

Multidisciplinary Team Work Can Improve the Care of Families With Parkinson's Disease

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Abstract

Parkinson's disease (PD) is now recognised as a multidimensional disease that involves motor and non-motor symptoms. As such, a multidisciplinary team should ideally be involved in the care of patients with PD. There are several approaches or models that can be used – simple parallel, consultative or collaborative approaches are usually based on informal sharing of information, whereas coordinated, multidisciplinary and interdisciplinary approaches involve more formalised teams usually having regular meetings and making group decisions. At the Movement Disorders Unit at the Tel Aviv Medical Centre, an interdisciplinary team approach has been used for the past 15 years. The team consists of neurologists, gerontologists, a psychiatrist, nurses, a social worker, a speech, language and swallow therapist, a sexologist, physiotherapists, an occupational therapist, a dietitian, a neuropsychologist, research assistants, genetic counsellors and secretaries. The centre has clinics for PD, atypical parkinsonism focusing on multiple system atrophy, autonomic dysfunction with an autonomic laboratory, sexual counselling service, a gait and falls prevention clinic, a special clinic for demented and psychotic patients and a genetic counselling clinic. In addition, a recent clinic for prevention of PD was opened for populations at risk. The centre also provides individual counselling to carers in a special carers' clinic and a wide variety of group therapy programmes for patients, carers and first-degree relatives. This holistic approach provides benefits to the patients, as well as their families and carers. However, published evidence on the benefits of multidisciplinary teams (or other partnering models) is lacking. The large-scale ParkinsonNet initiative in the Netherlands has not apparently resulted in improved outcomes for patients (at least not in the short term), whereas a smaller prospective study in Canada suggests improvements across a number of symptom scales. Both these surveys have measured cost savings with partnering programmes, which gives hope that despite the initial effort required to initiate team structures, they could be cost-effective in the longer term. More data are needed to confirm this suggestion.

Keywords

Parkinson's disease, multidisciplinary teams, partnering programmes

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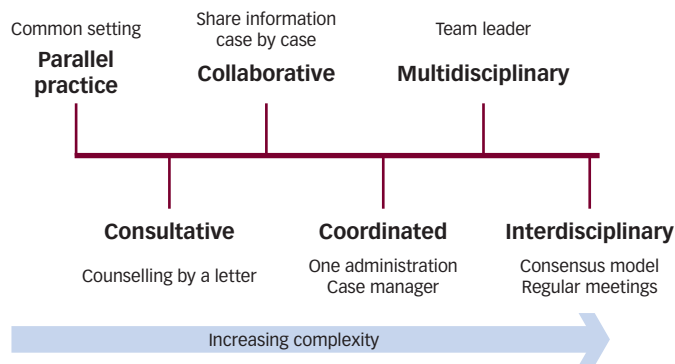
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Parkinson's disease (PD) is a very complex condition. Usually, there is a brief 'honeymoon' period after diagnosis, during which the motor symptoms are reasonably well controlled by medication. However, after three to five years a range of symptoms, such as motor response fluctuations, dyskinesia, gait problems and falls, become an increasing problem with a major impact on mobility and independence. Importantly, it is now clear that patients with PD have a high prevalence of non-motor symptoms, such as sleep disorders, psychiatric disorders, pain, gastrointestinal symptoms, depression/anxiety, apathy, behavioural changes, psychosis and dementia.¹⁻³ Furthermore, recent data demonstrate that social isolation, financial burden and domestic issues contribute to the already difficult situation, from the family's point of view.⁴⁻⁶ These non-motor symptoms have a major impact on quality of life (QoL), in addition to the motor difficulties.⁷ Thus, PD should be viewed as a multidimensional disease that includes:

- motor disturbances;
- autonomic disturbances;
- cognitive and affective disorders;
- sensory disturbances;
- sleep disorders;
- domestic problems;
- financial difficulties; and
- social difficulties.

It is crucial that a team of experts is involved in the care of such a complex condition and only a collaborative attitude by all therapists will be able to provide the multidimensional approach needed. However, the expense associated with involving a wider team cannot be ignored, and in this article the necessity of such expense is considered.

