Improving the quality of allied health care in Parkinson's disease through community-based networks: the ParkinsonNet health care concept

Maarten Nijkrake

ISBN: 978-90-9025755-6
Layout: Johan Korteland
Printed: Ipskamp Drukkers

The research presented in this thesis was carried out at the Departments of Neurology and Rehabilitation at the Nijmegen Centre for Evidence Based Practice and the Donders Institute for Brain, Cognition and Behavior, Radboud University Nijmegen Medical Centre.

The research was supported by grants from the Radboud University Nijmegen Medical Centre, the Netherlands Organisation for Health Research and Development (ZonMw), and the Royal Dutch Society for Physical Therapy (KNGF).

The publication of this thesis was financially supported by: Radboud University Nijmegen Medical Centre, Koninklijk Nederlands Genootschap voor Fysiotherapie (KNGF), Stichting van Alkemade-Keuls Fonds, European Foundation for Health and Exercise (Efox), Vereniging voor Oefentherapeuten Cesar en Mensendieck (VvOCM), Aride, Fastguide, FellowRoll, Boehringer Ingelheim and Novartis Pharma.

Improving the quality of allied health care in Parkinson's disease through community-based networks: the ParkinsonNet health care concept

Een wetenschappelijke proeve op het gebied van de Medische Wetenschappen

Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. mr. S.C.J.J. Kortmann,
volgens besluit van de college van decanen
in het openbaar te verdedigen op maandag 29 november 2010
om 15.30 uur precies

door

Maarten Jan Nijkrake
geboren op 7 februari 1978
te Hengelo (Overijssel)

Promotor:
Prof. dr. B.R. Bloem

Copromotores:
Dr. M. Munneke
Dr. S. Overeem

Manuscriptcommissie:
Prof. dr. M.W.G. Nijhuis - van der Sanden (voorzitter)
Prof. dr. H.P.H. Kremer (UMC Groningen)
Prof. dr. A.C.H. Geurts

Contents

Chapter 1
General introduction and aims

1

Terminology: Beside physiotherapists, also a smaller group of Cesar exercise therapists and Mensendieck exercise therapists can deliver exercise therapy in the Netherlands. The content of the evidence-based guideline for both exercise therapy Cesar and Mensendieck in PD is identical to the physiotherapy guideline. For that reason, the term "physiotherapy" also includes Cesar and Mensendieck exercise therapies in this thesis; the term "physiotherapist" also includes Cesar and Mensendieck exercise therapists.

Introduction

The organisation of health care for patients with a chronic condition needs to change, for two important reasons. First, because of the rising health care costs, and second, because of the suboptimal quality of care that is currently delivered to these patients.[4] Due to ageing of our population, the number of patients with a chronic condition is expected to rise.[6] For example, the number of patients with Parkinson's disease is expected to double in the next 20 years.[7] More patients with a chronic condition will use the health care system for a relatively long period, thereby contributing to the rapidly mounting health care costs. To tackle these rising costs, more efficient health care programs for chronic patients have to be developed. Policy makers and patient societies want to stimulate health scientists, professionals and insurance companies in the development of high-quality and efficient health programs for patients with a chronic disease.[8] These innovations should address a better collaboration between health professionals, better coordination of health care processes, less expensive forms of care (e.g. avoiding hospital visits) and care that is more specifically tailored to the specific needs of individual patients. This thesis focuses on the organization of allied health care for one common chronic neurological disorder, namely Parkinson´s disease. The emphasis will be on the organization of care for physiotherapy, as an example of an allied health discipline that is commonly engaged in PD.

Parkinson's disease

Common and devastating

Parkinson's disease (PD) is a neurodegenerative disease, the prevalence of which in Europe is estimated at around 1.3-1.5% for the population aged 60 years or above.[9] The four motor features of the disease upon which the diagnosis is currently based include akinesia, resting tremor, rigidity and postural instability (although the latter symptom is typically a late feature of PD) (see box 1.1). Other later developing motor symptoms include falls and freezing of gait.

Besides these motor symptoms, PD also features a wide range of non-motor symptoms (e.g. fatigue, autonomic dysfunction, depression, and cognitive decline). The mean age at onset for most patients is between the end 50s and mid 60s. The disease course is slowly but invariably progressive, and the life expectancy is almost normal. Particularly the late motor and non-motor symptoms have a high impact on the quality of life.[10] In a ranking that listed the top 10 of the most disabling chronic diseases, PD was ranked second, both in the list of physical disorder and the list of mental disorder.[11]

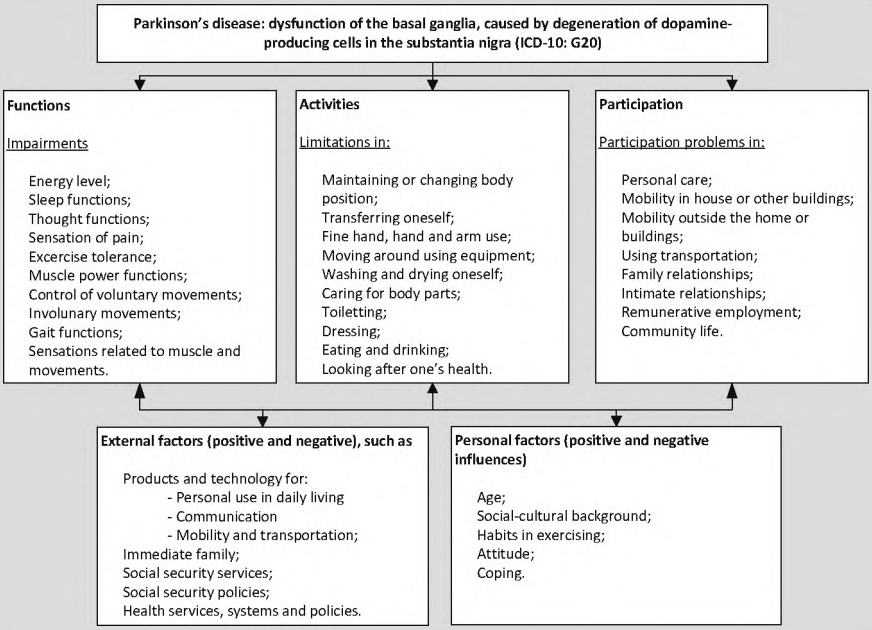
The slow disease course, the normal life expectancy and the high impact on quality of life imply that most patients use the health care system for long periods of time, and also intensively. This makes PD an expensive disease.[12] From both a social and financial perspective it is therefore relevant to identify more efficient and higher quality of care programs for these patients.

Box 1.1 What does Parkinson's disease look like?

Definitions of the four cardinal features

Akinesia is as an umbrella term for a symptom complex that can include bradykinesia (slowness of movement) and hypokinesia (poverty of movement, and movements that are smaller than intended), but also the progressive fatiguing and decrement of repetitive alternating movements. Tremor in PD is characterized by a frequency that typically ranges between 4-6 Hz when it is maximal at rest, and reduces with voluntary movement. Rigidity is an increased muscle tone that can be felt during passive movement of the head or limbs. Postural instability is often absent at onset and usually becomes present only after a few years. Postural reflexes become progressively deficient, and their failure is one of the causes for the frequent falls that become apparent in later stages of the disease.

Figure 1.1 Parkinson's disease according to the International Classification of Disability, Function, and Health (ICF).[3]



Pathophysiology

The exact aetiology of PD remains unknown, but the underlying pathophysiology is becoming clearer. Specifically, dopamine-producing cells in the substantia nigra of the basal ganglia degenerate progressively. When approximately 80% of dopamine in the striatum and 50% of the neurons in the substantia nigra are lost, the cardinal features of PD become apparent (see box 1.1).[13] In addition to these dopaminergic lesions, the brains of PD patients also become progressively affected by so-called non-dopaminergic lesions. This includes degeneration of other pigmented nuclei (such as the locus coeruleus), important brainstem centres such as the pedunculopontine nucleus, and eventually also cortical lesions.

Complex clinical presentation

The clinical presentation of symptoms in PD is complex for several reasons: (a) the spectrum of motor and non-motor symptoms is broad, involving multiple neural systems; (b) the expression of symptoms can differ widely between patients; (c) fluctuations in symptoms throughout the day may become apparent in later stages, and (d) environmental and personal factors play a larger role than in other chronic conditions (e.g. rheumatoid arthritis or diabetes).[14;15]

To better understand the impact of PD on daily functioning, the International Classification of Disability, Function, and Health (ICF) model is very useful.[16] This model, graphically depicted for PD in Figure 1.1, is a framework that illustrates the interaction between symptoms (defined as impaired body functions), limited activities and participation problems.[3] This model also accommodates the influences of environmental and patient factors on daily functioning. For example, a PD patient may freeze while passing a narrow space between his couch and the table in his living room. In this example, freezing of gait is the impaired body function (loss of control of a voluntary stepping movement) that results in the participation problem walking indoors (mobility in house). The narrow passage is a negative environmental factor that is known to provoke freezing of gait. If the patient decides to create more space in his living room to avoid a freezing episode, the chosen coping style is a positive personal factor.

