ORIGINAL ARTICLE

Psychoeducational intervention for people with Parkinson’s disease and family/carers: Preliminary results at baseline time

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Abstract
Introduction: Psychosocial adjustment affects the quality of life of patients with Parkinson’s disease (PD) and his/her family/carers. However, this is not usually addressed in clinical practice.
Objective: To evaluate coping skills, psychosocial adjustment and quality of life of patients with PD and their family/carers from a quasieperiment at baseline time.
Method: Quasi-experimental study carried out in Primary Care centres to evaluate the impact of a psychoeducational intervention in contrast with an informative intervention. The sample comprised 80 patients with PD and 80 family carers, divided into a control group and an experimental group. The psychosocial adjustment scale PAIS-SR, the coping scale Brief COPE and the quality of life scales PDQ-39 and SQLC were used in the data collection. The analysis of sociodemographic data and Student’s t tests was performed using SPSS 23.0.
Results: The patients and family/carers from the control group and the experimental group noticed a mild impairment in their quality of life and some difficulties in their psychosocial adjustment to illness. Both groups used coping skills with a medium-low frequency. Acceptance was the most used coping skill by patients and family/carers. No statistically significant differences were found between the control group and the experimental group.

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Introduction

Parkinson’s disease PD is the second most common neurodegenerative disorder, with a prevalence of 1% in people over the age of 60 in developed countries, affecting 10 million people worldwide. It is estimated that 160,000 people have been diagnosed with Parkinson’s disease in Spain, and that the annual cost of this disease is 1700€ per person.

PD can cause many motor and non-motor symptoms that affect quality of life. As the disease progresses the affected person finds it more difficult to perform their activities, which obliges them to make major changes to their social life. Very often, these changes are perceived as losses that are imposed by PD, which makes coping with the disease very complex.

Several research studies highlight that psychosocial adaptation to the disease is a factor that has a significant impact on the quality of life of people with PD, and that coping can predict their psychosocial adjustment to PD.

Therefore, in addition to addressing the symptoms of PD, the health system must adopt strategies to promote the psychosocial adjustment and coping of patients with PD. These strategies must also meet the needs of the informal carers of people with PD, since, in most cases, their involvement in the patient’s care affects their wellbeing and quality of life.

The current non-pharmacological interventions for PD that have been developed to improve quality of life do not address or evaluate psychosocial adjustment and coping, and do not focus on informal carers as well as patients with PD. A multi-disciplinary psychoeducational intervention was developed in the ReNACE research programme to respond to this situation in clinical practice, which focuses on improving the coping skills and psychosocial adjustment of PD patients and their family/carers. The effectiveness of this intervention was assessed through a quasi-experimental study with a control group (CG) and experimental group (EG).
The aim of this study was to assess the coping skills, psychosocial adjustment and quality of life, in baseline time, of participants in the study’s EG and CG.

Methods

Design

A quasiexperimental study with a CG and repeated measures in baseline time -T0-, post intervention -T1- and 6 months post intervention -T2. The EG received a psychoeducational intervention and the CG received routine care information. With this design we sought to determine the short and long-term impact on the quality of life of PD patients and their family/carers of a psychoeducational intervention compared to a purely informative intervention.

Experimental intervention and control group

The intervention received by the EG consisted of a 9-week psychoeducational programme to facilitate psychosocial adjustment to PD. Each week a 90-min face-to-face session was held with 15–20 patients as well as another parallel session, with 15–20 family members/carers. The group approach was used to enable an exchange of opinions between people living in a similar situation. The team who delivered the sessions comprised nurses, doctors, psychologists and social workers. The subjects covered were the symptoms and treatment of PD; healthy life habits; the intrinsic value of the person; resources available in the community for people with disabilities; psychosocial adjustment to the disease and coping skills; the benefits of empathy, patience and positive self-esteem; relaxation techniques for stressful situations; the importance of living in the present, taking part in leisure activities, and the benefits of laughing. In each session the professional introduced and asked the participants about a particular subject, so that they could reflect on their situation and share their experience.

