How to organize multispecialty care for patients with Parkinson's disease

Marjolein A. van der Marck, Bastiaan R. Bloem

1. Introduction

Neurodegenerative disorders like Parkinson’s disease (PD) typically include a broad range of motor and non-motor symptoms. Disease manifestations vary considerably across individuals and, importantly, the individual needs and priorities are highly diverse among patients. It is widely felt that this multifaceted nature of PD calls for a team-oriented and personalized model of care. However, such a multispecialty approach is complex to design, and there are no evidence-based templates that describe how multispecialty care should be organized. Here we elaborate on the various challenges associated with the organization of team-based care. We illustrate this by highlighting new research evidence for two different models of multispecialty team care in PD. We also discuss several critical components of multispecialty care, including composition of the team, collaboration forms between team members, and implementation of multispecialty care within everyday healthcare settings. We close by sharing some of the lessons learned from recent clinical trials on the clinical effectiveness of multispecialty team interventions in PD. This review underscores that designing multispecialty care within the setting of a modern healthcare system is almost as complex as PD itself, and that its scientific evaluation comes with significant challenges.
2.2. Allied healthcare

Allied healthcare can complement standard medical management, even for symptoms that are largely resistant to pharmacotherapy or surgery. Treatment goals and underlying working mechanism of allied healthcare differ from standard medical treatment [12]. In recent years, several allied health disciplines have become more evidence-based. The evidence grade is highest for physiotherapy [13] and speech–language therapy [14,15] (class II), followed by occupational therapy (class III). Other disciplines have been evaluated scarcely, and remain based mainly on practice-based evidence.

2.3. Patients and carers as team members

All multidisciplinary team interventions tested so far have been driven largely by professionals. However, there is increasing evidence (largely from outside the field of PD) that active involvement of patients helps to improve the quality of care and to reduce healthcare costs [4]. Empowering patients by self-management support and shared decision making improves self-efficacy, quality of life, treatment compliance and patient satisfaction. Such approaches are also attractive for PD patients, who wish to be more actively involved in self-management [4]. Indeed, involving PD patients as part of the team has been advocated [4], but research remains necessary whether and how patients should be engaged to obtain the best outcome. Limiting factors such as cognitive decline and difficulties with decision making should be considered when developing self-management programs for PD patients.

Support for informal carers should also be considered. Indeed, without addressing their needs, the treatment plan is likely incomplete. Caregivers and family members are often crucial in the patient’s disease management, but this may go at the expense of considerable stress [16]. In fact, offering a comprehensive multidisciplinary approach to just the patient might paradoxically create more stress among carers, perhaps because more intensive treatments also place greater organizational demands on carers [10,17]. Dedicated attention to carers could alleviate this concern, e.g. by asking occupational therapists to help caregivers gain more competence when assisting the patient, thereby helping them to maintain their own independence. Several well-designed trials are underway to formally test the merits of occupational therapy, including a focus on carers (see e.g. [18]).

3. What disease stage is most appropriate?

It is uncertain whether a team approach should be applied throughout all stages of PD, and for every single patient. The multidimensional symptom manifestation is present throughout the course of PD. Recent work revealed that non-motor symptoms are already common in early PD [19]. The impact of illness varies across stages, and priorities are different for patients with early versus late PD [20]. This argues for a regular examination of the needs experienced by patients, and for an according adjustment of team composition. Interestingly, recent work showed that routinely offering multispecialty care to all patients (irrespective of perceived needs) yielded only small benefits [10]. Future work must decide whether greater improvements can be obtained by restricting multispecialty care to a subgroup of patients that is in greatest need.

4. Collaboration between team members

There are several ways to organize team-oriented models, varying from relatively simple approaches (where professionals work independently from each other or have incidental consultation on an individual case level) to more formalised and complex models of teamwork [21]. Based on the communication and collaboration between team members, three different team concepts can be distinguished: multidisciplinary care, where each discipline is responsible for a specific patient need; interdisciplinary care, when team members work collaboratively through regular face-to-face meetings and make group decisions; and integrative care, which is characterised by a synergistically charged plan of care guided by consensus building and engagement of patients as team members [21]. Integrative models are most complex, with a high number of participants, many health determinants, a high need for communication and synergy, and an emphasis on the individual patient as a whole [21]. However, such complex integrative models do not necessarily represent the optimal model for organizing healthcare. In fact, it remains unclear which type of healthcare delivery offers greatest benefits to PD patients.

5. Setting

Various team-oriented approaches have been implemented into clinical practice of specialized PD centres worldwide. The organization differs extensively across these centres. For example, some centres have implemented their team approach as outpatient service, others as inpatient service. To illustrate the range of options, Table 1 describes several different settings of PD centres.

