnel. Afin de renforcer l'impact des entretiens, l'information pertinente était publiée dans un site Internet : <http://www.parkinsonism.cn/>. Après le cours de groupe, un programme de réadaptation individualisé et adapté comportant 24 sessions d'une demi-heure chacune pendant 8 semaines était offert au groupe intervention. **Résultats :** Le programme s'est déroulé harmonieusement et les patients atteints de MPI en ont été satisfaits. Après seulement 8 semaines, la qualité de vie reliée à la santé dans le groupe intervention s'est améliorée significativement ($p < 0,001$). Les patients et leurs soignants (es) du groupe intervention ont également rapporté une amélioration de l'humeur suite au programme. **Conclusion :** L'enseignement de groupe associé à un programme de réadaptation personnalisé semble constituer une intervention bénéfique et pratique, qui sert non seulement de complément au traitement médical des patients atteints de MPI mais aussi qui rejoint le besoin croissant de soins à long terme.

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Because of demographic changes and epidemiological transition, the need for management of chronic diseases and long-term care for the frail elderly are dramatically increasing. Some needs involve socially-oriented services while others are more medically focused, for example, idiopathic Parkinson's Disease (IPD). Idiopathic Parkinson's Disease is a degenerative neurological condition characterized by muscle rigidity, uncontrollable tremor, and a slowing of physical movement

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(bradykinesia), which eventually leads to a loss of physical movement (akinesia). Idiopathic Parkinson's Disease affects both men and women equally, as well as people of all ethnic and socio-economic backgrounds. The condition usually affects the elderly. The latest update on the prevalence of IPD in China was reported by Zhen-xin Zhang.¹ In a community-based, cross-sectional prevalence study undertaken in 1997-98, the prevalence of IPD among those over the age of 55 was 1.07%, and 1.67% for those over the age of 65. With the faster aging average rate than in developed countries,² the prevalence of IPD is rapidly increasing in China, suggesting that the considerable disease burden is becoming a sensitive problem for IPD patients, their families and the nation as a whole.

In the traditional perspective, the improvement of the movement symptoms is the target of treatment for IPD.³ A main symptomatic therapy can provide benefits for a few years, but as with many other neurodegenerative disorders, IPD is chronic, progressive, and presently incurable. Although some people in the later stages may become mentally confused or develop dementia, most retain their intellectual facilities while becoming increasingly physically disabled.

For at least two reasons, the increase in prevalence of IPD in aging society and the profound threat to quality of life among IPD patients, both the disease and its management generate many long-term care needs throughout the course of the illness, which should primarily focus on the improvement of patients' health-related quality of life (HR-QOL). Health-related quality of life refers specifically to an individual sense of well-being, purpose in life, autonomy, and the ability to maintain worthwhile roles and participate in significant relationships.⁴ On the other side of this issue, initiating the improvement of HR-QOL simultaneously delays or prevents the utilization of acute care hospitals, which is also an important factor for limited resource availability in developing countries, including China.

In this research, we designed a controlled clinical trial lasting eight weeks. Forty-four patients suffering from IPD were given a combination of group education with personal rehabilitation by medical care professionals. The aim was to empower people with IPD to deal with the challenges related to their disease and try to develop an effective and efficient program pattern focusing on the improvement HR-QOL for IPD patients.

At the beginning of the study, we attempted to answer two questions about the background of the trial. One was whether or not education improved HR-QOL in IPD patients. So far, the issue is unresolved.⁵⁻⁹ In the light of previous experiences and lessons, we modified our trial module, including the design and outcome measures introduced below.

Another issue is the value of the rehabilitation for IPD patients. Unlike the education issues, nearly all published papers reported a positive outcome for IPD patients.¹⁰⁻¹³ The Quality Standards Subcommittee (QSS)⁵ in the United States in 2006 concluded from eight graded Class II studies that exercise therapy resulted in improved functional outcomes, which were significant in the variety of modalities used. Overall, however, the magnitude of the observed benefit was small. Additionally, the benefit was not sustained once exercise therapy was discontinued. This implied that the key to the success of an exercise program is sustainability. Therefore the importance of community-based programs should be emphasized. As for the

function of community for those who need long-term care, the great concerns are how to integrate medical care with social services, how to integrate care in the home, community and institutions. This pilot study also seeks to raise public, professionals' and policy-makers' awareness of IPD management in a suitable manner.