Management of Parkinson's disease

There is currently no cure for PD. Current treatment is purely symptomatically, but can improve the quality of life substantially.[13] Dopamine replacement therapy using medication is the most effective treatment option.[17] Stereotactic deep brain surgery is a promising alternative but suitable for only a selected group of patients.[18;19] Unfortunately, medication and neurosurgery are only partially effective as they do not relieve all symptoms, or sometimes even induce complications. For example, dopamine replacement therapy can sometimes lead to orthostatic hypotension or 'on-period' freezing of gait, and thus worsen the risk of falls. Complementary to medical treatment, many patients rely on allied health professionals such as physiotherapists, occupational therapists or speech therapists to deal with limitations in activities or participation problems.[20;21]

To a lesser extent, patients also consult sexologists, social workers, psychologists or dieticians.

When medical treatment and allied health care interventions are compared with each other, essential differences in the focus, treatment goals and working mechanism become apparent, the essential ones are presented in box 1.2.[2] Medical interventions primarily focus on improving impaired body functions, aiming to correct nigrostriatal dysfunction. Allied health interventions primarily aim to improve the performance of a limited activity or a participation problem by teaching patients or caregivers to employ compensatory strategies. These compensatory strategies used by allied health care professionals aim to bypass the defective basal ganglia by engaging alternative neural circuitries that are still intact (cortical pathways and sensory systems).[22-26] Apart from the use of compensatory strategies, many patients resort to exercise therapy, most often supervised by physiotherapists, hoping to improve their gait and balance.[27-30] The effectiveness of allied health interventions has long been questioned because of serious methodological shortcomings, but fortunately allied health care is now increasingly changing into evidence-based practice.[20;31]

Box 1.2 Characteristics of medical management and allied health care in PD.[2]

	Medical management	Allied health care
Focus	• Disease process	• Impact of disease process on daily functioning
Treatment goals	• Reduce impaired body functions • Minimise disease severity	• Reduce disability due to impaired motor and non-motor body functions • Improve participation problems and limited activities in daily live • Improve level of activities
Working mechanism	• Correct nigrostriatal dysfunction	• Support compensatory (movement) strategies • Increase exercise tolerance
Scientific evidence	• Moderate to strong	• Limited (occupational therapy) to moderate or strong (physiotherapy, speech therapy)

An integrated approach for PD

Given the complexity of PD, an integrated approach would be preferable. When engaged as a complementary approach next to medical treatment, utilizing allied health care may increase the overall therapeutic efficacy (and perhaps also efficiency) as the risk of conflicting treatment plans or double interventions is reduced. For this reason, several specialized PD centers have started with multidisciplinary programs for their PD patients.

While both these centers and the representing patient societies firmly believe in this multidisciplinary approach, evidence supporting the advantage of an integrated approach is still limited. Although such an integrated approach is generally accepted in the world of e.g. falls prevention[27], evidence supporting the advantage of such an approach in PD is still limited. Positive effects for mobility, quality of life and well-being have been reported in uncontrolled studies.[32;33] Only one study used a controlled design to investigate the effects of multidisciplinary programs in PD.[34] Small improvements for mobility were found directly after the program. These findings are in line with the positive trends that are reported for multidisciplinary interventions in patients with other chronic conditions.[35] However, it is unknown whether these integrated care programs are also efficient, as small improvements still need to be weighed against the risk of potentially higher costs.[35] Another possible concern is the increased burden for the caregivers, who now need to actively work with a more complex and multifaceted health care system and more frequent consultations.[34]

The integrated approach for PD in practice

Let us assume for argument's sake that the effect for these multidisciplinary programs will be demonstrated and scientifically underpinned in the future (several large trials are in fact underway, one of which – the IMPACT trial – is currently running in the Radboud University Nijmegen Medical Center).[36] The natural question then arises whether the current health care system is prepared for the delivery of such integrated care to PD patients. This is actually uncertain, for several reasons. First, the integration of findings from different (allied) health professionals working within different settings requires communication and collaboration between health professionals. Our current health care system does not provide an intrinsic structure that facilitates communication and collaboration between physicians and allied health professionals.[37] A second concern is the level of expertise among health professionals regarding PD and its multidisciplinary treatment. Even when communication is optimal and collaboration structures are in place, professionals still need to be aware of the treatment possibilities and impossibilities of other disciplines involved in the care for PD patients. In the Netherlands, a survey study suggested that this was not fully the case for phy-siotherapy in PD.[21] It appeared that many patients with an indication for physiotherapy were not referred to a physiotherapist and vice versa ('false-negative referrals'). Moreover, a small proportion of patients without relevant health problems received prolonged treatment by a physiotherapist ('false-positive referrals'). These findings suggest that PD patients and physicians may not be not be fully aware of the referral criteria for physiotherapy in PD, and that some phy-

siotherapists are treating patients without an indication lengthy. Note that very similar problems are likely to exist for different allied health professionals or other disciplines involved in PD care, but this is not addressed in similar detail as for physiotherapy in this thesis. To improve allied health care in PD, quality improvement interventions are needed to improve communication, collaboration and PD expertise.

Towards better allied health care for patients with PD

In the work presented in this thesis, we have used a stepwise approach to improve allied health care in PD (see box 1.3). First, *Chapter 2.1* provides an overview of evidence-based allied health interventions for PD, based on a systematic review of the literature. Second, we identified barriers that may hamper the application of evidence-based interventions into daily practice, and this was done using a survey. This survey, which is described in *Chapter 2.2,* should clarify whether patients with an indication for allied health care are treated by capable professionals. The findings of *Chapter 2* are then used to design a tailor-made quality improvement intervention for allied health care in PD. *Chapter 3* describes the implementation of such an intervention on a small scale, to test its feasibility. After the completion of this exploratory phase in *Chapter 3*, we planned to study the most eligible component of the quality improvement within a randomized controlled trial design. Because quality improvements are specifically tailored interventions, we first developed valid and reliable outcome measures that can measure changes due to the intervention. *Chapter 4* describes the development and evaluation of two outcome measures: one for health status in PD patients and the other for quality of care. Both measures were then included in the design of a randomized controlled trial, of which the design and results are described in *Chapter 5.* Finally, the pros and cons of the quality improvement interventions and their implementation on a larger scale are discussed in *Chapter 6.*

Box 1.3 Stepwise approach to improve integrated allied health care in PD

Step 1.	Identifying evidence-based allied health care interventions
Step 2.	Identifying barriers in referral and consultation process of allied health care
Step 3.	Designing and piloting a tailor-made quality improvements
Step 4.	Preparing a randomized trial to evaluate the effects of the quality improvement intervention
Step 5.	Conducting a cluster-randomized trial to evaluate the quality of the improvement intervention
Step 6.	Providing recommendations for implementation and dissemination of the quality improvement intervention

Chapter 2
Strengths and limitations of allied health care in Parkinson's disease

2.1 Evidence-based allied health care interventions in Parkinson's disease

Published as: Nijkrake MJ, Keus SH, Kalf JG, Sturkenboom IH, Munneke M, Kappelle AC, Bloem BR: Allied health care interventions and complementary therapies in Parkinson's disease. Parkinsonism Relat Disord 2007;13 Suppl 3:S488-S494.

Summary:

Allied health care and complementary therapies are used by many patients with Parkinson's disease (PD). For allied health care, supportive scientific evidence is gradually beginning to emerge, and interventions are increasingly integrated in the treatment programs for PD patients. To evaluate whether such multidisciplinary programs are justifiable, we review the literature of allied health care and complementary therapies in PD. According to the level of available evidence, we provide recommendations for clinical practice. Finally, we discuss the need for an improved organization of allied health care, and identify topics for future research to further underpin the pros and cons of allied health care and complementary therapies in PD.

Introduction

The progressive nature and wide diversity of symptoms make Parkinson's disease (PD) a complex and challenging disorder for both patients and health care professionals, causing significant social and financial burden.[11;38] To tackle these challenges, recent guidelines recommend that health professionals should consider approaching their patients using a comprehensive, multidisciplinary approach.[39]

The most effective intervention for PD is symptomatic drug treatment using levodopa, but a drawback is that long-term use leads to response complications such as dyskinesias. For a subgroup of well-selected patients, neurosurgery is a good alternative.[40] But despite optimal medical management using drugs or surgery, patients continue to experience progressive deterioration of body functions, daily activities and participation. To treat these problems, allied health care interventions and complementary therapies are commonly engaged.[20;41] Allied health occupations such as physiotherapy, occupational therapy and speech therapy aim to maximize the performance of daily activities and minimize secondary complications, mainly by using compensatory strategies.[42] Estimates of current use of allied health care in PD range from 7-57% for physiotherapy, 9-25% for occupational therapy and 4-20% for speech therapy.[20;21] In addition, some 40-44% of patients in the United States and United Kingdom resort to complementary therapies, most commonly massage, vitamins, herbs and acupuncture.[41;43] Despite this widespread use of allied health care interventions and complementary therapies in PD, various practical concerns remain, including the level of supporting evidence and the degree of specific expertise among professionals and practitioners delivering these interventions.