Figure 1: Models for Multidisciplinary Teams*



Models for Healthcare Teams

The need for teamwork, which comes with having different experts in different disciplines associated with PD, may be obvious, but the aims of this approach go beyond simply optimising treatment outcomes. Nevertheless, giving optimal professional care in all motor and non-motor aspects of PD is an important aim. Additional aims include provision of more comprehensive care to the family members (spouse, first-degree relatives and even the personal carer); improving professionalism of the staff in the team and improving the workplace environment through fluent communication, true sharing of medical information, as well as emotions and stress, respecting the team members and supporting each other during crisis.

There are several models of teamwork for the care of families with PD; from parallel practice to interdisciplinary models that can be used (see *Figure 1*).⁸ The simplest form of team healthcare practice is the 'parallel model', in which independent healthcare practitioners work in one clinic and the patients go to the same place to meet different experts. The 'consultative model' involves exchange of advice between experts – usually through a formal letter concerning a particular patient, or is conducted ad hoc and informally on a case-by-case basis. Similarly, the 'collaborative model' involves independent healthcare workers sharing information (rather than the unidirectional advice that is given in the consultative model) on a particular patient on an ad hoc and informal basis.⁸ More formalised approaches to team healthcare practice include coordinated models that involve a formalised administrative structure and require communication and sharing of patient records among a team of healthcare workers, intentionally formed to provide treatment for families with PD or to deliver a specific therapy (for example, treatment by deep brain stimulation [DBS]). Such a 'coordinated model' requires a case coordinator (or case manager) who is responsible for ensuring the transfer of information between relevant team members.⁸ The 'multidisciplinary team' model includes a team leader who directs meetings (which may or may not be face-to-face) and integrates decisions and recommendations from individual team members. Finally, the most complex model is the 'interdisciplinary team' approach that emerges from multidisciplinary practice, but where the team members work according to a consensus model and decisions are made through regular face-to-face meetings.⁸

Within each model, there are variations in how these can be implemented. For example, when taking a multidisciplinary or interdisciplinary approach, this could be for intensive, short-term (days to weeks) intervention with hospitalised (inpatients) individuals, or for outpatient counselling, where one-time (single or few visits) counselling

is given through a detailed formal letter to the community team (such as the ParkinsonNet model in the Netherlands). Alternatively, as takes place at the Tel Aviv Medical Centre, the team at the outpatient clinic is involved with long-term (several years) treatment and follow-up.

The Tel Aviv Multidisciplinary Team

The Tel Aviv Medical Centre, Movement Disorders Unit provides team-based care for PD families through its outpatient clinic service, and to those PD patients hospitalised owing to any medical or social cause in the Department of Neurology or any other department in the medical centre. The centre runs an outpatient group therapy programme for patients, carers and first-degree relatives, as well as a carers' clinic for those who need personal counselling on how to manage their own difficulties or how to take care of their spouse who has PD. In addition, the centre is involved in educational programmes for healthcare personnel, medical students, nurses, physiotherapy and occupational therapy, and for the general public and the members of the Israeli Parkinson Association. The Movement Disorders Research Branch conducts multiple clinical trials, and other interventional and basic investigations into gait, cognition and the genetics of Ashkenazi Jews with PD. The multidisciplinary team includes neurologists, gerontologists, a psychiatrist, nurses, a social worker, speech, language and swallow therapists, physiotherapists, a sexologist, a dietitian, a neuropsychologist and psychologist specialised in rehabilitation and chronic diseases, research assistants, paramedics, genetic counsellors and secretaries. The centre has a large clinic for PD, special clinics for atypical parkinsonism focusing on multiple system atrophy and autonomic dysfunction (with an autonomic function laboratory), sexual counselling, gait and falls prevention, patients with cognitive decline and psychosis and a new genetic counselling service. A PD nurse specialist runs the carers' clinic. In addition, we recently opened a clinic for prevention of PD specially aimed at the population at risk, such as first-degree relatives.

Since 2007, the centre has managed over 1,500 patients with PD, many of whom were diagnosed at a younger age (mean 59 years) than at other centres in Israel. PD patients account for approximately 250 visits to the centre per month. A relatively large proportion of these patients have dementia, psychosis or other late complications, and many are participating in clinical trials. In the Department of Neurology, there are, on average, one or two hospitalised patients at time, and mean hospitalisation is 7–14 days.