METHODS

Sample identification and further diagnostic confirmation

The study was a single-blind, randomized, controlled clinical trial, with a pre-test/post-test quasi-experimental design. The flowchart of the trial used throughout the program is shown in Figure 1.

From the electronic clinical database of patients with IPD, 68 patients with early to moderate IPD were first identified as potential participants in the Specialized IPD Outpatient Clinics in Huashan Hospital affiliated with Fudan University. Further diagnostic confirmation to be eligible for this program was performed by two neurologists, according to the criteria set by Calne and colleagues,¹⁴ and assigned stages using the Hoehn and Yahr scale (H&Y).¹⁵ The inclusion criteria were a diagnosis as IPD in H&Y I, II or III grade that was inconvenient but not disabling, characterized by significant slowing of the body, early impairment of equilibrium on walking or standing, generalized dysfunction that was moderately severe, and stable drug usage without unpredictable and long-lasting off periods. These participants were capable of independently keeping a diary and visiting the hospital using public transport. For the convenience

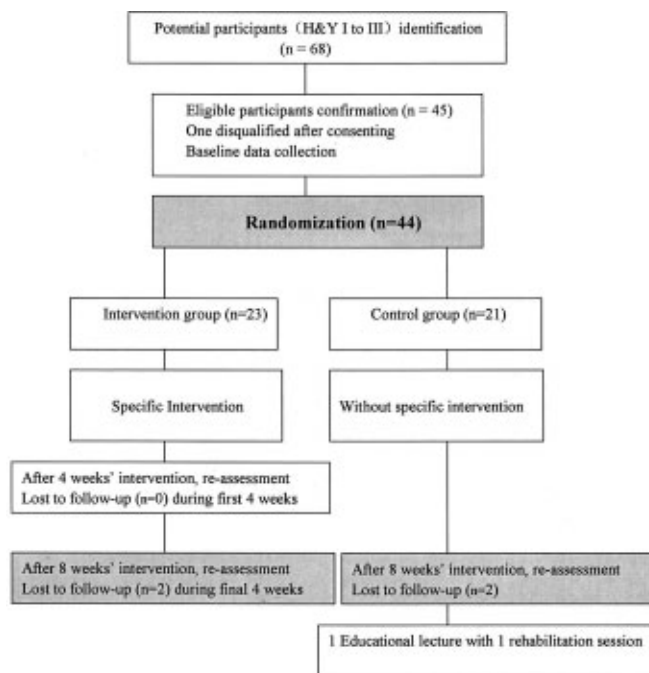


Figure 1: Flowchart of the clinical trial throughout the program.

of patient activity, the distances between the home and the hospital were taken into consideration. Most of them came from the nearby communities. The following cases were excluded: secondary PD (n=2), corticobasal degeneration (n=1), multiple system atrophy (n=2); presence of significant cognitive impairment (n=6), for which a Mini-Mental State Examination¹⁶ was used to screen (a maximum 30 points is possible with scores of 26 or less generally being reported by people with dementia); ongoing psychiatric drug reactions (n=4) (hallucinations, confusion, psychosis); chronic heart disease (n=3); and osteoporosis (n=2), or other significant co-morbidities (n=1); and refusal of the visit (n=2). Forty-five eligible participants out of 68 initially identified patients were informed about the study, and written consent to commit to the program and the follow-up assessment was given by each patient or, if appropriate, by their caregivers (a caregiver was defined as someone close to a patient who provided psychological, social, and physical support). After consenting, one patient was disqualified because of an emergency case in his family. Simple randomization among 44 participants was performed by one nurse via a computer-generated random number series. According to this generated sequence, participants were assigned on an individual basis to either an intervention group (n= 23) or control group (n=21). The randomization and allocation procedures were conducted after enrollment, obtaining informed consent, and baseline assessment.

Group educational program in combination with personal rehabilitation

The educational program was conducted by a team of multi-disciplinary professionals having previous patient teaching experience. Five neurologists specializing in movement disorders, who play predominant roles in this project, participated in the management of the syndromes, disease progress and medicines; five physical and occupational therapists (PT and OT) provided assistive rehabilitation devices, trained and instructed patients in independent daily living; one

registered dietitian understanding IPD provided advice on the appropriate proportion of nutrition and diet ingestion, especially for those patients who were taking Levodopa; one psychologist identified patients who had psychological problems and planned to interview them; in addition, one nurse was responsible for general information and day-to-day supervision.