This review aims to provide an overview of evidence-based allied health care interventions and complementary therapies in PD. For allied health interventions such as physiotherapy, occupational therapy and speech therapy, we will describe the 'core areas' (i.e. the specific disease domains where intervention is deemed to be useful). The search terms for occupational therapy[44], physiotherapy[5] and speech therapy[45] are published in detail elsewhere. For each specific area the level of available evidence is presented using EBRO criteria (Table 2.1.1). EBRO is an initiative of the Dutch Cochrane Center and the Dutch Institute for Healthcare Improvement (CBO, http://www.cbo.nl), a member of the Guidelines International Network (GIN). We next translated the available evidence into recommendations for clinical practice. Finally, we discuss the organization of allied health care in PD in order to enhance the quality of integrated care and discuss topics for future research.

Allied health care interventions

Although occupational therapy and physiotherapy are closely related, there are clear differences between these therapies with respect to their core areas. Whereas physiotherapy mainly aims to improve basic skills like gait or transfers in order to improve daily functioning, occupational therapy is focused more on being able to use these skills to perform complex activities like 'cooking' or

'going to a shop'.

For an optimal effect of allied health interventions, some general treatment principles must be considered. First, the site where treatment is delivered is important, and this depends on the treatment objective, the abilities of individual patients and specific environmental factors. Limitations in participation and activities are often related to the patient's home environment, hence promoting activities preferably takes place at home (Level 3[26]).

Table 2.1.1: Grading of the level of evidence for intervention studies

Level of scientific evidence of the intervention
1. Supported by one systematic review at quality level A1[1] or at least two independent trials at quality level A2[2]
2. Supported by at least two independent trials at quality level B[3]
3. Supported by one trial at quality level A2 or B, or research at quality level C[4]
4. Based on the expert opinion (e.g. of working group members) level D[5]

[1]**A1** *meta-analyses (systematic reviews), which include at least some randomized clinical trials at quality level A2 that show consistent results across studies;* [2]**A2** *randomized clinical trials of good methodological quality (randomized double-blind controlled studies) with sufficient power and consistency;* [3]**B** *randomized clinical trials of moderate methodological quality or with insufficient power, or other non-randomized, cohort or patient-control group study designs that involve inter-group comparisons;* [4]**C** *patient series;* [5]**D** *expert opinion.*

Second, involving the caregiver can be important (e.g. if cognitive functions of the patient are declined). Caregivers do not have to fulfil the role of therapists but can assist in using cues or cognitive movement strategies when needed (Level 4[5]). Third, the tempo and intensity of exercising have to be adjusted to the patient's individual cognitive and energy levels (Level 4[5]). Fourth, treatment must be tailored to 'on' and 'off' periods. If increasing physical capacities is the objective, training is best done in the 'on' period when performance levels are expected to be higher (Level 4[5]). However, patients who are regularly 'off' should particularly be learned to use compensatory strategies or cueing strategies during such 'off' periods (Level 4[5]).

Physiotherapy

A recent evidence-based guideline for physiotherapy in PD describes six specific core areas: gait, transfers, balance, body posture, reaching and grasping, and physical inactivity.[5]

Gait

Gait in PD is disturbed in two ways: a "continuous" type, characterized by an increased step frequency, a reduced stride length and height, slow walking speed, decreased trunk rotation and asymmetrically reduced arm swing; and an "episodic" or paroxysmal type (festination or freezing) which is only periodically present (typically under specific circumstances such as turning around or crossing a narrow passage).[46;47] Both types of gait abnormalities are aggravated during dual tasking. Gait improves by applying visual or auditory cues (Level 2[22;26;48;49]), by cognitive movement strate-

gies (Level 3[25]) and gait exercises on a treadmill (Level 2[50;51]). In addition, gait may be improved by training trunk mobility (Level 4[5]) and leg muscle strengthening (Level 2[29]). Furthermore, instructions can be given concerning arm swing, base of support, heel contact, step size (Level 2[22;52]) and turning around using a wide arch (Level 4[46]).

Transfers

Many PD patients perceive problems in performing transfers (e.g. rising from a chair or rolling over in bed).[21] Cognitive movement strategies are used to improve such transfers. The rationale behind cognitive movement strategies is that complex (automatic) movements are transformed into a series of separate components that are consciously executed in a defined sequence, and which each consist of relatively simple movement elements (Level 2[23;26]). Dual tasking during transfers should be avoided, and transfers can be guided using external cues to facilitate movement initiation (Level 3[24;25]).

Balance

Postural instability is a problem for many PD patients and can lead to falls.[53] Most falls are "intrinsic" (caused by patient-related factors, e.g. freezing during turning), but extrinsic factors (e.g. narrow doorways or slippery floors) also play a role.[54] Exercises to improve balance (Level 2[28;30]) and to prevent falls (Level 3[27;55]) were found to be effective. Furthermore, advice and information can be given concerning footwear, orthostatic hypotension, walking aids and environmental hazards (Level 4[46;54;56-58]).

Body posture

Posture in PD is typically stooped, often in combination with lateroflexion. Furthermore, reduced trunk flexibility is often present. Exercise programs focused on the coordination of muscle activity whilst maintaining posture and movement can facilitate performance of activities such as grasping, rolling over in bed or preserving balance (Level 3[59;60]). The change in posture towards flexion may be corrected by applying verbal or visual feedback (e.g. using a mirror) (Level 4[52]).

Reaching and grasping

Cueing strategies (to initiate and continue activities), cognitive movement strategies and the avoidance of dual tasking may help to improve the ability to reach, grasp and manipulate objects (Level 4[61]).

Physical inactivity

PD patients tend to be inactive, and this may cause secondary complications such as decreased aerobic capacity, muscle weakness, joint problems and osteoporosis.[47;62] Therefore, patients should be informed about the health benefits of exercise and encouraged to do sports (Level 4[63;64]).

Occupational therapy

Evidence-based guidelines for occupational therapy in PD are not yet available. The role of occupational therapy in PD rehabilitation is to enable patients and their caregivers to pursue meaningful activities and participation in the domains of self-care, work (family work, paid work, and voluntary work) and leisure activities.[65]

Because specific evidence for occupational therapy in PD is lacking, some insights might be gained from evidence obtained with other chronic disorders in which functional problems bear resemblance to PD. We will discuss occupational therapy interventions that appeared to have some potential for improving activities and participation in PD. The level of evidence has been adjusted accordingly when evidence was obtained from related areas or disciplines other than occupational therapy itself. For example, although there is level 2 evidence for using cues to improve gait, the strength of the recommendation for occupational therapy is weaker as there is limited evidence available for its effectiveness in improving the performance of functional activities.[48]

Improving limitations in participation and activities

Occupational therapy interventions in PD include teaching patients alternative and compensatory strategies to improve task performance. The main recommended strategies are: (a) directing attention towards specific aspects of a given activity (Level 3[66;67]); (b) using cognitive movement strategies to break down complex performance sequences of activities into single steps (Level 3[23;26;68]); (c) avoiding multiple tasking during activities (Level 4[54;69]); and (d) using external cues to initiate and maintain movements during activities (Level 3[48;67;70;71]). Occupational therapists may also advise patients and their caregivers to optimize the planning of daily and weekly routines considering factors such as energy levels, medication effects, speed of task performance and the possible need for structure to prompt initiation of activities (Level 4[72;73]). Moreover, advice on appropriately adapted equipment or other changes in the physical environment can be given to enhance independency, efficiency and safety in activity performance (Level 3[27;74]). Addressing the needs of caregivers on issues related to activities and participation, by providing them with information, advice and training is considered as an important part of occupational therapy in PD. These interventions aimed at the caregiver can improve their way of coping with complex situations and improve their competence in supporting the patient (Level 2[75-77]). For both patients and caregivers, encouraging self-management skills throughout the treatment process is a basis for learning to deal with problems (Level 3[78;79]).

Speech therapy

Evidence-based guidelines for speech therapy in PD are not yet available. Currently, speech and language disorders, dysphagia and drooling are mentioned most frequently by experts as the core target areas for speech and language therapy in PD.[39;80;81]

Speech and language disorders

Dysarthria in PD is characterized by reduced vocal loudness, hoarseness, imprecise articulation and monotony of both pitch and loudness.[82;83] In addition, PD patients appear to have diminished auditory feedback and do not increase their vocal level when needed.[84] Hypokinesia and rigidity are improved by cueing the patient to increase the intensity of speech.[83] The Lee Silverman Voice Treatment (LSVT) is based on this principle and aims to teach patients to use the mental cue "Think loud, think shout". This treatment results in an improvement of voice quality, respiration and articulation and thus intelligibility (Level 2[85]). To prevent strained voicing, some adaptations to the LSVT have recently been proposed. This modified treatment, which is known as the Pitch Limiting Voice Treatment (PLVT), learns patients to "Speak loud and low". The PLVT has proven to limit the increase in vocal pitch (Level 3[86]). Furthermore, information, advice and exercises may be given concerning cognitive problems, word finding difficulties, masked face and slowness in making conversations in order to improve communicative abilities of PD patients (Level 4[87]).

