

Knowledge of Parkinson's disease among patients and caregivers attending movement disorder clinic at a tertiary care centre in north India

Ravi Yadav, Garima Shukla, Vinay Goyal, Sumit Singh, Madhuri Behari

Department of Neurology, All India Institute of Medical Sciences, New Delhi, India

Abstract

Context: Few studies have been done to see the level of knowledge among patients and caregivers about Parkinson's disease (PD). **Aims:** The aim of the current study was to determine the knowledge of PD among patients and caregivers at a movement disorder clinic in India. **Settings and Design:** A tertiary care neurology facility in north India. **Materials and Methods:** We conducted a questionnaire based interview among the subjects collected on the annual PD day in 2006. **Results:** Out of 200 questionnaires that were distributed 172 subjects responded. Of these, there were 103 (59.8%) patients with PD and 69 (40.11%) caregivers. Mean age of the patients and caregivers was 55.4 ± 13.3 years and 49.4 ± 15.9 years respectively. Mean duration of PD was 6.8 ± 4.7 years (range-21). Ninety nine patients out of the 103 (96.1%) and 57 caregivers out of 69 (82.6%) had previously attended the PD education program. High scores (>90%) were obtained to questions on body parts affected, pathology in PD, main drug treatment, epidemiology and effect of exercise. Low scores were seen to questions on surgery in PD and biochemical abnormality in PD. No significant difference was noted in correct answers among patients and caregivers on duration of PD. **Conclusion:** Patients and caregivers had adequate knowledge about PD. Patient and caregiver education programs may be useful in imparting knowledge about PD.

Key Words

India, Knowledge, Parkinson's disease

For correspondence:

Dr. Madhuri Behari, Department of Neurology, All India Institute of Medical Sciences, New Delhi, India.

E-mail: madhuribehari@gmail.com

Ann Indian Acad Neurol 2012;15:294-6

Introduction

Parkinson's disease (PD) is one of the most common late life neurodegenerative disorders. Despite advances in the treatment in the form of drugs and neurosurgical procedures the benefit of these is still not being passed to the vast majority of the patients in the developing countries. Very little information is available about the knowledge of Parkinson's disease patients or their caregivers in India

This study was done to get an insight into the knowledge about PD among patients and their caregivers at a tertiary care center in India.

Materials and Methods

The patients and caregivers visiting the Parkinson's day commemoration program at the tertiary care neurology Centre in North India were asked questions about PD in 2006. All subjects gave an informed consent and they were assigned numbers to conceal their identity. The ethical clearance was not taken as study involved the use of collections of data that contained only non-identifiable data about human beings.

The questions were divided into three parts covering etiology, symptomatology and treatment of Parkinson's disease. Supplementary material: Questionnaire)

A questionnaire consisting of 10 multiple choice questions with four options each were provided to subjects who had to mark the correct option in a stipulated time. Questionnaires in both local (Hindi) and English languages were distributed among the attendees of the program out of whom 172 were returned. The questions that were asked included: one question on body part affected in PD, two questions on the cause of PD, one on symptomatology of PD, four questions on medical and surgical treatment options in PD, one on effect of exercise in PD and

Access this article online

Quick Response Code:



Website:

www.annalsofian.org

DOI:

10.4103/0972-2327.104339

one on mode of transmission in PD. Data regarding name, age and educational status was also collected from the subjects. They were also asked if they had attended similar educational program on PD earlier or not.

Results

Of the 200 questionnaires 172 were available for analysis. The respondents consisted of both the patients (n=103) as well as the caregivers (n=69). There were 140 men (81.4%). The mean age among patients was 55.4 ± 13.3 years and 49.4 ± 15.9 years among the care givers. [Table 1] Most respondents were educated up to primary school, ($n = 152$, 88.4%) whereas only 16 (9.3%) were graduates. Responses to the different questions are shown in Table 2. Mean duration of PD was 6.8 ± 4.7 years. There were 85 (82.5%) male patients and 55 (79.7%) male caregivers. Out of the 103 patients 99 and 57 out of 69 caregivers had previously attended the PD education program. There was no significant difference between the patients and caregivers in number of correct responses given. Also there was no significant association between the duration of disease or educational status of respondents and the maximum number of correct responses.

Discussion

The response rate of 172 (86%) out of 200 was rather good in the study. As compared to the studies that use postal surveys where the response rates were only 40% our response rates were 86% and the respondents were actively involved in the whole process of answering.^[1]

Comparing with other medical disorders like rheumatic heart disease, cancer and epilepsy there are no studies that assess the

knowledge, attitudes and perceptions of the general population or patients and caregivers about Parkinson's disease.^[2] Ability for optimal living demands knowledge about the sickness, medications, side-effects and knowledge about the best way to go on living with PD, hence the need for educating the patients and the caregivers. There is also dearth of studies, which assesses the impact of concurrent education program of Parkinson's disease for the caregivers and the patients. Many patients or caregivers who had not attended previous education programs also fared well in answering the maximum correct answers. The reason for this could have been the regular exposure to PD experts during consultations rather than patient education programs alone. They had also received knowledge by means of pamphlets and books about Parkinson's disease in the clinic for education purpose and personalized counseling. This could also be the cause of significantly higher number of correct answers. The absence of any significant difference between the answers of the caregivers and patients suggests that whole family is involved in the care of patient with PD in a significant manner including the patient and the caregiver. The maximum numbers of incorrect answers were regarding the surgical options and timing of surgery in PD. Only patients who had undergone surgery or were contemplating it could answer the question correctly. In a hospital-based study on 34 patients of PD, authors found 29 patients had no knowledge of the disease, and only one caregiver had superficial knowledge of the disease.^[3]

It has previously been shown that the patients despite having a chronic, progressive neurological disease, perceived themselves as hopeful and engaged in a health promoting lifestyle.^[4] However, there is a chance of potential bias in our study considering the study group mainly comprised of patients and caregivers who have been mostly educated and informed about PD by means of various educational programs. This result hence cannot be extrapolated to the general population in the country.