The CG participants received the routine care information over 5 sessions. In these sessions, they were given information about the symptoms of PD and its treatment, the importance of healthy lifestyle habits, and the resources available for people with disabilities. For the CG to be comparable to the EG, the sessions were 90 min long, with 15–20 people, one session per week, with patients and family/carers in different rooms.

Scope of the study

Six primary care centres of the Navarre Health Service – Osasunbidea took part in this study, which started in March 2015. This project took place in the community, because this is where these people need to rely on coping skills to enable them to live with their PD. Choosing the community and primary care centres as the scope of the study fits the lines of action defined under the National Health System’s Chronicity Strategy, which highlights primary care as the benchmark of quality care for people with chronic disorders. In order to avoid contamination between the CG and the EG participants, they were randomised according to their primary care centre. By tossing a coin (heads – control group; tails – experimental group), the experimental intervention was allocated to 3 primary care centres and the CG to another 3 centres.

Participants

The participants in this study were people diagnosed with PD, cared for as outpatients by the chosen health centres, over the age of 18, at any stage of the disease, resident in Navarre and with preserved cognitive capacity, as determined by their consultant physician.

The family/carers of people with PD also took part in this study, over the age of 18, resident in Navarre, and living with the patient or actively helping with their care.

The patients and family/carers participated on an individual basis. In other words, there was no obligation for the patient and their family/carer to take part together, because it was important to include people with no regular family member, and family/carers of patients with cognitive impairment who had not been able to take part in the study.

Consecutive case sampling was used in this study in the participating centres. The sample size was calculated using the STATA programme to detect a medium-large difference (10 points) in the quality of life of the participants after receiving the intervention. Taking into account the 95% confidence level, 80% statistical power and predicted losses of a maximum 25%, a total of 104 patients and 106 carers was required.

Variables

In this quasiexperimental study the variables were: quality of life (dependent variable); coping skills; psychosocial adjustment to the disease; sociodemographic characteristics; and the stage of PD, which was measured only in patients with Hoehn and Yahr classification.

Data collection

The instruments used to collect the data with the CG and EG group participants were:

- The Psychosocial Adjustment to Illness Scale (PAIS-SR). The scale was applied to the patients with PD and the family/carers. It is a scale with 46 items that assess the effects that the disease might have on family and social relationships, and on the ability to undertake tasks at work/home. Each item is assessed with a Likert scale of 4 answer options scored from 0 to 3. The maximum total score, obtained by adding all the items, is 138 points. However, a score above 62 points indicates that the person has difficulties in adjusting to their illness.
- The Brief COPE scale. This scale was used for patients with PD and their family/carers. It comprises 24 items classified into 12 styles of coping: self-distraction, active coping, denial, substance use, use of emotional support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion. Each item asks how often each coping skill is usually used, 1 being never
and 4 very often. Each coping style comprises 2 items; therefore the highest score is 8 and the lowest 2. Interpreting this scale enables the coping skills most used by the person to be identified.

- Quality of life scale PDQ-39.\textsuperscript{17,18} This scale was used for the patients with PD. It comprises 39 items that measure how PD affects the patient’s quality of life. Each item can be rated according to a Likert scale of 5 points. The result ranges from 0, which is the best score, when there are no problems, to 100, which is the poorest score, when the person’s quality of life is greatly impaired.

- Quality of life scale SQLC.\textsuperscript{19,20} This scale was used for the family/carers. It is a 16-item scale that measures the impact of the disease on the quality of life of carers. The result of this scale classifies the level of impact on the quality of life of carers into 4 grades\textsuperscript{19}; no impact from 41 to 149 points; mild from 100 to 140 points; moderate from 86 to 99 points, and severe if less than 85 points.