Swallowing

Swallowing problems are common in advanced PD, ranging from slower chewing and infrequent choking on liquids to inability to drink or eat normal food consistencies.[88] A positive effect on swallowing can be obtained with the LSVT (Level 3[89]) or with verbal cues to improve the initiation of swallowing (Level 4[90]). Taking smaller sips or slightly adapting head posture may help to prevent choking on liquids (Level 4[91]). Furthermore, the principles of cognitive movement strategies can be translated to swallowing. For example, repetitive tongue pumping may be improved by training the patient to use the sequence 'Take a bite – chew – stop – strong swallow' (Level 4[83]).

Drooling

Drooling (unwanted loss of saliva) is common in PD and has significant social and emotional consequences.[92;93] Although many investigators acknowledge that drooling in PD is probably caused by a combination of decreased swallowing frequency, diminished lip closure and stooped posture, there is a lack of adequate behavioural treatment strategies (Level 4[94]). It has been suggested that training swallowing frequency with an auditory cue (metronome) can have a positive effect (Level 3[95]Furthermore, patients may be advised to use reminders for lip closure and to correct their stooped posture (Level 4[52;94]).

Other allied health care interventions

Many other allied health professionals such as the dietician, social worker and sexologist can be involved in the treatment process of PD patients. However, there is a lack of studies that have formally evaluated the efficacy of these treatments. Therefore, only level 4 recommendations can be provided.

Dietician

PD patients are at risk for weight loss and malnutrition due to a variety of reasons, including (among others) physical limitations (e.g. dysphagia), cognitive dysfunction (e.g. forgetting to eat in demented patients), apathy, depression and loss of appetite (e.g. due to hyposmia).[96-98] The dietician can help to optimize the nutritional status of patients. An additional role is to coach patients in avoiding high protein meals together with intake of medication, as proteins interfere with gastrointestinal absorption of levodopa (Level 4[96;97;99]). In addition, the dietician informs patients not to follow unconventional nutritional therapies that may exacerbate malnutrition (Level 4[98]), and may give patients nutritional advice if constipation is present (Level 4[100]).

Social work

The role of social work for PD has not been studied scientifically, but social workers are increasingly engaged in many centres as part of the multidisciplinary team. Possible target areas where social workers can provide support from a social perspective include disease acceptation and coping, relational aspects, support of the financial situation (e.g. in patients with pathologic gambling, or expensive adjustments to the house), addictions, legal issues with respect to driving and work situation (Level 4[101]). Advice must be tailored to each patient's individual social and cultural background.

Sexologist

Sexual dysfunction is common in PD for both women and men.[102] Women report difficulties with arousal, reaching orgasm, low sexual desire, and sexual dissatisfaction. Men report erectile dysfunction, sexual dissatisfaction, premature ejaculation, and difficulties reaching orgasm. Furthermore, antiparkinson medication – in particular dopamine receptor agonists – can cause hyper sexuality as part of the dopamine dysregulation syndrome.[103] In addition to adjustments to the medical treatment regime (implemented by the neurologist), sexologists have an important counselling function for both patients and their partners, for example with respect to aids to improve sexual functioning (Level 4).

Complementary therapies

Use of complementary therapies is common in PD. Examples include Tai Chi (to improve balance), Qigong (to improve general well-being, e.g. through breathing patterns combined with meditation), massage (for relaxation), acupuncture (for e.g. sleep disturbance), and nutritional supplements (to prevent or correct possible nutritional deficiencies). Percentages of PD patients that use at least one of these complementary therapies range from 40% in the UK and USA to 60% in Singapore.[41;43;104] Due to lack of proper research studies, only level 4 recommendations can be provided.

Tai Chi

In elderly subjects, Tai Chi is effective in improving balance (Level [27]). In Tai Chi, exercises are slowly and consciously executed in a defined sequence. This principle of Tai Chi has some resemblance to cognitive movement strategies and might therefore be beneficial for PD patients (Level 3[105]). However, this has never been investigated in controlled studies.

Qigong

Exercises in Qigong combine practice of motion and rest, both guided by mental imagery.[106] In terms of physiotherapy Qigong can be classified as active low-energy exercises with sustained movements of limbs, trunk, face, tongue and breathing coordination. Qigong aims to improve general well-being, and there are preliminary indications that Qigong may have both immediate and long-term (6 months) effects on the UPDRS-III (motor part) (Level 3[106]).

Massage

Many PD patients receive regular therapeutic massage to alleviate symptoms. The associated benefits of massage that have been described in qualitative studies are general improvements such as relaxation, improved sleep and emotional health.[107] However, therapeutic massage has not been investigated in high quality studies, hence the efficacy of massage is unknown.

Acupuncture

Previous studies have shown that acupuncture is safe and well tolerated in patients with PD, but it does not improve quality of life, ADL, depression or UPDRS scores (Level 3[108-110]).

Nutritional supplements

The aim of nutritional supplements in PD is to prevent or correct possible nutritional deficiencies. However, the use of nutritional supplements might potentially cause harmful adverse effects and could intervene with antiparkinson medication. Therefore, greater awareness of the risks of nutritional supplements is warranted (Level 4[98]).

Towards optimal organization of allied health care

In many countries, allied health care is commonly prescribed for patients with PD. Moreover, integrated multidisciplinary care programs are increasingly implemented in Parkinson centres, hoping that provision of optimal non-medical support may support patients and their families, and allow them to live in their home situation as long as possible.[111;112] It is still an open debate whether this will merely increase the health care costs (a team is more expensive than a solitary neurologist) and increase the strain on e.g. the carers, or whether multidisciplinary team work can help to reduce costs (e.g. by preventing hip fractures or delaying nursing home admission.[12;34] Only few research studies have been performed, and these have thus far failed to provide convincing support for a multidisciplinary approach.[34;113]

Several practical issues are important to consider. First, allied health professionals should be familiar with the evidence-based strategies of interventions in their specific discipline, in order to avoid unnecessary treatment where evidence is lacking, and to deliver optimal treatment where evidence is becoming available. Previous studies reported that many allied health professionals lack specific expertise in PD[21;65]. For everyday clinical practice, it is crucial that evidence is translated into guidelines with practical recommendations. It will therefore be necessary to develop such practically oriented and evidence-based guidelines for allied health disciplines. A second issue is the generally poor communication among allied health professionals, and between allied health and medical specialists. This is likely due to the fact that most health professionals are insufficiently aware of the (im)possibilities of treatment strategies that can be delivered by other disciplines.[20] Finally, objective criteria for referral to allied health care are missing, and there are no rational quality indicators that can help professionals in deciding when a treatment is complete.[114] Consequently, the current health care system is characterised by false-negative referrals (patients are inadvertently not being referred), false-positive referrals (in patients who are unlikely to benefit from allied health) and other forms of "over-treatment" (chronic maintenance therapy in patients without formal need for further therapy).
In order to tackle these issues, there is a need to improve the quality of education, collaboration and communication. Several new approaches appear to be feasible, but the efficacy of these interventions remains to be demonstrated.[111;112]

Discussion

It is evident that there is a great need for well-designed, randomized controlled trials evaluating the efficacy, costs and limitations of allied health care and complementary therapies in PD.[20;109] Such trials are now beginning to emerge, as exemplified by the large RESCUE trial that evaluated the effect of various cueing strategies for gait.[48] This trial offered a much needed contribution to the field of allied health, because the principles of cueing strategies can now be investigated for other limitations in activities and participation (e.g. self-care, work and leisure activities). With the advent of such trials, there is also a need for improved outcome measures to document the effect of allied health interventions, in particular at the level of activities and participation (which are important targets for occupational therapy).

The call to further scrutinize complementary therapies appears justified by that fact that many PD patients currently utilize such complementary therapies. However, fundamental quantitative studies among both PD patients and complementary practitioners about the exact mechanisms, standard therapy and benefits of specific complementary therapies are perhaps the first step towards stronger evidence and recommendations for clinical practice.

Acknowledgements

This work was supported by the Netherlands Organisation for Health Research and Development (grant number 945-04-357, to M. Munneke and B.R. Bloem; grant number 016.076.352, to B.R. Bloem).

2.2 Allied health care in PD: referral, consultation, and professional expertise

Published as: Nijkrake MJ, Keus SH, Oostendorp RA, Overeem S, Mulleners W, Bloem BR, Munneke M: Allied health care in Parkinson's disease: referral, consultation, and professional expertise. Mov Disord 2009;24:282-286.