In a recent study from India it was found that majority of patients were ignorant about their disease, importance of compliance to medicines and about precautions to be taken. The diseases included were coronary artery disease, chronic pulmonary disease, hypertension and diabetes.^[5] This study again emphasizes the need for adequate patient education and the role of specialty clinics in imparting the knowledge.

More information about PD in print and electronic media is needed and establishment of dedicated movement disorder

Table 1: Baseline characteristics of the total 172 respondents

Characteristics	Patients	Care givers
N (%)	103 (59.8)	69 (40.1)
Age (mean \pm SD; range)	55.4 ± 13.3 ; 68	49.4 ± 15.9 ; 62
Male gender	85 (82.5)	55 (79.7)
Duration (months)	81.7	-
Previously attended education program	99 (96.1)	57 (82.6)
Primary education	87 (84.5)	65 (94.2)

Table 2: The frequency of correct and wrong answers of questions asked in the study

Questions	Correct answers (%) Patient /carer	Incorrect answers (%)	Unanswered (%)
Body part affected in PD	166 (97.08)	5 (2.92)	1 (.01)
Pathology in PD	157 (91.3)	13 (7.6)	2 (.02)
Biochemical abnormality in PD	109 (63.4)	56 (32.6)	7 (4)
Main symptom of PD	150 (87.2)	17 (9.9)	5 (2.9)
Main treatment of PD	165 (95.9)	2 (1.2)	5 (2.9)
Epidemiology of PD	162 (94.2)	5 (2.9)	5 (2.9)
Effect of Exercise in PD	160 (93)	7 (4.1)	5 (2.9)
Percent of genetics in PD	148 (86)	14 (8.1)	10 (5.8)
Stage at which operation is done in PD	96 (55.8)	70 (40.7)	6 (3.5)
Which operation is not done in PD	58 (33.7)	104 (60.5)	10 (5.8)

SD = Standard deviation, *Figures in parenthesis are percentage values

clinics and centers of excellence with special education programs would go a long way in increasing the awareness and knowledge of PD in India.

Conclusion

The patient and caregiver education programs may have a positive role on imparting knowledge to patients and caregivers of PD. Studies are needed to understand the knowledge, attitude and perceptions regarding Parkinson's disease among general population.

Questionnaire

There were three questions about cause of PD, two about epidemiology, two on symptoms and three on treatment. Correct answers are in bold letters.

- Parkinson's disease is related to which part of the body?
 - Liver
 - Kidney
 - Brain
 - Heart
- Parkinson's disease is due to
 - Degeneration of specialized cells
 - Lack of blood supply
 - Swelling
 - Infection
- The cause of Parkinson's disease is
 - Decrease in dopamine level
 - Increase in dopamine level
 - Decrease in serotonin level
 - Decrease in acetyl choline level
- Following is the main symptom of early Parkinson's disease
 - Diminution of eye sight
 - Loss of memory
 - Tremors in the hands
 - Unsteadiness of the legs
- Following is the main treatment of Parkinson's disease
 - Aspirin
 - Phenytoin
 - Pramipexole
 - Levodopa
- Which of the following statement is correct about Parkinson's disease?
 - This disease is more common in children
 - In this disease the body becomes stiff and all the activities become slow
 - This disease spreads from one person to another by touch
 - This disease is more common in women
- Which of the following statements is true about Parkinson's disease
 - exercise is not required in Parkinson's disease
 - exercise worsens Parkinson's disease
 - exercise causes softness of body and improves movements
 - it does not cause any change.
- In how many people do Parkinson's disease run in family (it is genetic)
 - 10-15%
 - 25-30%
 - 50-60%
 - More than 75%
- In Parkinson's disease operation is done at what stage of the disease?
 - In the early stage of the disease
 - When disease is advanced and there is memory loss
 - When disease is advanced and there is dyskinesia due to medicines
 - When disease is advanced and there is tendency to fall frequently
- Out of the following operation which is not done in Parkinson's disease
 - Deep brain stimulation
 - Shunt operation of brain
 - To produce a lesion (damage) in pallidum/thalamus
 - Implantation of stem cells in brain

References

- Van Der Wardt EM, Taal E, Rasker JJ. The general public's knowledge and perceptions about rheumatic diseases. *Ann Rheum Dis* 2000;59:32-8.
- Seydel ER, Taal E, Wiegman O. Risk-appraisal, outcome and self-efficacy expectancies: Cognitive factors in preventive behavior related to cancer. *Psychol Health* 1990;4:99-109.
- Lee KS, Merriman A, Owen A, Chew B, Tan TC. The medical, social, and functional profile of Parkinson's disease patients. *Singapore Med J* 1994;35:265-8.
- Fowler SB. Hope and a health-promoting lifestyle in persons with Parkinson's disease. *J Neurosci Nurs* 1997;29:111-6.
- Beniwal S, Sharma BB, and Singh V. What we can say: Disease literacy. *J Assoc Physicians India* 2011;59:360-4.

How to cite this article: Yadav R, Shukla G, Goyal V, Singh S, Behari M. Knowledge of Parkinson's disease among patients and caregivers attending movement disorder clinic at a tertiary care centre in north India. *Ann Indian Acad Neurol* 2012;15:294-6.

Received: 29-02-12, **Revised:** 20-03-12, **Accepted:** 22-04-12

Source of Support: Nil, **Conflict of Interest:** Nil