



## **Impact of Parkinson's Disease on Patient Participation in Daily Life: Results of an International Survey**

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### **ABSTRACT**

Everyday activities that patients with Parkinson's disease (PD) find particularly challenging and frustrating are seldom fully considered in the design of treatment strategies and care management, which generally focus on controlling the motor symptoms of the condition. To determine which disease and medication-related factors patients with Parkinson's disease regard as common obstacles affecting their desire and ability to go about their daily lives we developed the Participation in Life (PIL) survey. The survey set out to ascertain what, and how frequently, disease and medication-related symptoms and problems (physical, psychological/emotional, and sleep/nocturnal complications) affected the daily lives of people with PD. Responses were received from 6815 individuals with PD from 14 countries; ninety-seven percent (6593/6815) of respondents were taking PD medication. We found a high level of unmet physical and psychological patient needs that highlight the requirement for improvement in the treatment and management of PD patients. The symptoms and problems that affected the respondents' PIL were feeling tired (6285/6815=92%), difficulty writing (5835/6815=86%), tremor (5343/6815=78%) and feeling depressed or miserable (5324/6815=78%). Getting to sleep, staying asleep, the side-effects of PD medication and the wearing off of PD medication between doses each affected the PIL of over 60% of respondents (n=4336, 4952, 4417 and 4290, respectively).

**Key Words:** Quality of Life – Activities of Daily Living – Parkinson's Disease – Tremor – Sleep – Participation in Life.

## INTRODUCTION

Patients with Parkinson's disease (PD) experience difficulties in carrying out daily activities because of disease-related loss of movement and movement control<sup>1</sup>, such as that caused by bradykinesia, rigidity and tremor<sup>2</sup>, and as a result of emotional symptoms, such as depression. Physicians often fail to realise the full impact that the disease has on patients' daily lives. Medication and care strategies often focus on the motor symptoms of the disease rather than the overall needs of the individual<sup>3</sup>.

As the percentage of the elderly population increases globally, the incidence of PD is expected to increase. In order to aid new drug development and to optimise treatment and care strategies, we recognised the need for better understanding of those aspects of the disease that most commonly had a detrimental impact on patients' lives.

Several tools have already been successfully developed to measure patients' self-perceived severity of physical, emotional and social function<sup>4,5,6,7</sup>. These questionnaires are useful tools for measuring health-related quality of life (QoL) and psychological parameters<sup>8</sup> but they do not assess which disease-related symptoms and problems patients themselves find most commonly interfere with their ability and desire to participate fully in everyday activities.

The international Participation in Life (PIL) survey was designed to investigate the extent PD patients in different countries find that their symptoms and medication-related problems affect their ability to undertake even the simple tasks they meet on a day-to-day basis. As all these symptoms and problems tend to increase in severity with progression of the disease<sup>5,9</sup>, we also set out to investigate any changes as the disease progressed.

## METHODS

The PIL questionnaire was designed in collaboration with NOP (National Opinion Polls) Healthcare on behalf of the European Parkinson's Disease Association (EPDA) following initial discussions with PD patients and their carers. The PIL questionnaire listed those challenges or symptoms that PD sufferers had previously reported as making everyday activities and actions difficult to carry out. Each respondent was asked to assess the extent to which each challenge or symptom affected their ability to go about their own life on a daily basis. They were asked to rate the effect of each one as: always, often, sometimes, never or not applicable. The survey also included questions modelled on the 4-point SASS questionnaire (the Social Adaptation Self-Evaluation

Scale, a valid and reliable evaluation of patient social functioning – related to their motivation and behaviour in depression)<sup>10</sup>. The respondent's sex, age, marital status, year of diagnosis and frequency of dosing regimen were also recorded. The anonymity of the respondent was preserved at all times.

The questionnaires were developed in English and then translated. They were assessed before use by a small group of patients and carers in each participating country to determine their ease of use and comprehension following translation. They were distributed to individuals with PD with pre-paid reply envelopes.

Patients from a total of 14 countries took part: Argentina, Belgium, Brazil, Czech Republic, Denmark, Finland, France, Netherlands, Poland, Republic of Ireland, Spain, Sweden, United Kingdom and the United States of America. The questionnaires were sent directly to individuals (whose names were provided by local PD associations, or physicians) or to local PD associations who then dispatched the questionnaire to their individual members. A control group was not included due to impracticalities in identifying and enrolling a suitable group in each country.

NOP Healthcare collected and analysed the data from each questionnaire. Each response was designated a score: always = 3, often = 2, sometimes = 1 and never = 0. The total number (n) and percentage (%) of patients were tabulated for each question by response and stratified by year of diagnosis. The mean and standard deviation (SD) of each question score was calculated. The mean question scores of respondents were also grouped by time since diagnosis (before 1990, 1990 to 1995 and after 1995).

