

Improving outcome in Parkinson's disease

Parkinson's disease (PD), shaking palsy or paralysis agitans was described in 1817 by James Parkinson in his publication 'An essay on the shaking palsy' (Burch and Sheerin, 2005). PD is a syndrome characterized by bradykinesia, rigidity and tremor. In addition to reduced mobility, postural instability and falls, patients can experience difficulty in swallowing, malnutrition, depression and dementia.

PD is more common in the elderly but can affect any age group. About 2% of people above the age of 65 years are affected and a substantial number of patients with PD remain undetected (de Rijk et al, 1997). With the growing elderly population the incidence and prevalence of PD will continue to rise. PD not only affects the individual but also has a significant impact on families, caregivers and the community (Caap-Ahlgren et al, 2002).

The long-term management of PD presents a special challenge, in which a multidisciplinary approach and the education of patients and their caregivers is essential. There are a number of different models to improve care, such as PD clinics, specialist PD nurses, patient and family support groups and various education programmes (Montgomery et al, 1994; Shimbo et al, 2004). Non-governmental organizations such as Parkinson's Disease Society and European Parkinson's Disease Association also play an important role in providing help, support and funding (Baker, 1992).

An effective model (Ianseck, 1999; Kale and Menken, 2004) should provide a multidisciplinary assessment for correct diagnosis and intervention, information and a management plan, giving patients the support confidence and reassurance they need. The PD club was introduced at the day hospital in Bridlington as a means of education, to improve awareness of the needs of patients and caregivers and to provide shared care involving a multidisciplinary team (Nasar et al, 1999). The club meets every 2 months in the day-hospital

and, in addition to assessment and therapy, discussions, seminars and demonstrations are organized after consultation with the patients and caregivers.

Multidisciplinary team

The team includes a geriatrician and a nurse specializing in PD, a pharmacist, dietitian, physiotherapist and occupational therapist. In addition other specialists are invited as appropriate, and include a community psychiatry nurse, GP, medical social worker, speech and language therapist, member of housing department, patient's advocate, ear, nose and throat specialist, dental surgeon, clinical psychologist, psychiatrist and neurologist.

The consultant geriatrician provides updated concepts with current best evidence for management, as well as assessment, diagnosis and follow up. The nurse specializing in PD provides assessment, acts as the day-hospital coordinator to organize club meetings and is the point of contact and key person for communication between patients, caregivers and other team members.

The pharmacist and physician outline the role of medication and availability of different drug regimens. The duration of action, side effects of the drugs and how to avoid them is also detailed. Patients are advised on how to manipulate and adjust the dosage in order to achieve the best possible effect.

Advice from the dietitian helps to correct malnutrition and has a positive effect on drug therapy and symptoms. Areas covered, which have been requested by the patients, include soft and pureed diet, food supplementation, diet and medication, constipation and diet, healthy eating and role of antioxidants.

A speech and language therapist is also involved at an early stage to manage problems of drooling, swallowing and communication.

The occupational therapist and physiotherapist play a vital role. The therapist empowers the patient to learn

techniques, adapt his/her behaviour and lifestyle and adjust the environment to facilitate independence. Group therapy in the form of exercise with music, relaxation and breathing exercises are advised. The occupational therapist liaises with social services for the housing and equipment needs and counselling from the social worker regarding pensions, benefits, finances and housing has proven very helpful. Formal counselling regarding problems and difficulties with sexual health can also be given.

The caregiver's role is recognized and valued and they are provided with help and support to reduce emotional stress and maintain good health.

Our experience

Before each meeting patients and caregivers are given the opportunity to select topics for discussion or demonstrations. At the end of two such meetings, questionnaires were sent out to patients and caregivers to ascertain the usefulness of the club discussions and demonstrations, in an attempt to identify areas needing attention and to measure the effectiveness of the club activities in PD care.

Out of the 32 questionnaires sent, 29 (90.6%) were returned. All patients knew that they could contact the day-hospital coordinator any day of the week and felt that the PD club helped them to understand their condition and the treatment. Over two-thirds of patients could manage their medication better, could cope better, found club meetings helpful in planning diet, knew when to get support at home, could discuss their problems freely and felt that club discussions helped them generally. Over 70% of patients attended the club more than twice and patients and caregivers suggested that the PD club meetings should be held every month.

