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

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SUMMARY

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.

1. Introduction

Neurodegenerative disorders like Parkinson's disease (PD) are typically characterized by a wide range of motor and non-motor symptoms [1,2]. Such a broad symptom complex is very disabling for patients. Moreover, due to the progressive neurodegeneration, patients must adapt continuously to new disabilities and limitations in daily life during the course of the disease. Additionally, the clinical presentation varies greatly across individuals, both in terms of disease manifestation and rate of progression. Importantly, different patients have very diverse needs and priorities, and they vary greatly in the perception of their most troublesome problems [3]. This complex and multifaceted nature of neurodegenerative disorders poses significant challenges for the everyday management of each individual patient, particularly in this current era where patients increasingly demand a personalized approach with specific attention to their own specific priorities [4].

To tackle this complexity, a multispecialty approach (with contributions by experts from multiple complementary disciplines) seems preferable over a single-clinician approach. This need is accentuated by the fact that current medical management cannot control all symptoms satisfactorily. Team-oriented care can take many different forms, and several issues must be addressed when designing and implementing such a multispecialty approach. Examples of unresolved issues relate to which specific disciplines should be involved, and how the team members should collaborate to achieve the best outcome. In current PD care, it is becoming more fashionable to involve multiple different health professionals, but the effectiveness of their services appears suboptimal [5]. One problem is that, despite overlapping treatment goals, the various different specialists typically work in isolation and parallel to one another, instead of delivering a collaborative effort. Crucially, despite growing international recognition for the potential importance of multispecialty team care [6,7], there is currently insufficient evidence on (cost-) effectiveness to justify a widespread implementation in clinical practice. Obtaining high-quality evidence is especially challenging for multispecialty interventions, due to their multiple active and interacting components [8]. Moreover, assessing the effectiveness of multidisciplinary care models is difficult because they must be implemented and evaluated within a constantly changing healthcare environment [9].

Here, we will elaborate on several unresolved issues associated with the organization of multispecialty care. We illustrate the many challenges by describing two different organization types of multispecialty care for PD patients which have been taken to the test recently [10,11].

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2. What is the best team formation?

2.1. No standard template

Although multidisciplinary care is increasingly recommended for PD management [6,7], there is no standard evidence-based template how to organize this. A wide range of professionals might be involved. Indeed, over 20 disciplines might have potential value for PD care [6], including medical specialists (among others neurologists, psychiatrists), specialized nurses, and allied healthcare professionals (such as physiotherapists, occupational therapists, speech–language therapists, dieticians, social workers, sexologists and neuropsychologists). However, it is unknown which combination is best, or what the relative contribution is for each specialist within a team. Considering the heterogeneous clinical presentation among PD patients and their diverse personal priorities, an individually tailored approach seems preferable over a one-size-fits-all approach, but there is no evidence to support this assumption.

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