At first, considering patients have the right to take part in the management of their own illness, 68 potential subjects' families, including patients and their caregivers, were interviewed by telephone. They were asked to select one among the four options listed in Table 1 as necessary health education for IPD patients. The answers in order of preference were focused on rehabilitation, mental health, diet, and the latest advance in treatment. They explained that they did not put much hope in medicine because of the adverse side-effects of the anti-parkinsonism agents. They assumed that the development of rehabilitation approaches that work in conjunction with current treatment would be very important for them, so they eagerly volunteered for the trial. In addition, both the PD patients and their caregivers anxiously requested encouragement and support from the medical staff. All of them only hoped that the trial would actively empower people affected by IPD and those living with and/or caring for them to improve their quality of life by dealing with physical/psychosocial problems that might result from the disease.

After that, to ensure the effective and efficient outcome, the educational programs were carefully designed by all participating professionals together. The original resources were the evidence-based data together with their professional experience. Three group lectures on health education specific to the patients with IPD were mainly delivered to the intervention group in Huashan Hospital. The theme was "Not a lonely journey, as your friend, we---experts specializing in IPD---would love to join with you." Three domains of the management of IPD were mentioned, "How to manage your routine Meal, Mood and Moving after suffering from IPD." Each lecture was scheduled for 45 minutes (excluding breaks), and designed as an interactive

Table 1: Results of phone interview on preferences for potential health education contents about IPD (n=68)

Contents of education	Number of subjects with preference*	Concrete requests from interviewee
Diet	12	Measures against unplanned weight loss due to nutrient depletion
Mental health	26	More encouragement and support from medical staff
Rehabilitation	27	Development of rehabilitation program in conjunction with current treatment
Latest advance in medicine	3	Introduction of latest advance in curative medicine for improvement of movement disorders, or treatments with less side-effects

* Number of interviewees who selected the corresponding content as the one that most interested them

dialogue rather than a traditional lecture. The content was concentrated on managing day-to-day disease-impacted problems with the emphasis on relaxation rather than limitations. Patients were also encouraged to share their own experiences and ways of overcoming daily life difficulties. To strengthen the impact of the lectures, relevant information was published on a website (<http://www.parkinsonism.cn/>), and patients who attended the lectures in the intervention group were empowered by convenient access to the most appropriate information as often and whenever they needed it. To increase the capacity and confidence of patients to put into practice repeatedly the information on the website, we provided specific support for them---“In fact, you also can surf the Internet.” To handle the inconvenience due to the muscle rigidity and uncontrollable hand tremor, special methods of resetting the mouse, stylus and keyboard of the computer were recommended to them in the lectures.

Specific intervention for “meal” (the first domain of the management of IPD delivered in the first group lecture) was mainly provided by the registered dietitian. The highly specialized medical nutrition therapy necessary to meet the challenges of patients with IPD was provided. Redistributed protein diets, drinking as much water as possible prior to “open-medication,” rich food sources of fiber, both soluble and insoluble, and other nutrients---calcium and vitamin D---were listed. Specific intervention for “mood” (the second domain of the management of IPD) was addressed by the psychologist in the second group lecture. Patients were evaluated for psychological distress by Zung Self-Rating Depression Scale (SDS)¹⁷ and Beck Anxiety Inventory (BAI).¹⁸ Prescription antidepressant or/ and anxiolytic medications, psychotherapy and “talk” therapy which can relieve depression and anxiety disorders were available on request. Specific intervention for “moving” (the third domain of the management of IPD) was done by the combination of the third group lecture with the personal rehabilitation made up of 24 half-hour sessions during eight weeks conducted by PT and OT. Rehabilitation in our program was utilized as an adjunct to the group education and pharmacologic therapies for IPD patients. Standard physical therapy and tailored occupational therapy components were designed based on previous significant evidence.¹⁰⁻¹³ For example, the individual treatment including “cued” exercises with visual (mirror), auditory, and tactile feedback;¹⁰ treadmill training with body weight support;¹¹ balance training and high-intensity resistance training;¹² and active music therapy¹³ were assigned to various patients according to their deficiency in movement by experienced PT and OT in the Department of Rehabilitation of Huashan Hospital. Meanwhile, these staff prepared patients for practical exercise that could be done both at home and in the community.

During eight weeks, participants had access to interviews and consultations with the professionals of this team.

Caregivers for these patients were all encouraged to attend activities on their own.