The model of multidisciplinary teamwork used at the Tel Aviv Movement Disorders Unit involves only group members that are specialised in movement disorders and committed on a long-term basis. Most interventions are conducted at the centre (rather than patients being referred elsewhere), and three 'multipurpose' rooms at the centre are dedicated to external staff members. All team members record any information on the patient, their disease and management in a single patient file. The PD nurse specialist is the team coordinator. Two weekly meetings (an hour each) are scheduled that bring together all team members to discuss clinical, investigational and practical issues. However, most interactions between team members to discuss patient care are unscheduled and informal. The team model used in Tel Aviv is designed to put the family (spouses, children and other carers) of the patient with PD at the centre of the process, and separate clinics for the families are included as part of the service. It is our view that all motor and

non-motor symptoms of PD affect the patient and the entire family, as do many other factors such as the patient's friendships and working relationships, and the general financial burden.

When a patient first comes to the Tel Aviv Movement Disorders Unit, they meet a nurse before being assessed by a neurologist. It is the neurologist who decides which other team members will be involved in the continuous care of that specific family (see *Figure 2*). Group therapy sessions are frequently used at the centre and involve many different team members. Group physiotherapy sessions (hydrotherapy) occur weekly and involve approximately 10 patients per session. Group sessions led by social workers and nurses are separated according to different groups. So, for example, separate sessions will involve carers, others will involve the families of the patients with PD and sessions with patients are usually sub-divided by age, gender or stage of disease. Additional sessions are led by social workers and speech therapists and these involve approximately 10 patients per session to facilitate communication. These speech sessions go beyond traditional speech therapy, last eight weeks and involve the spouse of the patient in some sessions. They aim to improve communication in daily social situations, help the patient deal with psychosocial aspects of communication and they focus on loudness, timing and confidence of speech. After the initial eight weeks, follow-up meetings take place every three months. The inclusion of a sexologist as part of the team is important for the patient and family in order to de-stigmatise sexual issues, raise awareness of some of the sexual problems encountered in PD and improve communication about these problems. These issues are dealt with more effectively if a sexologist is part of the multidisciplinary team, than if the patient is referred to a separate specialist clinic.

The centre runs specific clinics for patients receiving DBS. The clinic is run by a nurse specialist and a neurologist but on a case-by-case basis involving all team members. The service is provided to the patient but also to the families of patients and provides counselling and support before, during and after surgery, as we have realised that family support throughout the process is crucial for the success of DBS.

As previously stated, the involvement of families of patients in group therapy sessions is an important part of the model used at Tel Aviv, and one increasingly important part of this is genetic counselling for first-degree relatives of patients with LRRK2 (leucine-rich repeat kinase 2) G2019S or glucocerebrosidase (GBA) mutations. This is a particular issue in Israel, where 35 % of the Ashkenazi Jews with PD have a genetic mutation associated with the disease (see *Figure 3*). At the Tel Aviv Movement Disorders Unit, there are, at the present time (April 2010), 143 patients with mutation in the GBA gene and 120 patients with mutation G2019S in the LRRK2 gene. The presence of these mutations must be well characterised as this has an impact on genetic counselling – for example, mild mutations in the GBA gene (N370S/+) infer a three-fold greater risk of developing PD for children of carriers, but severe mutations will increase the risk for children by approximately 10-fold or more. Similarly, the type of mutation in the GBA gene affects the mean age of onset of the disease. Thus, the type and severity of mutation have a major impact on the first-degree relatives and on the counselling they require.

Based on our experience at the Tel Aviv Medical Centre, the neurologists have changed their viewpoint from seeing team members as advisors to seeing them as part of a group that makes group decisions, with members working together in an integrated

Figure 2: Team Members That Interact With Patients With Parkinson's Disease at Their First Visit to the Tel Aviv Movement Disorders Unit