6. Two approaches towards multispecialty care

We next describe two types of multispecialty care in more detail, highlighting differences in organization and setting (Tables 2, 3) [10, 11]. We selected these because both were recently tested for (cost-)effectiveness in large trials.

The first (Canadian) model, in the Centre for Movement Disorders (Markham, Ontario), offers both the evaluation of patients and the actual intervention within one centre [11]. Patients receive chronic care from a movement disorders specialist supplemented with support, teaching and assistance from PD nurses and social workers, tailored to the patients’ individual needs. This specialized team approach differs from regular care in Canada, which is provided by a general neurologist alone, without support from additional health professionals. The second (Dutch), integrated, model offers a customised assessment in a tertiary referral centre (Parkinson Centre Nijmegen) by a comprehensive team of PD experts from various disciplines [10]. During a
multidisciplinary meeting, the recommendations of all team members are integrated into a single treatment plan, which is then outsourced to ParkinsonNet, a community-based network of specialized therapists working in the patient’s own home environment [22].

Both models have been evaluated for clinical effectiveness (Tables 3, 4) [10,11]. Using a randomized controlled design, the clinical effectiveness of the Canadian model has been compared to stand-alone care by a general neurologist [11]. After 8-month follow-up, intervention patients improved significantly on quality of life, motor functioning, depression and psychosocial burden. Caregiver burden did not differ between both groups. The Dutch model has been evaluated on cost-effectiveness using a non-randomized controlled design, comparing the integrated healthcare model – one region featuring the expert centre and ParkinsonNet network – to control regions where this infrastructure of care was not available. This trial also had an 8-month follow-up. Intervention patients improved significantly (but in absolute sense modestly) on activities of daily living, quality of life, anxiety, depression, perceived general health and non-motor symptoms. Quality of care scores also improved. There were no differences for caregiver burden (except for one subscale) or healthcare costs [10].

The results of both trials favoured multispecialty expertise care, as compared to regular care. However, the effects for the Canadian model were more robust than those for the Dutch model, where only small and clinically irrelevant improvements were shown, and which disappeared after correction for baseline differences. Although both interventions and trials shared common elements (individually tailored approach, involvement of multiple disciplines, treatment by PD experts, 8-month follow-up), they also differed on several aspects (Tables 2, 3). We will address possible explanations for the different results, and consider several lessons learned from these trials.

### 6.1. Variability in intervention and control care

When evaluating customised interventions, it is impossible to apply the same standardisation as in single intervention studies (like drug trials). Indeed, in none of the two trials there was uniformity of care in intervention or control care. Drug trials are simpler in

### Table 1

<table>
<thead>
<tr>
<th>Setting</th>
<th>Example of expert PD centre</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
<td>Clinical Research Centre for Movement Disorders &amp; Gait at the Kingston Centre (Melbourne, Australia)</td>
<td>Intensive treatment</td>
<td>Concern how patients can maintain improvements in own home situation</td>
</tr>
<tr>
<td>Outpatient</td>
<td>Centre for Movement Disorders (Markham, Ontario); Tel Aviv Movement Disorders Unit (Tel Aviv, Israel)</td>
<td>Initial assessment and subsequent care delivery both controlled within a single centre, and delivered by experts</td>
<td>Not always feasible, because many patients must be treated chronically</td>
</tr>
<tr>
<td></td>
<td>Parkinson Centre Nijmegen (The Netherlands)</td>
<td>Initial assessment by team of experts; delivery of care near the patient's home by specialized community-based professionals</td>
<td>Insufficient control over actual implementation of proposed healthcare plan</td>
</tr>
</tbody>
</table>

### Table 2

Specific elements of two multispecialty team interventions

<table>
<thead>
<tr>
<th>Setting</th>
<th>Example of expert PD centre</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian model [11]</td>
<td>Relatively small team: • movement disorders specialist • PD nurse • social worker</td>
<td>Comprehensive team: • movement disorders specialist • PD nurse specialist • social worker • physiotherapist • occupational therapist • speech-language therapist • sleep specialist • dietician • sexologist • neuropsychologist • neuropsychiatrist • rehabilitation specialist • geriatrician</td>
<td></td>
</tr>
<tr>
<td>Organization of team work</td>
<td>Multidisciplinary model, hierarchically structured with daily contact between team members.</td>
<td>Integrative model within expert centre, based on consensus and shared decision-making during regular integrated team meetings; supplemented with multidisciplinary regional networks in the community (physiotherapists, occupational therapists, speech-language therapists).</td>
<td></td>
</tr>
<tr>
<td>Setting and treatment implementation</td>
<td>Expert centre, general neurologist no longer involved.</td>
<td>Expert centre and community networks; treatment delivered by community neurologist and community professionals outside centre.</td>
<td></td>
</tr>
</tbody>
</table>
design, as a certain drug is provided at a specific dose, frequency and study duration. However, evaluations of team care are faced with a much more complex and variable design: a variety of disciplines is involved, who offer a diverse set of therapies at a variable intensity, frequency, and treatment duration. In both studies, these multispecialty approaches were tailored to each patient's specific needs. This complexity was increased further by the choice of control intervention. Pharmacological trials often include a placebo or a 'gold standard' treatment. Yet, usual care in PD does not include such a straightforward control. For example, in the Dutch trial [10], many control patients received allied health treatment in the community, and this may have masked greater benefits for the intervention patients.