Baseline and re-assessment

The study took place from December 2007 to February 2008. Before, within and after the eight weeks, patients were clinically evaluated by two neurologists with expertise in movement

disorders who were blinded to the group allocation. Demographic and clinical data on the patients were collected at the baseline assessment. After completion of the first four weeks’ intervention, the patients in the intervention group were reassessed for the second time, and those participants served as their own controls. As soon as the whole trial lasting eight weeks was over, both groups were reassessed.

To control for variations due to the drug cycle, the assessment was performed after each patient took a first morning dose of anti-parkinsonism drug or three hours before the next dose in the evening, which meant the same time of day in the one phase---“open medication.”

After final assessment, the control group at the end point received the same educational lecture and one concentrated rehabilitation session.

Medical treatment for IPD in both groups continued throughout the study.

The study protocol was approved by the ethics committee of Huashan Hospital affiliated with Fudan University.

Outcome measures

HR-QOL. The HR-QOL was assessed using the idiopathic Parkinson’s Disease questionnaire-39 (PDQ-39).¹⁹ It was designed to measure aspects of health relevant to patients with IPD, which consist of 39 items addressing eight domains: mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort. Lower scores indicate better perceived health status. The Chinese version of the questionnaire has been found to be of sufficient reliability.²⁰ The questionnaires were completed by verbal questioning of patients from trained interviews.

UPDRS. The Unified Parkinson’s Disease Rating Scale (UPDRS) is a rating tool to follow the longitudinal course of IPD, which measures symptom severity and the effectiveness of intervention in IPD.²¹ For this study, participants’ symptoms were assessed using Part II-Activities of Daily Living (ADL), possible range 0–52, which assesses dependency on others for routine daily activities on a scale from 0 (fully independent) to 100% (fully dependent), with higher scores indicating greater disability; and Part III - Motor Exam (ME), possible range 0-108, which assesses severity and progression of motor symptoms on a scale from 0 (normal moving) to 100% (barely moving), with higher scores indicating more severe movement symptoms.

Schwab and England Activities of Daily Living (SEADL). SEADL is used to self-rate the ability to perform activities of daily living, ranging from 0% to 100%, where 0% represented total disability and 100% indicated total independence.²²

For the above tests, the state of the patient was defined as “open-medication,” referring to the same assessment point like the baseline. Because the drugs are individualized for each patient, change in drug therapy can confound the interpretation of outcomes. We sought to refrain from changing patient drug schedules if possible. The relevant information was presented in the results.

Zung Self-Rating Depression Scale (SDS). It is a reliable and valid 20-item self-report questionnaire covering psychological and somatic symptoms associated with depression.¹⁷ Most people with depression score between 50 and 70, a score of 70 and above indicates severe depression, while a score between 40 and 49 indicates states of mild depression.

Global patient's mood status (PMS). Considering all the ways affected, patients marked a 100 mm-visual scale that presents global PMS on a horizontal analogous scale, with one end labeled as "pessimism" and the other end as "cautious optimism." This instrument was explained so that patients would understand that the overall range of mood status was represented by the scale, and that they could objectively self-assess their present state, then mark the matched point on this line. The scales were scored in mm from the left end of the line to the patient's mark.

Caregiver's mood status (CMS). An additional global assessment of the caregiver's mood status was completed by the caregivers themselves. Each of them summarized the stress level experienced by the patient in their care. The scoring system was arranged with: 1 as Good, 2 as Moderate; and 3 as Poor.

Data analysis

All statistical tests employed were two-sided and were performed using SPSS version 15. The p level of significance was set at 0.05.

Descriptive statistics were obtained for each variable as required. To determine whether parametric or nonparametric methods should be used, the data were checked for normality using histograms.

Baseline characteristics were compared using Levene's Test for Equality of variances and independent sample t-tests or Mann-Whitney U test.

For pre- and post-comparisons of PDQ-39 and UPDRS, within-group differences from baseline to four weeks after intervention, the Wilcoxon's signed-rank test was used.

Regarding differences between the intervention and control group, the change scores of PDQ-39, UPDRS ADL, UPDRS ME, SEADL, Zung SDS and PMS were analyzed using repeated measures and multivariate analysis of variance (ANOVA) process of the general linear model in SPSS. The change score of CMS was analyzed by Cumulative Logistic Regression.

RESULTS

Demographic and clinical data of IPD patients.