The data collection took place in the participant’s health centre. If the participant asked for help, the professional in charge of the data collection, read the question and the answers out loud and stated the option chosen by the participant. If the patient/family member did not attend the scheduled appointment, they were told by telephone that the questionnaire would be sent to them by post to their home address for them to complete and return in the stamped, addressed envelope provided in less than a week. If they had any queries regarding the questionnaire, the participant could call the phone number shown in the letter.

## Data analysis

Descriptive and frequency analyses were performed of the sociodemographic data and the Student’s $t$-test for independent samples with SPSS 23.0. The significance level was set at $p < 0.05$.

## Ethical considerations

This study was approved by the Ethics Committee of the University of Navarre and by the different participating primary care centres. All the people with PD and family/carers participated in this study voluntarily after being informed of its characteristics and signing their informed consent. The data of all the participants were handled confidentially.

## Results

The study was carried out with all the participants that met the inclusion criteria and answered the questionnaire (80 patients and 80 family/carers). The sociodemographic data of the participants, distributed into a CG and an EG, are shown in Table 1. Along general lines, it can be observed that most of the patients were men, with a basic level of education and in the initial stages of PD. In contrast, the family/carers were mostly female, with basic or university levels of education.

The results of the participants in terms of quality of life, psychosocial adjustment and coping skills are shown in Table 2. However we summarise the main findings below. We found that the quality of life of the family/carers, on average, was mildly affected, in both the CG and the EG.

With regard to psychosocial adjustment, we found that the patients and family/carers in the CG and EG perceived mild difficulties in their psychosocial adjustment to the disease.

On the Brief COPE scale,\textsuperscript{15,16} the patients and their family/carers in the CG and the EG achieved average scores, close to 50 points. Considering that the score’s maximum

### Table 1 Sociodemographic characteristics of the participants.

<table>
<thead>
<tr>
<th></th>
<th>Control group</th>
<th>Experimental group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients (n = 40)</td>
<td>Carers (n = 40)</td>
</tr>
<tr>
<td><strong>Age in years, mean (SD)</strong></td>
<td>73.2 (7.3)</td>
<td>61.1 (14.6)</td>
</tr>
<tr>
<td><strong>Gender, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>26 (65)</td>
<td>6 (15)</td>
</tr>
<tr>
<td>Female</td>
<td>14 (35)</td>
<td>34 (85)</td>
</tr>
<tr>
<td><strong>Basic education, n (%)</strong></td>
<td>29 (72.5)</td>
<td>16 (40)</td>
</tr>
<tr>
<td><strong>Vocational training, n (%)</strong></td>
<td>1 (2.5)</td>
<td>7 (17.5)</td>
</tr>
<tr>
<td><strong>University education, n (%)</strong></td>
<td>10 (25)</td>
<td>17 (42.5)</td>
</tr>
<tr>
<td><strong>Civil status, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>7 (17.5)</td>
<td>6 (15)</td>
</tr>
<tr>
<td>Married/partner</td>
<td>26 (65)</td>
<td>30 (75)</td>
</tr>
<tr>
<td>Widowed/divorced</td>
<td>7 (17.5)</td>
<td>4 (10)</td>
</tr>
<tr>
<td><strong>Hoehn and Yahr, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>22 (55)</td>
<td>–</td>
</tr>
<tr>
<td>Stage II</td>
<td>6 (15)</td>
<td>–</td>
</tr>
<tr>
<td>Stage III</td>
<td>8 (20)</td>
<td>–</td>
</tr>
<tr>
<td>Stage IV</td>
<td>4 (10)</td>
<td>–</td>
</tr>
</tbody>
</table>
total score is 96 and that this indicates that the person often uses the coping skills assessed, it is reasonable to assume that the participants developed coping skills with a low-medium frequency. When we analysed the coping styles separately (see Table 3), the results show that acceptance was the coping skill most used by the patients in the CG and the EG, followed by emotional support. The most used coping skill in the family/carers of both groups was also acceptance. However they used active coping after that. The least used coping skill was substance use, both by the patients and the family/carers in the CG and in the EG.