6.2. Study design

Randomised controlled designs represent the highest standard for obtaining evidence. However, a randomised design is not always feasible when evaluating multispecialty interventions. In the Dutch trial [10], a better matching for baseline disease severity could have been achieved using a fully randomised design within a single participating region, but this was impossible because of a risk of contamination. Specifically, with randomisation within a single region, control patients could have gained access to specialised care in the regional networks. In contrast, the Canadian trial was designed as a randomised, controlled trial with a waiting list design: intervention patients were rescheduled to immediate assessment, whereas control patients visited the centre after eight months [11]. However, this trial had other methodological constraints. For example, no data on drop-outs were gathered, impeding intention-to-treat analyses.

6.3. Targeting the right patient

The inclusion process also differed between both trials: in the Canadian trial, patients had an indication for referral to multidisciplinary care, whereas in the Dutch trial, all patients were included, irrespective of perceived need for intervention [10,11]. It is conceivable that referrals in the first situation were made for more complex patients or those that were more interested in specialised care [11]. Conversely, many patients (33%) in the Dutch trial declined referral to the expert centre, among others because they anticipated little gain [10].

In most studies on the effectiveness of team care in PD, severely affected patients were largely underrepresented [10,11,17,24,25]. However, these patients might particularly benefit from a comprehensive assessment because they are faced with an increasing number of disabilities. In fact, baseline attributes have been linked to effectiveness, such that multidisciplinary rehabilitation seemed most valuable for those patients with higher perceived needs [25]. However, it remains to be established whether patients with very advanced PD can still benefit from a comprehensive team approach, for example because dementia hampers effective implementation of treatment recommendations.

6.4. Choice of outcome measures

A particular challenge is the selection of adequate outcomes that fit the multispecialty intervention (depending on the nature and number of disciplines involved). The Canadian trial involved three disciplines, and the outcomes (rating emotional and psychosocial functioning) presumably corresponded well with the actual content of healthcare delivered by the PD nurse and social worker [11]. Conversely, the Dutch trial opted for a wide-ranging approach, with optional access to a team featuring 13 different health professionals. Their input was tailored to each patient’s individual needs, creating an enormous variety of care arrangements that complicated the choice for specific outcomes [10]. Indeed, with multifaceted interventions aimed at both motor and non-motor symptoms, it becomes difficult to assess the effectiveness using a single outcome. More specific outcomes that reflect the actual intervention more closely (e.g. gait speed for those receiving physiotherapy) might be more suitable for capturing treatment effects. However, such specific measures cannot be selected as primary outcome since each patient receives a customized set of interventions. Thus, the focus of one primary outcome cannot determine the full effect of all treatments sufficiently. A better alternative is to perhaps include multiple outcomes [27], but this creates new statistical challenges.

---

Table 3

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Process evaluation</td>
<td>Partly (within centre)</td>
<td>Yes</td>
</tr>
<tr>
<td>Usual care (control arm)</td>
<td>General neurologist, access to allied health therapists, but lack of expertise.</td>
<td>Predominantly general neurologist, sometimes supported by PD nurse. Access to non-specialised allied healthcare [5].</td>
</tr>
<tr>
<td>Design</td>
<td>Randomised Controlled Trial: randomised after inclusion in the trial to immediate intervention or usual care/waiting list</td>
<td>Controlled Trial: intervention region (integrated model) versus control regions (usual care)</td>
</tr>
<tr>
<td>Blinding</td>
<td>Patients referred to expert centre for team assessment before inclusion.</td>
<td>Patients offered team assessment in expert centre after inclusion.</td>
</tr>
<tr>
<td>Data analyses</td>
<td>No data on drop-outs collected</td>
<td>Intention-To-Treat</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Primary: quality of life</td>
<td>Primary: activities of daily living and quality of life</td>
</tr>
<tr>
<td></td>
<td>Secondary: motor and total UPDRS scores, depression, psychosocial functioning</td>
<td>Secondary: motor scores, economical evaluation</td>
</tr>
<tr>
<td></td>
<td>Caregiver burden</td>
<td>Range of other outcomes including non-motor symptoms, general quality of life and well-being, and quality of care</td>
</tr>
<tr>
<td></td>
<td>Caregiver burden</td>
<td></td>
</tr>
</tbody>
</table>