## **RESULTS**

Forty-two percent (6815/16147) of the questionnaires despatched were returned, with the response rate varying between 70% (Poland, n=164) and 16% (Spain, n=180). The number of respondents varied between countries; the most were from Sweden (n=1182, response rate 57%) and the USA (n=1048, response rate 26%) and the fewest were from Argentina (n=133, response rate 35%) and Poland (n=164, response rate 70%). All other data were comparable across countries and continents.

Respondent characteristics are presented by year of diagnosis in Table 1. 87% of respondents were aged between 51 and 80 years, and 75% of respondents were married. More males than females responded to the questionnaire (57% vs. 42%).

Results are presented in Table 2. The most common problems that at least sometimes affected the ability of respondents to go about their daily lives were feeling tired (92% respondents of which 60% were often or always affected) and difficulty writing (86% respondents of which 63% were often or always affected). A high proportion of respondents also reported that PD symptoms of tremor (78% respondents) and feeling depressed or miserable (78% respondents) at least sometimes affected their daily lives. Sleep related problems and complications were prevalent in over 60% of respondents who had difficulties getting to sleep an/or staying asleep. Over 60% of respondents felt that the side effects and/or the wearing off of the dose of their PD medication at least sometimes affected their ability to go about their daily lives.

As time since diagnosis increased, more patients appeared to be affected at least sometimes by their physical symptoms, psychological/emotional problems, and sleep problems. In addition, the number of patients having to take PD medication more than three times a day showed an increase, as did the number reporting medication-related\* problems. The numbers of respondents experiencing problems from tremor and difficulty remembering things, were consistently high at all stages of the disease\*.

## DISCUSSION

The impact of Parkinson's disease goes beyond the physical effect on movement or control of movement. The progression of the disease and the extent of its symptoms can affect not only an individual's ability to take an active role in everyday life, but also his or her desire to do this.

The daily lives of up to three in four questionnaire respondents were affected by either tremor, depression, daytime tiredness, difficulty writing and/or sleep problems. 97% of respondents were taking some form of PD medication. Over 60% of respondents admitted that their lives were affected by the side effects of their PD medication and the wearing off of the beneficial effect of their medication between doses. Disturbances in sleep suffered by PD patients have often been attributed to the lack of nocturnal symptom-control offered by traditional shorter-acting PD medications such as levodopa<sup>11,12</sup>. Lack of sleep is likely to contribute to daytime tiredness and depression.

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\* The medication taken by each patient was not documented, as comparing the differences between medications was deemed to be beyond the scope of this study. However, at the time of the survey fieldwork, older medications such as levodopa and pergolide had been on the market for some time. Levodopa was the most commonly prescribed medication world-wide. Of the newer medications, ropinirole was available in most countries and pramipexole was available only in the US and Denmark.

\* Tremor was found to always, often or sometimes affect 79% of those diagnosed before 1990, 79% of those diagnosed between 1990-1995 and 78% of those diagnosed after 1995. Difficulty remembering things was found to always, often or sometimes affect 78% of those diagnosed before 1990, 75% of those diagnosed between 1990 and 1995, and 73% of those diagnosed after 1995.

Tremor, difficulty writing, drug side effects and 'on/off' periods have been reported as chief complaints by people with PD in previous studies<sup>5,6,13,14</sup> although the actual severity of symptom/problem was measured rather than the extent to which patient's lives were affected. Despite the different measures, it appears that the proportions of patients who suffer from these symptoms in our survey are higher than in previous studies.

Mild changes in neurologic function occur with normal ageing but generally do not substantially interfere with everyday activities unless disease intervenes<sup>15</sup>. No control population was used in our survey but similar studies with control patients have shown that depression<sup>16</sup>, a low degree of independence and a lack of energy<sup>17</sup> are higher in PD patients than in healthy controls.

We observed that patients who had been diagnosed with PD before 1990 appeared to be taking medication more frequently and their PIL was more affected than patients who were diagnosed after 1995. This is assumed to be related to the severity of symptoms worsening with disease progression<sup>9,18</sup>.

## **CONCLUSION**

The daily challenges of patients with Parkinson's disease (PD) are seldom fully considered in the design of treatment strategies and care management, which generally focus on controlling the motor symptoms of the condition. Our PIL survey provides the evidence to support what people with PD have been telling the EPDA for a long time, highlighting the extent to which PD and certain treatments affect their lives.

The survey has helped reveal that long relied upon traditional therapies are not enough to satisfy all aspects of the disease. The unmet patient needs identified should be considered during drug development and the planning of care strategies. There is a need for doctors to consider new therapies, which can prolong the window of effective treatment for people with PD, enabling them to continue to participate as fully as possible in everyday life.

## **ACKNOWLEDGEMENT**

This paper was supported by an educational grant from Pharmacia, Peapack, NJ, US

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