Summary:

There is evidence for the efficacy of allied health care in Parkinson's disease (PD). However, barriers exist that hamper implementation of evidence into daily practice. We conducted a survey to investigate: (a) to what extent PD patients currently utilize allied health care for relevant problems in the core areas of allied health care; and (b) the level of PD-specific expertise among allied health professionals. Questionnaires were sent to 260 patients and 297 allied health professionals. Referral rates were 63% for physiotherapy, 9% for occupational therapy, and 14% for speech therapy. PD patients with problems that can potentially be alleviated by input from allied health professionals are often not being referred. Furthermore, most patients were treated by allied health professionals who lacked PD-specific expertise. Current referral to and delivery of allied health care in PD are suboptimal. Evidence-based guidelines for allied health care in PD and active implementation of these guidelines are needed.

Introduction

Allied health care in Parkinson's disease (PD) provides a distinct therapeutic approach that may complement standard medical treatment such as medication or neurosurgery.[115] The evidence for the benefits of allied health care in PD is still limited, but increasing rapidly.[48;55;116] In order to provide optimal allied health care in daily clinical practice, not only evidence is crucial. Obviously, evidence needs to be translated into clinical guidelines and subsequently be implemented into daily practice.

However, there are barriers that hamper translation of evidence into daily practice. For example, the referral process to allied health care and the PD-specific expertise of allied health professionals may be suboptimal, e.g. patients needing allied health care are not always referred.[21;65;117] We therefore conducted a survey among both PD patients and allied health providers to investigate: (a) to what extent PD patients utilize allied health care for relevant problems in the core areas of allied health care; and (b) the level of PD-specific expertise among allied health professionals. We focused on the 'core specialties' of allied health care for PD: physiotherapists, occupational therapists and speech therapists.

Methods

Study design

We performed a questionnaire survey that focused on referral to and consultation by allied health professionals in a representative cohort of PD patients, and on the level of PD-specific expertise among a representative group of allied health professionals. The questionnaires were first field tested and optimized among five PD patients and 10 professionals. Final questionnaires were sent by mail and reminders were sent within four weeks. The local medical ethics committee approved the study.

Referral and consultation

Subjects

All patient records of two large medical centres that jointly cover the entire catchment area of Nijmegen (± 230.000 citizens; ± 225 km^2)[118] were screened. We approached all patients with idiopathic PD according to the Gelb criteria[119] with Hoehn en Yahr stage I-IV,[120] living independently in the community. Questionnaires were sent to 260 eligible patients, and 217 (83.1%) questionnaires were returned. Of the participants, 66% were male, the mean age (±SD) was 66 (±10.2) years and mean disease duration was seven years (±6.1).

Questionnaire

The questionnaire contained 40 items concerning limitations in the performance of daily activities and participation, arranged into 12 domains (Table 2.2.1). These domains cover the core areas for physiotherapy[5], occupational therapy[65] and speech therapy[80;121] in PD. Furthermore, patients were asked to report the number of falls in the preceding year and whether they utilized allied health care in order to prevent falls.

Analysis

For each domain, patients rated: (a) whether they perceived problems in performance of an activity on a five-point scale (from 0 = 'no problems' to 4 = 'severe problems'); (b) whether they wanted to improve this symptom on a five-point scale (0 = 'not willing to improve' to 4 = 'very much willing to improve'); and (c) whether allied health care was used to improve the problems on these specific domains. The perceived problems were defined as a 'patient-relevant problem' if rated '2', '3' or '4' on both 'problem in the performance of an activity' and on 'willing to improve the problem' for a specific domain. Frequencies were calculated for patient-relevant problems. We calculated the proportion of patients with a patient-relevant problem that consulted allied health care.

Professional expertise

Subjects

All physiotherapy (n=197), occupational therapy (n=22) and speech therapy (n=79) practices located in the catchment area of Nijmegen were approached. Questionnaires were returned by 198 allied health care professionals (66%). Eighty three professionals were excluded from the analyses, because they had not treated any PD patients during the previous year. A total of 115 questionnaires (86 physiotherapy, 12 occupational therapy, 17 speech therapy) were used for final analyses.

Questionnaire

Questionnaires contained items concerning work setting, work experience in years, the number of PD patients treated yearly, PD-specific education, perception of expertise in treating PD patients, and familiarity with treatment options for PD by other professionals.

Analysis

The perception of PD-specific expertise and familiarity with treatment options by other professionals were rated using a five-point scale (0 = 'insufficient' to 4 = 'very good'). Allied health professionals were categorized into 'specific expertise' if rated '3' or '4' on PD-specific expertise, and defined as 'familiar' if they rated '3' or '4' on familiarity with the treatment options of other professionals. Descriptive statistics were then performed for those with and without PD-specific expertise.

Results

Referral and consultation

At the time of the questionnaire, 62.5% of the patients used physiotherapy, 8.5% occupational therapy, and 14.4% speech therapy. The patient-relevant problems and any utilization of allied health professionals for these specific problems are presented in Table 2.2.1.

Physiotherapy was mostly aimed at relevant problems in the domains of gait, posture, transfers and balance (range 66.4-56.4%). Only about 3% of the patients utilized occupational therapy for relevant problems concerning arm and hand activities, gait, transfers, balance, posture, leisure activities, personal care, domestic activities or work activities.

Table 2.2.1. Patient-perceived relevant problems and the consultation of allied health care to counteract these problems.

Domain	Patient relevant problems [a] (n=216)	Allied health care utilized for relevant problems [b]			
		% PT	% OT	% ST	% No AHC
Arm/hand activities [c]	118 (54.6%)	23.7	1.7	1.7	72.9
Gait	116 (53.7%)	66.4	2.6	-	35.3
Transfers	115 (53.2%)	56.6	2.7	-	45.1
Balance	103 (47.7%)	56.4	2.0	-	44.6
Posture	98 (45.4%)	61.9	2.1	-	39.2
Leisure activities	89 (41.2%)	21.3	-	-	78.6
Speech	80 (36.9%)	-	-	20.0	80.0
Personal care	79 (36.6%)	-	2.6	-	97.5
Domestic activities	78 (36.0%)	-	1.3	-	98.7
Work activities	70 (32.4%)	20.0	1.4	2.9	75.8
Drooling	66 (30.6%)	-	-	6.1	95.4
Eating	43 (19.9%)	-	-	9.3	90.7

[a] patient relevant problem, problem in both the performance of an activity and willing to improve this activity; [b] percentage of number of patients with relevant problems; [c] including reaching and grasping; AHC, allied health care; PT, physiotherapy; OT, occupational therapy; ST, speech therapy

Speech therapy was utilized mostly for speech and voicing problems (20.1%) and less often for problems concerning eating and drooling (range 9.3-6.1%).

Nearly 60% of patients reported at least one fall in the preceding year, but only 33% of these patients received physiotherapy or occupational therapy in order to prevent future falls. Fifteen patients used physiotherapy without having a patient-relevant problem. This was not the case for speech or occupational therapy.

Professional expertise

The expertise of allied health professionals is presented in Table 2.2.2. More than 75% of the allied health professionals reported a lack of PD-specific expertise, even though these professionals were treating most of the PD patients. Allied health professionals with sufficient PD-specific expertise treated more patients in the previous year, than those without (physiotherapy 7.0 versus 3.3, occupational therapy 9.3 versus 3.2, speech therapy 4 versus 3.1). No differences were found for professional setting or number of years of working experience between professionals with and without PD-specific expertise. More than 50% of the allied health professionals were unfamiliar with the treatment options of other professionals and had not followed educational programs concerning PD.

Discussion

This study demonstrates that PD patients often do not utilize allied health care, despite having relevant problems that are potentially amenable to therapeutic intervention. Furthermore, if patients are being referred to allied health care, they are typically treated by professionals without sufficient PD-specific expertise.

Referral and consultation

In line with previous studies, we found that patient-relevant problems of PD patients were often not treated by allied health professionals.[20;117;122] This may be relevant, as there is increasing evidence for the benefit of allied health care; e.g. to introduce compensatory strategies to improve gait or transfers.[23;48] When patients were referred, it was most often to a physiotherapist. It may be that the most frequent patient-relevant problems fall within the domains that 'traditionally' belong to physiotherapy. Furthermore, most evidence is currently available for interventions within physiotherapy.[115]

The low frequency of allied health consultations may be explained by a lack of referrals, or problems *after* referral. In the Netherlands, neurologists are responsible for most of the allied health referrals[21], and it is possible that neurologists are insufficiently aware of the indications for allied health care, or lack time to screen for these indications. It is also possible that patients themselves decline referral to allied health professionals. In the Netherlands, allied health care is compensated by the health insurance, so financial concerns are not a likely explanation. Our study was limited in the fact that we did not include neurologists or nurse specialists to inquire about the above issues.

Table 2.2.2. Characteristics of allied health care professionals categorized into specific PD expertise (experts) and no specific PD expertise (non-experts).