UPDRS, Unified Parkinson’s disease rating scale.
Table 4
Synopsis of controlled trials evaluating team-based interventions in PD

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Intervention and duration</th>
<th>Team members (alphabetical order)</th>
<th>Blinding</th>
<th>Study duration</th>
<th>Outcomes</th>
<th>Sample size</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>[17]</td>
<td>RCT, including pre-post test design (early versus late intervention)</td>
<td>6-week individual training and group activities</td>
<td>Occupational therapist, Physiotherapist, PD nurse, Speech-language therapist, Access and referral to social services care manager, neurologist, psychologist</td>
<td>Assessor</td>
<td>6 months after study entry</td>
<td>PD Disability questionnaire, PDQ-39, SF-36, EQ-5D, stand–walk test, NHPT, HADS, UPDRS speech items Caregiver: CSI, EQ-5D</td>
<td>144&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Pre-post test: declined disability, physical limitations, general health, health-related quality of life, caregiver strain RCT: declined mental and general health</td>
</tr>
<tr>
<td>[23]</td>
<td>Controlled trial with waiting list design</td>
<td>6-week educational program with weekly 2-hour session</td>
<td>Dental hygienist, Dietitian, Nurse, Occupational therapist, Physician, Physiotherapist, Psychologist, Social worker, Speech therapist</td>
<td>–</td>
<td>10 weeks</td>
<td>SF-12</td>
<td>97</td>
<td>No differences</td>
</tr>
<tr>
<td>[24]</td>
<td>RCT, including pre-post test design with intervention vs usual care (late intervention)</td>
<td>8-week group education with personal rehabilitation</td>
<td>Dietician, Movement disorders specialist, Nurse, Physiotherapist, Psychologist, Social worker, Speech therapist</td>
<td>Assessor</td>
<td>4 weeks (pre–post test) 8 weeks (RCT)</td>
<td>PDQ-39, UPDRS II and III, SEADL, Zung SDS, PMS</td>
<td>44</td>
<td>Pre-post test: improved bodily discomfort RCT: improved quality of life, motor function, activities of daily living, and mood</td>
</tr>
<tr>
<td>[25]</td>
<td>RCT, with 3 groups: (1) no rehabilitation, (2) 18 hours, (3) 27 hours</td>
<td>6 weeks of group sessions and (for group 3 only) individualised self-management rehabilitation, Attentional control social sessions (9 hours) for group 2</td>
<td>Occupational therapist, Physiotherapist, Speech–language therapist</td>
<td>Assessor (14% unblinding)</td>
<td>6 weeks, 2 months, 6 months</td>
<td>PDQ-39&lt;sup&gt;b&lt;/sup&gt;, Walking activity and endurance [26]</td>
<td>117 116 [26]</td>
<td>More patients in intervention group with improved quality of life compared with controls (directly after intervention and after 6 months)</td>
</tr>
<tr>
<td>[10]</td>
<td>Controlled trial with intervention versus control regions (usual care)</td>
<td>On-going care, individualised assessment in expert centre and treatment outsourced to regional specialists</td>
<td>Dietician, Movement disorders specialist, Occupational therapist, Physiotherapist, PD nurse, Psychiatrist, psychologist, Rehabilitation specialist, Sexologist, Sleep consultant, Speech–language therapist, Social worker</td>
<td>Patients and clinical staff</td>
<td>8 months</td>
<td>ALDS&lt;sup&gt;b&lt;/sup&gt;, PDQL&lt;sup&gt;b&lt;/sup&gt;, UPDRS III, healthcare costs, NMS Scale, HADS, falls, FES-I, FOGQ, SPDDS, UPDRS IV, SF-36, PAS, overall well-being (VAS), quality of care Caregiver: BELA-A-k, HADS, SF-36</td>
<td>301</td>
<td>Improved activities of daily living, quality of life, non-motor symptoms, anxiety and depression, perceived general health, quality of care</td>
</tr>
</tbody>
</table>

<sup>a</sup> 7 duplicate patients.  
<sup>b</sup> Primary outcome.