Demographic and clinical characteristics of patients at baseline were summarized in Table 2. There was no statistically significant association between the two groups in age, sex, duration, disease severity and educational background (independent t-tests for continuous variables including disease severity, and Mann-Whitney U tests for sex and education background). A total of 40 patients completed the study. Two patients in the intervention group were lost to follow-up after the completion of first four weeks' intervention and re-assessment. Two persons were lost to follow-up in the control group.

HR-QOL. After four weeks' intervention, only the subscale for bodily discomfort improved ($p < 0.001$), including various bodily symptoms, such as muscle pain, muscle cramps or spasms, aches and pains in joints (shown in Table 3). After eight weeks' treatment, in the intervention group the PDQ-39 score

Table 2: Demographic and clinical characteristics of IPD patients in the study*

	Intervention group (n=23)	Control group (n=21)	Excluded group (n=24)
Age (yr)	64.6 ± 6.8	62.6 ± 6.9	65.3 ± 6.6
Sex [†]	21.7	23.4	22.8
Height (cm)	165.9 ± 5.8	167.5 ± 8.0	162.5 ± 5.7
Weight (kg)	63.2 ± 9.8	63.5 ± 7.7	65.1 ± 5.6
Education [‡]	23.2	21.7	22.5
MMSE	28.2 ± 1.4	28.2 ± 1.3	25.6 ± 1.1
Hoehn and Yahr [§]	2.2 ± 0.5	2.2 ± 0.6	Not applicable [¶]
Duration (yr) ^{//}	5.4 ± 3.5	5.4 ± 2.6	Not applicable [¶]

IPD: idiopathic Parkinson's disease; MMSE: Mini-Mental State Examination; * Data are presented as mean ± standard deviation except for sex and education in which mean rank was used; † Sex: 1-2 (1=male; 2=female); ‡ Education: 1-3 (1=junior school; 2=high school; 3=undergraduate); § Hoehn and Yahr scale: 1-5 (1: unilateral disease; 2: bilateral without postural instability; 3: bilateral disease with postural instability; 4: considerable disability but able to walk independently; 5: wheelchair-bound or walking only with assistance) was treated as a continuous number; //Duration: after being diagnosed to being recruited; ¶ Not applicable: some of patients in the excluded group were not confirmed as IPD

Table 3: Comparison between baseline and after 4 weeks' intervention of eight domains of PDQ-39 within intervention group

	PDQM	PDQA	PDQE	PDQS	PDQSS	PDQCog	PDQCom	PDQB
Baseline								
Mean	13.8	9.2	4.3	4.1	0.6	4.7	2.2	3.4
SD	7.4	4.1	3.7	3.9	1.5	2.1	2.3	2.3
Median	12	9	4	4	0	5	1	3
After 4 weeks								
Mean	13.6	8.9	4	3.7	0.7	4.4	2	1.2
SD	6.9	4	3.4	3.7	1.5	2.1	2.1	1.3
Median	12	9	3	3	0	4	1	1
Mean negative rank	3.2	3.7	2.5	3.4	0	2.5	2	10
Mean positive rank	5	2.5	0	1.5	1	0	0	0
p-value*	0.24	0.84	0.66	0.1	0.32	0.59	0.1	0.001

SD: standard deviation; PDQ-39: Parkinson's disease questionnaire-39; PDQM: subscale of PDQ for mobility; PDQA: subscale of PDQ for activities of daily living; PDQE: subscale of PDQ for emotional well-being; PDQS: subscale of PDQ for stigma; PDQSS: subscale of PDQ for social support; PDQCog: subscale of PDQ for cognition; PDQCom: subscale of PDQ for communication; PDQB: subscale of PDQ for bodily discomfort; * Within-group differences were evaluated by Wilcoxon's signed-rank test

improved from 43 (40 ± 4.3) to 27 (25.4 ± 4.0), suggesting a 37% change in the scoring range. When compared with the control group, the variation was significant ($p < 0.001$) (see Table 4).

UPDRS. After four weeks' intervention, UPDRS corresponded to PDQ-39, in which a significant difference was not noted. After a specific intervention of eight weeks, compared with the control group, the improvements in the intervention group were in their activities of daily living and their movement (illustrated in Table 4).