	Physiotherapists (n=86) [a]		Occupational therapists (n=12)		Speech therapists (n=17)	
Professional characteristics	Experts	Non-experts	Experts	Non-experts	Experts	Non-experts
N (%)	17 (19.8)	66 (80.2)	3 (25.0)	9 (75.0)	3 (17.6)	14 (82.4)
PD patients treated, number (%)	119 (35.4)	217 (64.6)	28 (49.1)	29 (51.9)	12 (21.8)	43 (88.2)
Work setting [b]:						
% primary care	100	100	33.3	0	66.7	50.0
% institutional care	17.6	6.1	100	100	66.7	50.0
Work experience in years, mean (±SD)	21.2 ± 7.0	18.6 ± 8.1	9.7 ± 2.5	10.8 ± 11.4	17.7 ± 5.7	16.5 ± 9.8
PD patients treated yearly, mean (±SD)	7 ± 7.4	3.3 ± 2.7	9.3 ± 6.0	3.2 ± 1.0	4 ± 1.7	3.1 ± 2.7
% education on PD	35.3	10.6	0	22.2	66.7	14.3
Familiarity with other treatment options:						
% familiar with speech therapy	35.3	6.1	33.3	0	66.7	7.1
% familiar with occupational therapy	47.1	4.5	33.3	0	33.3	7.1
% familiar with neurological treatment	35.3	19.7	66.7	0	66.7	0
% familiar with PD nurse specialist	17.6	1.5	33.3	0	33.3	0

[a] Three missing cases; [b] professionals can work in both settings

Professional expertise

In our survey, the professionals that perceived themselves as 'PD-experts' did treat more patients per year than the non-experts. However, the number of PD patients treated yearly by the experts was still low (< 10 patients/year per therapist) and this may explain why educational programs are scarce, why only a small number of professionals is participating in these programs and why only a small number of professionals is aware of the possibilities of other disciplines involved in the care of PD patients.

Conclusion

We recommend the development and implementation of evidence-based guidelines for speech therapy and occupational therapy, as was recently done for physiotherapy.[5] This implementation may be facilitated by PD specific health care networks, in which physicians and allied health professionals participate.[123] Feasibility studies for this concept have been performed for rheumatoid arthritis.[124] In the past five years, we have set up such PD-specific networks in large part of the Netherlands. Within these networks, a selected number of professionals are specifically trained to use evidence-based guidelines, and patients are specifically referred to these dedicated professionals according to explicit protocols. This concept is currently being evaluated in a controlled, cluster randomized trial for health benefits, cost-effectiveness and guideline adherence.[123]

Acknowledgements

This research was supported by grants from the Radboud University Nijmegen Medical Centre and the Netherlands Organisation for Health Research and Development (947-04-357). B.R. Bloem was supported by a VIDI research grant (016.076.352) from the Netherlands Organisation for Health Research and Development.

Chapter 3
The ParkinsonNet Concept as quality improvement intervention

3

3.1 The ParkinsonNet Concept: development, implementation and initial experience

Published as: : Nijkrake MJ, Keus SH, Overeem S, Oostendorp RA, Vlieland TP, Mulleners W, Hoogerwaard EM, Bloem BR, Munneke M: The ParkinsonNet concept: development, implementation and initial experience. Mov Disord 2010;25:823-829.

Summary:

The quality and efficiency of allied health care in Parkinson's disease (PD) must be improved. We have developed the ParkinsonNet concept: a professional regional network within the catchment area of hospitals. ParkinsonNet aims to: (1) improve PD-specific expertise among allied health personnel, by training a selected number of therapists according to evidence-based guidelines; (2) enhance the accuracy of referrals by neurologists; (3) boost patient volumes per therapist, by stimulating preferred referral to ParkinsonNet therapists; and (4) stimulate collaboration between therapists, neurologists, and patients. We describe the procedures for developing a ParkinsonNet network. Our initial experience with this new concept is promising, showing an increase in PD-specific and a steady rise in the patient volume of individual therapists.

Introduction

There is increasing evidence for the effect of specific interventions delivered by physical therapists, occupational therapists and speech therapists in Parkinson's disease (PD).[5;115] Unfortunately, care is suboptimal because allied health therapy is usually provided by generally active professionals that lack PD-specific expertise.[21;125] There are two reasons for this lack of expertise. First, allied health personnel are generally not trained according to evidence-based guidelines. Second, each therapist treats only a limited number of PD patients (typically only four patients per year).[125] This low patient volume does not stimulate therapists to improve their knowledge about PD or specific guidelines.

To boost the quality of allied health care for PD, a multifaceted approach is required to: (a) improve the expertise among professionals; (b) increase the patient volume per therapist, and (c) enhance collaboration between professionals. We therefore developed the ParkinsonNet concept: a regional professional network that tackles all three aspects. Here, we describe the development and implementation of this ParkinsonNet concept, as well as our initial experience.

Methods

Design of ParkinsonNet

The initial concept of ParkinsonNet was conceived in January 2004 and implemented in the catchment area of three hospitals in the region of the city of Nijmegen, The Netherlands. The first element of ParkinsonNet is selection of a restricted number of professionals within a given region, to increase PD patient volume. We estimated the required number of therapists based on actual referral rates (63% physical therapy; 9% occupational therapy; 14% speech therapy)[125] and the geographic pattern of the catchment area (±520.000 citizens; ±600 km^2). In addition, we considered a maximum travel time of about 15 minutes by car, for patients and therapists. Based on this, we intended to include about 19 physical therapists, nine occupational therapists and nine speech therapists.

We then delivered a multifaceted intervention, consisting of continuous education and means to improve communication (Table 3.1.1). The goals were: to improve the expertise of the selected therapists; to re-organize the referral process; and to enhance collaboration and communication between the selected therapists and referring physicians. Specific components of this intervention were targeted at either allied health personnel, the participating physicians (including their PD nurse specialists), or PD patients. Details of all components, target groups, and implementation in time are summarized in Table 3.1.1.

Participating allied health professionals were required to pay an initial fee of €500 for the first two years (2004-2005), and could prolong their participation with a contribution fee of €95 for the year 2006.

Evaluation of the ParkinsonNet concept

We also evaluated the impact of ParkinsonNet on the quality of care. For our initial evaluation, we only addressed physical therapy because the number of therapists was sufficient for a reliable analysis. Furthermore, physical therapy was the only discipline for which evidence-based guidelines were available in 2006,[5] permitting us to monitor adherence to guideline recommendations.

ParkinsonNet was evaluated in terms of: (a) the implementation process; (b) PD-specific knowledge among therapists; (c) adherence to guideline recommendations by therapists; and (d) patient volume per participating therapist.

a) Implementation of ParkinsonNet

For this purpose, we asked ParkinsonNet therapists to rate their satisfaction with each component of the new network on a numeric rating scale (0= not satisfied at all; 10= very satisfied). We also monitored whether therapists had participated in the baseline training course, whether they had paid a site visit to the neurology outpatient clinic, and whether they had attended the subsequent seminars.

Table 3.1.1. ParkinsonNet intervention, graphically depicted as proposed by Perera.[126]

Year	PN	UC		Components (C) with their aims (A) and target group (TG)
2004	a b c	b	a	**C:** selection of a restricted number of interested professionals who are geographically covering the region. **A:** to increase patient volume of a selected number of professionals. **TG:** all allied health professionals in the area of Nijmegen.
			b	**C:** dissemination of the evidence-based guideline for physical therapy in PD by the Dutch Royal Society for Physical Therapy. **A:** to increase evidence-based practice for physical therapy in PD. **TG:** members of the Dutch Royal Society for Physical Therapy.
2005	d e f d g h i j f d		c	**C:** four-day basic course[a] focusing on PD, multidisciplinary treatment, guidelines for physical therapy and current standards for speech and occupational therapy. **A:** to improve PD expertise. **TG:** ParkinsonNet professionals.
			d	**C:** 3-hour seminar[a] covering PD related topics, suggested by ParkinsonNet professionals themselves and organized by the ParkinsonNet project group. **A:** to continuously improve PD expertise. **TG:** ParkinsonNet professionals.
			e	**C:** one-day visit of allied health professionals to an affiliated neurology outpatient clinic. **A:** to improve collaboration and communication **TG:** ParkinsonNet professionals and neurologists.
			f	**C:** digital newsletter with PD related topics and seminar announcements send by the project group. **A:** to improve communication between the project group and ParkinsonNet professionals. **TG:** ParkinsonNet professionals and neurologists.
			g	**C:** ParkinsonNet website online, including names and addresses of all ParkinsonNet professionals. **A:** to inform patients, neurologists and other referring physicians where to find ParkinsonNet professionals, and to improve patient volume of these professionals **TG:** patients, neurologists and other referring physicians.