ALDS, AMC Linear Disability Score; BELA-A-k, Belastungsfragebogen Parkinson Angehörigen – Kurzversion; CSI, Caregiver Strain Index; EQ-5D, EuroQol 5D; FES-I, Falls Efficacy Scale – International; FOGQ, Freezing of Gait Questionnaire; HADS, Hospital Anxiety and Depression Scale; MADRS Montgomery–Åsberg Depression Rating Scale; NHPT, Nine Hole Peg Test; NMS, Non-Motor Symptom; PAS, Parkinson Activity Scale; PD, Parkinson’s disease; PDQ-39, Parkinson’s Disease Questionnaire, 39 items; PDQL, Parkinson’s Disease Quality of Life questionnaire; PMS, Patient’s Mood Status; RCT, Randomised Controlled Trial; SCOPA-PS, Scales for Outcomes in Parkinson’s disease – Psychosocial questionnaire; SEADL, Schwab and England Activities of Daily Living; SF-36, Short Form 36; SPDDS, Self-assessment Parkinson’s Disease Disability Scale; UPDRS, Unified Parkinson’s Disease Rating Scale (Part II is Activities of Daily Living, Part III is Motor Score, Part IV is Complications of therapy); VAS, Visual Analogue Scale; Zung SDS, Zung Self-rating Depression Scale.
6.5. Blinding

Blinding also differed between the two trials. Patients were not blinded to group assignment in the Canadian trial, and this might have contributed to a larger influence due to placebo effects [11]. In contrast, patients in the Dutch trial were not informed about the differences between the regions [10]. Yet, no trial thus far was designed with full blinding, keeping both patients, clinicians and research staff unaware of treatment allocation (Table 4).

6.6. Contrast with usual care

It is also important to understand the setting where the research was performed. The Canadian trial compared a multidisciplinary/specialist approach with stand-alone care by a general neurologist without access to PD nurses or social workers [11]. In the Netherlands, usual care already involves multiple healthcare professionals, and many patients receive some form of allied healthcare [5,10]. Consequently, the Dutch trial compared a formal organization of team care with a less formally structured collaboration between healthcare professionals [10]. The contrast between the intervention and usual care was therefore limited. It is possible that the Dutch approach might afford larger effects when implemented in different settings, e.g. in countries where allied healthcare is not part of usual care.

6.7. Process evaluation

Ideally, process evaluations should be included as an integral element of clinical trials [8], to explore the actual implementation of interventions, and to explain discrepancies between expected and observed effects. In the Dutch trial, the process evaluation showed that many patients were not interested in the comprehensive assessment at the expert centre, highlighting the need to select appropriate patients [10]. In addition, the process evaluation provided transparency about the healthcare delivered, indicating that both patient groups received care by multiple disciplines, and this helped to explain the limited contrast between both groups.

6.8. Evidence from other studies

The evidence for effectiveness of team care in PD remains limited to a few controlled trials which produced inconsistent findings [12, 28,29]. Table 4 reflects the large variability in research design, nature of multispecialty interventions and choice of outcomes among trials. This heterogeneity complicates direct comparisons. Moreover, all studies had methodological shortcomings, including loss of follow-up and potential bias due to study design, blinding and selection methods [17,24,25].

Several uncontrolled studies that used a pre-test versus post-test design reported improvements in health, quality of life, and disability [12]. Marked improvements in patients’ outcome were reported immediately after a short-lived intervention [24]. One pre–post test study showed benefits for patients [30], but follow-up data using an RCT design showed no sustained effects for six months [25]; however, the group difference declined with time, suggesting that the benefits were short-lived. Such findings, and knowing that PD is a progressive condition, suggest a need for on-going care. The Canadian and Dutch trials followed patients for eight months [10,11], but longer follow-up is required to fully appreciate cost-effectiveness. Future trials should investigate how multispecialty care can be reinforced to achieve sustained effects despite disease progression.

7. Conclusion

In light of the multidimensional nature of neurodegenerative diseases, a team-oriented approach – including pharmacological and non-pharmacological interventions provided by multiple disciplines – seems warranted. Although multispecialty approaches are increasingly acknowledged as the optimal management for the motor and non-motor symptoms of PD, there is no accepted standard for organizing these team models of healthcare. The evidence thus far points modestly in favour of team/specialist intervention, but does not offer the final answer on how to optimally design team-based care in PD management. The present review provides an inventory of the available scientific evidence, as a basis for development of further evaluations that remain needed to better substantiate the potential benefits and cost-effectiveness of multispecialty team care. This emerging and exciting field offers challenges to both clinical practice and scientific research, and offers hopes for PD patients who crave for better treatments of this debilitating disease.

Conflict of interests

The authors have no conflicts of interest to declare.

References