Other comparisons. For the Schwab and England Activities of Daily Living (SEADL), the result produced an equivocal value. The means and the standard errors between pre- and post-trial were duplicated after the intervention. Of course, no significant differences were found. Probably, this indicator was not suitable for the short-term intervention for patients with IPD. Individuals with IPD have a higher incidence of depression than other subjects, though the disease itself and/or emotional problems and/or the disability caused by disease can contribute to psychological well-being. In this study, the average score (25.0 ± 1.3) of SDS did not support the presence of depression among participants in our study. Also, there was no meaningful difference in pre-post measures for the total sum scores (Table 4).

A significant improvement was shown in mean ratings on the global patient's mood Barometer (median changed from 38.1 to 58.4) in the intervention group compared with the control group (39.1 to 39.3). Anecdotal reports from the patients offered additional insights into the value of the program. All of them reported feeling stronger and more confident about the future. They mentioned that the program not only provided helpful

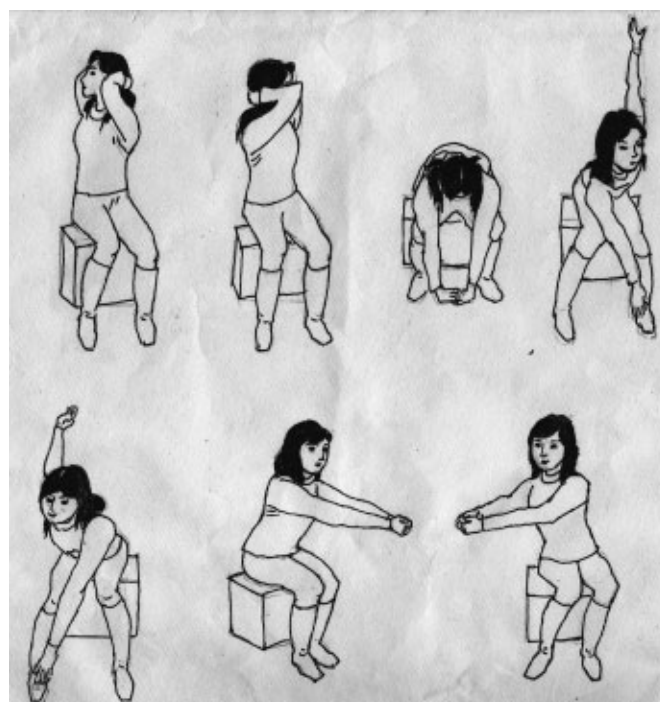


Figure 2: Pictures drawn by one participant in our program in one of the rehabilitation sessions.

Table 4: Comparisons of changes in physical and mental status between intervention group and control group

	Baseline		After 8 weeks' intervention	
	IG	CG	IG	CG
PDQ-39				
Mean	40.0	42.6	25.4	42.5
SD	4.3	4.5	4.0	4.2
p-value*		0.001		
UPDRS II				
Mean	10.5	12.7	5.5	13.1
SD	1.3	1.4	1.3	1.3
p-value*		0.001		
UPDRS III				
Mean	28.6	30.4	15.8	29.3
SD	2.9	3.0	2.5	2.7
p-value*		0.001		
SEADL				
Mean	0.8	0.8	0.8	0.8
SD	0.2	0.2	0.2	0.2
p-value*		Not applicable		
Zung SDS				
Mean	25.0	24.7	24.8	24.8
SD	1.3	2.0	1.2	1.6
p-value*		0.1		
PMS				
Mean	38.1	39.1	58.4	39.3
SD	1.5	1.3	2.4	2.5
p-value*		0.001		

SD: standard deviation; IG: intervention group; CG: control group; UPDRS II: UPDRS ADL; UPDRS III: UPDRS ME; SEADL: Schwab and England Activities of Daily Living; Zung SDS: Zung Self-Rating Depression Scale; PMS: Global patient's mood status; * p-value represents interaction p-value. Significant results indicate that within-individual change over time was different according to the allocated group; p-value was calculated by multivariate repeated measures ANOVA using general linear model procedure in SPSS with sphericity assumption

information for dealing with PD, but also improved their skills to overcome the inconvenience accompanying the syndromes. After being involved in the program, during the intervention, nobody felt the need to increase the necessary dosages, and four people who were relieved from dyskinesias reduced their dosage after consulting with neurologists. Twenty persons reported less constipation and sounder sleep. Eighteen persons reported that they resumed their leisure activities with great ease. One painter picked up his painting brush once more to draw a group of rehabilitation-related pictures in the scene after he had been forced to abandon his favorite leisure activity for five years. His drawing was shown in Figure 2. Eleven persons reported they are probably capable of doing housework if they have to live alone. And the moods of caregivers were significantly uplifted compared with the control group (Table 5). Seventeen caregivers reported that since the intervention, the facial expressions of their spouse returned to normal. One person exclaimed: "My

husband can smile again! I am so happy about this." We had never expected that this program would also provide a team atmosphere so congenial for the patients and their caregivers, who felt the exchange of experiences and ideas within the group was helpful. They suggested a similar kind of activity should be launched and continued as much as possible.