Discussion

Identifying the needs of people with PD, their caregivers and their family members is very important in improving

the overall outcome. Although patients and their caregivers want to know more (Hayes, 2002; Gracia and Solis, 2005) they may not report their concerns owing to a variety of reasons, such as not knowing who to contact, lack of information and understanding, fear and anxiety, and formal consultation and time restraint in the clinics.

The PD club can provide a medium of education, some degree of reassurance and a way forward. The meetings provide the patient and his/her caregivers with the opportunity to meet different people and learn more about the disease and management strategies. It enables them to access the means by which they can maintain their own independence and know where they can find help. The PD club provides social interaction and an atmosphere for free discussion without fear and anxiety. It provides psychological and physical support, educating patients and caregivers and improving compliance in medication. PD club is also improving communication and understanding between health-care professionals. Advice and support from a multidisciplinary team is helping sufferers of PD to maintain a more purposeful and dignified lifestyle.

Conclusions

The feedback and analysis from the PD questionnaire clearly indicates that the club is fulfilling the needs of patients and their caregivers. It provides a forum for the patients, caregivers and health-care professionals and improves communication. Shared care and a holistic approach is helping the community and

provides the best care and support for patients and caregivers. The PD club is complementary to existing services. The philosophy and concept of the PD club should be widely adapted to improve the overall management of PD with better quality of life for the patient and their caregivers. **BJHM**

MA Nasar

Consultant Physician and Geriatrician

Bridlington Hospital

Bridlington

North Yorkshire YO16 4QP

RN Bankar

Specialist Registrar in Medicine

Scarborough General Hospital

Scarborough

The authors would like to thank Philippa Dyer and the team members for their enormous efforts in making the Parkinson's disease club a success and are grateful to the patients and their caregivers for their valuable comments and feedback.

Baker M (1992) The role of the voluntary sector: pump primer or pit prop. *J Neurol Neurosurg Psychiatry* **55**(Suppl): 45-6

Burch D, Sheerin F (2005) Parkinson's disease. *Lancet* **365**: 622-7

Capp-Ahlgren M, Dehlin O (2002) Factors of importance to the caregiver burden experienced by family caregivers of Parkinson's disease patients. *Aging Clin Exp Res* **14**: 371-7

de Rijk, MC, Tzourio C, Bretter MM, et al (1997) Prevalence of Parkinsonism and Parkinson's disease in Europe: the EUROPARKINSON Collaborative Study. European Community Concerted Action on the Epidemiology of Parkinson's disease. *J Neurol Neurosurg Psychiatry* **62**: 10-15

Garcia JM, Solis MJ (2005) Nurses who treat Parkinson patients: what do they know and what do they want to know? *Rev Enferm* **28**: 42-50

Hayes C (2002) Identifying important issues for people with Parkinson's disease. *Br J Nurs* **11**: 91-7

Ianseck R (1999) Key points in the management of Parkinson's disease. *Aust Fam Physician* **28**: 897-901

Kale R, Menken M (2004) Who should look after people with Parkinson's disease? *BMJ* **328**: 62-3

Montgomery EB Jr, Lieberman A, Singh G, et al (1994) Patient education and health promotion can be effective in Parkinson's disease: a randomised controlled trial. PROPATH Advisory Board. *Am J Med* **97**: 429-35

Nasar MA, Dyer P, Short C, Wilmot C (1999) What is the role of Parkinson's Disease Club in PD care? *Parkinsonism Relat Disord* **5**(Suppl): 53

Shimbo T, Goto M, Morimoto T et al (2004) Association between patient education and health-related quality of life in patients with Parkinson's disease. *Qual Life Res* **13**: 81-9

KEY POINTS

- Long-term management of Parkinson's disease remains challenging and educating patients and caregivers is important.
- A multidisciplinary approach with good communication between health-care professionals, patients and caregivers is essential.
- There are various existing models for help, support and management of Parkinson's disease.
- The Parkinson's disease club is recommended as a complementary model to improve the overall management in Parkinson's disease.