2006	f d f d k f d f d		h	**C:** information letter covering ParkinsonNet rationale, referral criteria and website hyperlink, sent by mail. **A:** to improve patient volume of ParkinsonNet professionals by preferred referrals. **TG:** all referring physicians in the area of Nijmegen.
			i	**C:** patient information brochure, including the names and addresses of ParkinsonNet professionals, sent by mail. **A:** to improve patient volume of ParkinsonNet professionals by preferred referrals. **TG:** neurologists, other referring physicians and PD nurse specialists in the area of Nijmegen.
			j	**C:** structured referral form with evidence-based indications for allied health care, sent by mail. **A:** to improve the accuracy of referrals to allied health professionals. **TG:** neurologists, other referring physicians and PD nurse specialists in the area of Nijmegen.
			k	**C:** web-based facility online, including a library with recent PD literature, a forum and mailbox; decision-supportive electronic patient record for physical therapy based on the guidelines. **A:** to improve PD expertise and communication. **TG:** Parkinson-Net professionals

*PN, ParkinsonNet; UC, usual care. Components that are delivered at the same time are displayed side by side, while those delivered consecutively are shown one beneath each other. Squares represent interventions that are delivered once with a fixed content and circles interventions that are continuous with a content adjusted in time. *Certified for physical therapists by the Dutch Royal Society for Physical Therapy.*

b) PD-specific knowledge among ParkinsonNet physical therapists

For this purpose, all ParkinsonNet physical therapists completed a detailed examination, consisting of 73 questions based on the evidence-based guidelines. This examination was completed before the baseline-training course, at the end of the course, and one year thereafter.

c) Adherence to guideline recommendations by physical therapists

We also measured adherence to the evidence-based guideline for physical therapy in PD.[5] As a control group, we approached all 86 generally active therapists in a comparable region, of whom 26 responded. Of these 26 therapists, eight had treated at least one PD patient in 2006, and these eight professionals were included as controls. Guideline adherence was measured with a questionnaire, which included questions on guideline implementation, and 16 quality process-indicators. The 16 indicators were systematically derived from guideline recommendations.[127;128]For each indicator (e.g. application of cueing strategies to improve gait), adherence was rated on a five-point scale, ranging from 0 (never) to 4 (always). For each group, a total guideline adherence score was calculated. Furthermore, for each group we calculated the proportion of therapists who "regularly or always" followed indicators based on guideline Level 2 evidence (at least two randomized clinical trials of moderate methodological quality).[5]

d) Patient volume of physical therapists

The number of PD patients treated by each ParkinsonNet physical therapist was measured annually using a questionnaire. The number of PD patients in 2003, prior to the start of ParkinsonNet, was derived from a previous survey performed among the same population of physical therapists in 2004.[125]

Statistical analysis

Differences in guideline adherence between groups were calculated with the Mann-Whitney U test for continuous variables, and the Chi-Square test for discrete data. Differences in knowledge test scores (baseline versus 1 year after the course), and PD patient volume over the years, were compared using Wilcoxon Signed Rank Test.

Results

Implementation of ParkinsonNet

In May 2004, all allied health professionals in the area of Nijmegen (n=297) were invited for an information evening in which the ParkinsonNet concept was presented. Following this evening, 60 physical therapists, 11 speech therapists and nine occupational therapists volunteered to participate (i.e. more than the projected number of therapists needed to obtain global coverage of the entire region). If professionals working in the same area of the Nijmegen region had volunteered, we advised these therapists to decide amongst themselves who was going to participate. If a decision could not be made, the project group selected the participant based on a written motivation. Eventually, 37 professionals (19 physical therapists, 9 occupational therapists and 9 speech therapists) enrolled in ParkinsonNet in September 2004. The ParkinsonNet intervention started in October 2004 with a 4-day training course. The web-based education facility was the final component to be implemented (in 2006) (Table 3.1.1).

Evaluation of ParkinsonNet

a) Implementation

Satisfaction scores with the various components of the ParkinsonNet intervention ranged from 6.7 to 8.1, with the highest score for the baseline training course (Table 3.1.2). The participation rate for the baseline training course was 100%, for the onsite visits 81%, and for the follow-up seminars in 2005 and 2006 between 75% and 100%. All therapists prolonged their participation in the ParkinsonNet project for 2006.

b) PD-specific knowledge among ParkinsonNet physical therapists

PD-specific knowledge among ParkinsonNet therapists increased significantly immediately after the course, and also remained higher after one year, compared to baseline (Table 3.1.2).

c) Adherence to guideline recommendations
Both ParkinsonNet therapists and control therapists were aware of the existence of evidence-based guidelines for physical therapy in PD. However, ParkinsonNet therapists were more familiar with the content of the guideline and more often applied guideline recommendations (Table 3.1.2). This was further illustrated by the higher guideline adherence scores of ParkinsonNet therapists compared to control therapists.

d) Patient volume per physical therapist
The number of PD patients treated annually by ParkinsonNet therapists increased steadily between 2003 and 2006. This resulted in a more than seven-fold increase in annual patient volume for ParkinsonNet therapists compared to control therapists (Table 3.1.2).

There were no differences between ParkinsonNet therapists and control therapists with respect to gender, working hours per week, and work experience in years (Table 3.1.2).

Discussion
We have developed the ParkinsonNet concept to improve the quality of PD care delivered by allied health professionals. To increase patient volume per therapist, we decreased the number of professionals involved in a certain region. The selected ParkinsonNet professionals were continuously trained to follow evidence-based guidelines. ParkinsonNet also encourages and supports intensive collaboration and communication between allied health professionals, neurologists, PD nurse specialists and patients. In this paper, we describe our initial experience with this ParkinsonNet. Therapists' expertise with PD and the annual patient volume per professional increased significantly compared to therapists delivering usual care, suggesting that ParkinsonNet may provide a viable concept.

The patient volume per ParkinsonNet physical therapist increased steadily over the three-year follow-up. There is conceivably a direct relation between patient volume and health outcomes, although this relationship has not been investigated for allied health care in PD. However, a comparable relationship has been shown for several surgical interventions, where dedicated referral of complex patients to specialized professionals (leading to higher patient volumes) improved both patient and process outcome.[129-131] Adherence to PD treatment guidelines increased significantly among ParkinsonNet therapists compared to a small cohort of general therapists. We found similar results in a recent study that aimed to develop and evaluate quality indicators for physical therapy in PD.[127] This latter study showed significant guideline higher adherence scores for ParkinsonNet therapists (35.1±4.2) compared to generally active physical therapists (22.2±7.7).[127] The observed rise in patient volume may have been one of the factors that influenced guideline adherence, but the educational component of ParkinsonNet may have contributed as well. It remains difficult to define a required minimum patient volume per therapist, but based on the present report and the

Table 3.1.2. Results for ParkinsonNet physical therapists and general physical therapists. Values are numbers (%) or mean ± SD.

	ParkinsonNet therapists (n=19)	Control therapists (n=8)	P
General characteristics			
Males	10 (53%)	6 (75%)	0.28
Working hours per week	34.2 ± 8.9	35.8 ± 7.7	0.35
Work experience in years	20.4 ± 8.8	18.9 ± 7.4	0.56
Implementation of ParkinsonNet			
Satisfaction with interventions (0 = low; 10 = high)			
Course	8.1 ± 0.4	n.a.	
Seminars	7.5 ± 0.5	n.a.	
Information brochure	7.5 ± 0.8	n.a.	
Referral form	7.0 ± 0.8	n.a.	
Website	7.6 ± 0.6	n.a.	
Newsletter	7.7 ± 0.8	n.a.	
Web-based facility	6.7 ± 0.6	n.a.	
ParkinsonNet in total	7.5 ± 0.6	n.a.	
PD specific knowledge			
Right answers in knowledge test (0-73) [a]			
Before course	38.4 ± 7.5	-	
After course	53.1 ± 3.9	-	
One year after course	48.8 ± 8.5	-	
Guideline adherence			
Guideline knowledge			
Knows existence of guideline	19 (100%)	7 (88%)	0.12
Knows content of the guideline well	15 (79%)	2 (25%)	0.04
Applies most of the recommendations	16 (86%)	3 (38%)	0.05
Therapists frequently following Level 2 indicators			
Application of cueing strategies to improve gait[26,48]	19 (100%)	5 (63%)	0.01
Application of cognitive movement strategies to improve transfers[23,26]	19 (100%)	4 (50%)	0.03
Guideline adherence score (0= poor; 64= good)	50.9 ± 5.0	34.1 ± 12.3	0.01
Annual volume of PD patients [b]			
2003	8.1 ± 9.2	-	
2004	9.6 ± 10.8	-	
2005	12.6 ± 9.6	-	
2006	17.6 ± 10.8	2.4 ± 1.2	0.01

n.a., not applicable; [a] significant difference between before course and one year after course; [b] significant difference between 2003 and 2006

quality indicators study,[127] we suggest that therapists need to treat at least ten PD patients per year. This level was reached in the second year after implementation of ParkinsonNet, and numbers of patients seen annually by each therapist continued to rise in the ensuing years.