It is noteworthy that no statistically significant differences were identified between the CG and the EG in quality of life, psychosocial adjustment and coping skills (see Table 2). This would enable the effect of the intervention to be evaluated better later.

### Discussion

In this study, the quality of life of the people with PD was mildly impaired. This finding might be associated with the fact that around 50% of the patients were Hoehn and Yahr stage 1, since previous research studies indicate that quality of life tends to reduce as the severity of the disease and its motor and non-motor symptoms increase.

Similarly, we observed in this study that the quality of life of the family/carers was also mildly impaired. It is
important to underline this result, since care for the family/carer is not always adequate. However, their involvement in the support and care of people with PD can cause major changes in their roles and, as we found in this study, impair their quality of life.\textsuperscript{9,10} Therefore interventions to promote health and prevent injury/disease need to be implemented for family/carer that meet as yet uncovered needs and help reduce their stress levels.\textsuperscript{9,10}

Coping capacity is a specific area that could be worked on with both family/carer and patients. According to the results of this study, the patients with PD and their family/carer developed coping skills with a low-medium frequency and perceived some difficulties in adjusting to the disease. We also identified that the patients with PD and their family/carer used different types of coping strategies. According to the classification by Lazarus and Folkman,\textsuperscript{11} the participants developed problem-focussed coping strategies (they sought to resolve the problem causing the discomfort directly) and emotion-focussed coping strategies (aimed at regulating the emotional response to the problem).\textsuperscript{22,23}

Another result was that the patients with PD had a slight tendency to develop more emotion regulation coping skills, such as acceptance or use of emotional support, which are associated with less constructive coping than that of problem-centred strategies.\textsuperscript{22,23} This lower use of active coping strategies by PD patients has been evidenced previously, being lower than that observed in patients with other chronic diseases.\textsuperscript{24} According to previous research studies,\textsuperscript{22,23} active coping is associated with better quality of life than the passive or avoidance coping style, such as denial, that was sometimes used by the study participants.

Therefore, it is important that the care plans of patients with PD are regularly assessed for diagnoses of ineffective coping [00069] and readiness for enhanced coping [00158]. In other words, nursing care must address not only the fatigue or constipation that occur with a diagnosis of PD,\textsuperscript{4} but also the experience of the person, the psychosocial changes that they are undergoing, and their coping responses.\textsuperscript{26,27} It is important for nurses to enable patients with PD and their family/carer to realise that the way they cope with the disease is an essential component in their recovery and treatment, since it can impact their quality of life.

Nursing care for a person’s ability to cope must be ongoing, since coping skills are constantly changing, cognitive and behavioural efforts to overcome challenges.\textsuperscript{21} PD, because it is neurodegenerative in nature and due to the unpredictable fluctuations of its symptoms, demands a great effort from patients and their family/carer to adjust, which makes coping an especially important aspect of their social and health care. Individualised care is essential of the coping capacity of a patient with PD and their family/carer, because no coping style is definitely more effective than another.\textsuperscript{22} By contrast, it is most important that the person is able to alternate their coping strategies to identify the strategy that best helps them adjust to every situation in their particular circumstances.\textsuperscript{21}

With regard to the limitations of this study, it should be noted that the voluntary nature of participation makes it difficult to generalise the results, since there was the possibility that some of the patients were not able to participate because they had entered a stage of the illness that excluded them from the study.\textsuperscript{26} Similarly, a larger sample size would be necessary to evaluate the later effect of the psychoeducational intervention. Another limitation is the low severity of disease in the study group; therefore it would be advisable to evaluate the intervention for patients more severely affected by PD. And finally, this research study should be performed on different populations, since the results might have been influenced by the context of the participants.

To conclude, we observed that the quality of life and adjustment to their illness of patients with PD and their family/carer was impacted. Therefore it is important for primary health professionals to have the resources to record and develop psychoeducational interventions that focus on reinforcing this population’s coping skills. This would provide people with PD and their family/carer comprehensive care of higher quality.

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**Conflict of interests**

The authors have no conflicts of interest to declare.

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**References**