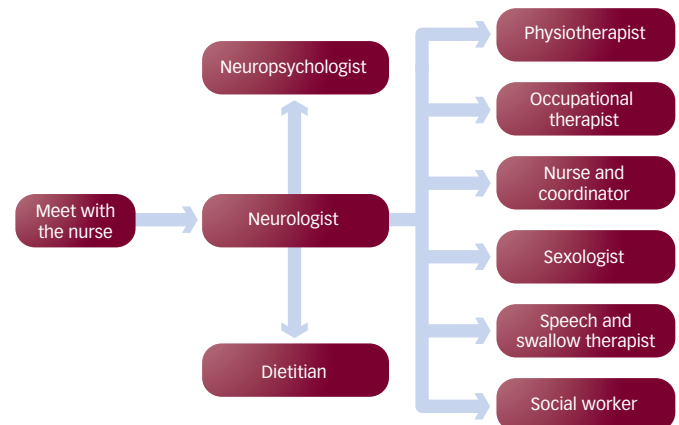
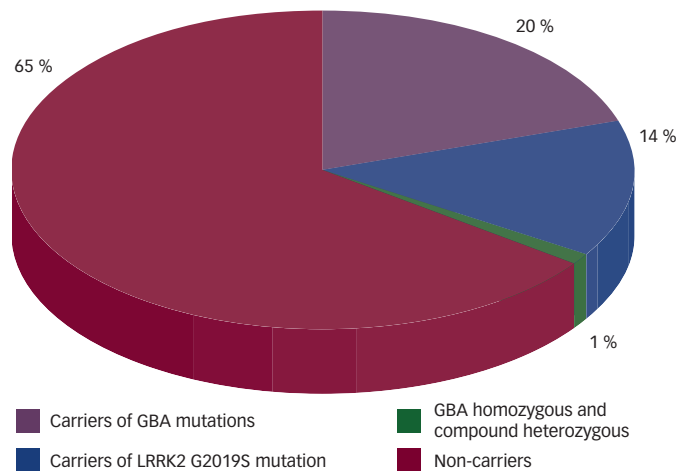


Figure 3: Ashkenazi Jewish Patients With Parkinson's Disease and Mutations to the LRRK2 or GBA Genes at the Tel Aviv Movement Disorders Unit



GBA = glucocerebrosidase; LRRK2 = leucine-rich repeat kinase 2.

fashion. Accepting the professionalism of the team members, and their unique added value to the care of the family with PD, is at the base of the success of teamwork in centres for families with PD.

Experiences from Other Groups

In the Netherlands, the ParkinsonNet group has assessed the effects of physiotherapy networks on the quality of care of patients with PD.⁹ Two clusters of patients were assessed: one group received additional specialised physiotherapy, the other group received 'usual care'. After six months, there was no significant difference in general function (motor scores or different aspects of disease severity) or QoL between the two patient groups.⁹ However, the total cost of managing the disease was significantly reduced in the group receiving specialised physiotherapy – in particular, cost of medication, cost of day-hospital rehabilitation, cost of paid homecare and cost of informal care were reduced in the group receiving specialised physiotherapy.⁹

In Toronto, Guttman et al. have compared a small group of patients with PD that was treated by their primary neurologist (n=49) with a group that received treatment from a multidisciplinary team that included a movement disorder specialist, a specialist nurse and a

social worker (n=51) (Guttman, personal communication). Those treated by a multidisciplinary team were treated immediately, whereas those treated by their primary neurologist in isolation had a delay of six months before treatment was initiated. After six months, many aspects of disease were improved in the group treated by a team compared with the group treated by their primary neurologist – significant differences were observed in the Unified Parkinson's Disease Rating Scale (UPDRS) total and III scores ($p=0.019$ and $p=0.036$, respectively); Parkinson's Disease Questionnaire (PDQ) total score ($p=0.032$); Scales for Outcomes in Parkinson's Disease – Psychosocial Questionnaire (SCOPA-PS) score ($p=0.042$) and Montgomery–Asberg Depression Rating Scale (MADRS) total score ($p=0.001$). In addition, the mean cost-per-physician service was significantly reduced in the group receiving treatment from a multidisciplinary team. This study was the first attempt to assess the effect of a multidisciplinary team approach in a prospective randomised trial, but the results stem from a small group of patients

and more work is needed to draw firm conclusions on the clinical benefit and cost–benefit of such an approach.

Conclusions

Setting up a multidisciplinary team at a centre where none exists can be time consuming and may involve a change in mindset among those who would be involved in the team. Furthermore, we do not yet know how cost-effective such an approach is for the management of PD. However, our experience at the Tel Aviv Movement Disorders Unit suggests that the multidisciplinary approach to the management of PD has benefits for the patient, their families, their carers and the healthcare team. Communication between team members and the patients, and respect between team members, are important to the optimum functioning of such a team. As a more integrated approach to disease management becomes more commonplace, the value of these teams may become more apparent. ■

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