DISCUSSION

The present study integrated group education with personal rehabilitation into a new program. From the outcome measures, both the assessment of movement and the estimate of mood, it seemed that the majority of patients enjoyed the program. This project was shown to have short-term positive effects on IPD patients' HR-QOL. After the intervention, participants' movement, well-being and self-efficacy were significantly better. This research also sought to emphasize the importance of holistic intervention for IPD patients²³ and to initiate the guidelines for the management of IPD in China.

Recently, within a consortium of seven European countries, an education program for people with IPD and their caregivers was developed.^{24,25} In Japan, to improve the quality of medical care, the Japanese government has decided to cover patient education under national health insurance, specifically in relation to lifestyle-related chronic disease and intractable diseases.²⁶ To our knowledge, this is the first study in China to evaluate the effectiveness and efficiency of a patient education scheme especially for IPD.

The Quality Standards Subcommittee⁵ also pointed out that the public is demanding convenient and efficient education in every part of the world, and greater knowledge about disease progression will benefit the patients and their caregivers even more. As designed in our study, to deal with the health problems of IPD patients, the educational program should involve specialists in management of motor symptoms cooperating with professionals in other fields. Cheng et al also claimed that there was significant room for improving aspects of IPD care quality among patients without involvement of a specialist.²⁷

In the present clinical trial, rehabilitation was introduced as one factor in the educational program. This enriched the content of the educational program, and objectively helped patients to develop and adjust the necessary skills in their daily life. The benefits of rehabilitation promoted the compliance of patients with our educational program. Providing guidance and training for the disabled and their families also can promote self-help and family care to delay or prevent deterioration of the disease. Highlighting the potential of health services, such as education and rehabilitation, will be useful in long-term care. Although our study was initially performed in a general hospital, the maintenance of the improvement in patient's functions and the transmission of this effective model will depend on the development of community and home health care services.

One of the limitations of the present study is possibly the lack of control intervention. Future study to evaluate the effectiveness of the combined intervention should consider such interventions as "rehabilitation alone," "rehabilitation with web access," "attending lectures with or without the web access," or "not attending lectures but with the web access." Second, the improvement observed may simply be related to improvement in depressive symptoms, which a non-specific intervention might

Table 5: Comparison of caregiver's mood status after 8 weeks' intervention between intervention group and control group by cumulative logistic regression analysis

	Coefficient Estimate	SE	95% CI		p-value
			Lower	Upper	
Main effects terms					
Intervention group*	-2.47	0.79	-4.0	-0.9	0.002
Control group	0				
CMA1	1.43	0.52	0.4	2.5	0.01
Intercept [†]					
for CMA2=1 (Good)	1.64	1.05	-0.4	3.7	0.12
for CMA2=2 (Moderate)	4.21	1.28	1.7	6.7	0.001

SE: standard error; CI: confidence interval; CMA1: covariate, the global caregiver's mood status at baseline; CMA2: dependent variable, the global caregivers' mood after 8 weeks' intervention; Caregiver mood status was scored as 1, 2, and 3 for good, moderate, and poor, respectively; * Negative parameter estimate indicates that intervention group is associated with lower CMA2 score (that is, better mood) after follow-up; † Intercept for highest level of dependent variable not available

achieve even though in our present study depressive mood as measured by Zung¹⁷ SDS did not change over the time period. Nevertheless, all interventions had been planned in advance of the trial aiming at targeting the improvement of specific domain of IPD patients' physical and emotional functions, and their outcome measures were to reflect the specific aspect of the improvement except for meal intervention. Future study should use other relevant questionnaires or some laboratory tests to assess the related status. Finally eight weeks' group education with personal rehabilitation may be short for IPD, so an appropriate duration of the intervention should be evaluated by further study with a longer follow-up period to determine the efficiency and effectiveness of such intervention.

In conclusion, group education combined with a personal rehabilitation program appears to be a beneficial and practical intervention, not only complementing the medical treatment for IPD patients but also meeting the growing demand for long-term care.

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