Many determinants facilitate or impede implementation and acceptance of a complex new intervention.[132] For ParkinsonNet this process turned out to be very successful. Specifically, we were able to recruit the projected number of allied health professionals, participation rates for network activities were high, while expertise increased considerably after the baseline training course and remained at an acceptable high level in the ensuing years. Overall, satisfaction with all components of the intervention was high, and all selected professionals prolonged their participation.
The implementation success may result from two factors. First, we did not start 'from scratch'. The concept had previously been examined in a professional network of physical therapists with expertise in rheumatoid arthritis (Fyranet).[124] We learned from this pilot that it is important to limit the number of participating professionals, otherwise patient volumes do not increase sufficiently and therapists lose their interest to participate. As a 'side effect', the selection procedure may have led to include a subset of therapists with a specific interest in PD and a particular dedication to the topic. This may indeed explain some of the positive outcomes. As such, the selection procedure should be regarded as an integral part of the ParkinsonNet intervention.
A second explanation for the success of ParkinsonNet is that this concept is based on a careful baseline examination of the shortcomings within allied healthcare for PD patients.[125] This survey showed that allied health professionals expressed a clear desire to increase their PD-specific expertise, and requested improved collaboration with fellow therapists, referring medical specialists and patients.[125] We tailored the contents of ParkinsonNet to these specific needs.

Stimulation of collaboration between network participants is the third core element of ParkinsonNet. Improved collaboration has benefits for ParkinsonNet professionals, referring physicians and PD patients, for several reasons. First, patients are empowered in their disease management by providing them with transparent information where they can find optimal care in their region. For this purpose, we use printed and web-based brochures that contain the names and addresses of all participating ParkinsonNet therapists. Second, PD care becomes more efficient, for example by streamlined and fast referrals from neurologists to dedicated regional therapists with PD expertise. Moreover, the use of structured referral forms assisted neurologists in selecting the proper indications for referral, and may also have resulted in better tailored answers from allied health professionals.[133]

Limitations of this pilot study are the limited number of participating therapists, and the implementation of ParkinsonNet in just one area. However, this initial network delivered a proof of principle (as well as proof of feasibility), which is crucial before starting a formal trial,[134] and before disseminating the network to other regions. We have meanwhile been able to extend this Parkin-

sonNet concept to now 60 regions in the Netherlands, and there is interest to also implement the ParkinsonNet concept abroad. In addition, we recently started a large randomized clinical trial to evaluate the physical therapy component of ParkinsonNet. The design of this trial and the first baseline findings are described in *chapter 6.1*.[135]

Acknowlegdements
We would like to thank P. Hoogendoorn (Dutch Parkinson's disease Society, PPV), T. Lemmers (Royal Dutch Society for Physical Therapy, KNGF), M. van Uden, (Dutch Association for Occupational Therapy, EN), C. Kok (Dutch Association for Logopedics and Phoniatrics, NVLF), M.A.M. Schmidt, A.J.G. Tinselboer and B.J.M. de Swart (respectively occupational therapist, PD nurse specialist and speech therapist of the multidisciplinary PD team of the Radboud University Nijmegen Medical Centre) for their participation in the ParkinsonNet advisory board.

In January 2004, a project group (M.J.N., M.M., B.R.B., R.A.B.O.) designed the first concept of ParkinsonNet and implemented the network in the catchment area of three hospitals in the region of Nijmegen, the Netherlands. An advisory board (see acknowledgements) was asked to give feedback on the concept and to give their professional support during a meeting with the project group in February 2004.

Chapter 4
Development of outcome measures to detect changes due to ParkinsonNet

4

4.1 Quality indicators for physiotherapy in Parkinson's disease

Published as: Nijkrake MJ, Keus SH, Ewalds H, Overeem S, Braspenning JC, Oostendorp RA, Hendriks EJ, Bloem BR, Munneke M: Quality indicators for physiotherapy in Parkinson's disease. Eur J Phys Rehabil Med 2009;45:239-245.

Summary:
Our aim was to develop quality indicators for physiotherapy in Parkinson's disease (PD) according to international criteria. Indicators were based on an evidence-based guideline for physiotherapy in PD. Guideline recommendations were transformed into indicators and rated for their relevance by an expert panel. Relevant indicators were incorporated into a questionnaire termed 'Quality Indicators for Physiotherapy in PD' (QIP-PD). The QIP-PD was piloted among 105 physiotherapists. The adjusted version was evaluated in 46 physiotherapists with specific expertise in PD and in 795 "general" physiotherapists. The following clinimetric aspects of the QIP-PD were tested: completeness of answers, response distribution, internal consistency, and discriminative power. The reliability of the QIP-PD was evaluated by interviews among a randomly selected cohort of 32 PD experts and 32 general physiotherapists. The expert panel selected 16 indicators, which were transformed into an adjusted 17-item QIP-PD. The adjusted QIP-PD was completed by 41 expert physiotherapists and 286 general physiotherapists. Completeness of item scores ranged from 95-98%. Six items were excluded from the final analyses as they showed ceiling effect among both groups, or lacked discriminative power. The total QIP-PD score for the 11 items was significantly higher for expert physiotherapists (35.1 ± 4.2) compared to general physiotherapists (22.2 ± 7.7; P = 0.01). Internal consistency was good (Crohnbach's alpha 0.84). QIP-PD scores of therapists and interviewers (correlated using Intraclass Correlations Coefficients) ranged from 0.63 to 0.75. The QIP-PD is a relevant, feasible, valid, discriminative and reliable instrument to measure adherence to guidelines for physiotherapy in PD. In addition, the results underscore that quality improvement interventions for physiotherapy in PD are needed, as guideline adherence is suboptimal in physiotherapists without specific PD expertise.

Introduction

In the Netherlands, 60% of patients with Parkinson's disease (PD) use physiotherapy to overcome limitations in daily activities and participation restrictions related to gait, balance, posture, transfers and physical capacity.[21;125] Evidence for the efficacy of physiotherapy for patients with PD has evolved rapidly during the last decade.[31]Randomized controlled trials of good methodological quality have shown that compensatory strategies such as cueing and cognitive movement strategies, can effectively improve gait, balance and transfers.[23;48;55]

In 2004, an evidence-based guideline for physiotherapy in PD was developed according to standardized, international criteria.[5] This guideline was disseminated among members of the Royal Dutch Society for Physiotherapy and became freely accessible through the internet (www.kngf.nl).[136] However, dissemination of guidelines does not automatically equal rapid implementation into clinical practice. Active implementation strategies for physiotherapy guidelines are therefore recommended.[137] Several implementation strategies have been designed for physiotherapy guidelines, but valid and appropriate instruments measuring guideline adherence for physiotherapy in PD are lacking.[137] The use of process quality indicators has been suggested to be among the best ways to estimate adherence.[128]

Process quality indicators are measurable elements of health care processes for which evidence or consensus exists that they are indicative for the quality of health care. Process-indicators should rely on high quality scientific proof, and should preferably be derived systematically from guidelines.[128] A first step is to transform guideline recommendations into potential indicators, before an expert panel rates these indicators on important aspects of quality of care (e.g. efficacy, safety). Prioritized indicators are then operationalized and piloted to obtain indicators that are relevant, measurable (e.g. complete answers and a good response distribution), reliable (e.g. good internal consistency and test-retest correlations) and sensitive (e.g. discriminative between groups).

Cheng developed a broad set of feasible and valid quality indicators for PD treatment, but these include only one indicator about referral for physiotherapy to improve daily activities.[114] Given the relevance and complexity of physiotherapy for PD, we have systematically developed a specific set of quality process-indicators for physiotherapy in PD. After a pilot study in 105 physiotherapists, the indicators were evaluated in both a group of general physiotherapists and a group of therapists with specific PD expertise, to assess measurability, discriminative power and reliability.

Methods

Study design

Based on the Dutch evidence-based guidelines for physiotherapy in PD[5;136], we systematically developed a set of quality process-indicators in six consecutive steps according to international criteria (Table 4.1.1).[128;138] In addition to these criteria, we applied the indicators among two groups of physiotherapists with an essential difference in PD expertise to evaluate both clinimetric aspect as well the discriminative power.

Table 4.1.1. Steps in the development and application of quality process-indicators for physiotherapy in PD

Step 1: Translation of concrete guideline recommendations into potential indicators by the authors
Step 2: Expert panel rating the relevance of each indicator for quality of care (effectiveness, efficiency, acceptability and measurability)
Step 3: Operationalization of relevant quality indicators into questionnaire: 'Quality Indicator for Physiotherapy in Parkinson's disease' (QIP-PD)
Step 4: Testing the QIP-PD among a small cohort of both PD expert physiotherapists and general physiotherapists for face validity and completeness of answers (refining definitions and, adding or removing indicators if necessary)
Step 5: Applying the adjusted QIP-PD on a representative cohort of both PD expert physiotherapists and general physiotherapists. Exclusion of incomplete items (> 10% of answers missing), items showing acceptable adherence in both groups (> 75% of physiotherapist frequently following the item) or items significantly ($P \leq 0.05$) lacking discriminative power between both groups Calculating internal consistency and total QIP-PD score for all included items
Step 6: Interviewing a random sample of physiotherapists to determine physiotherapists-interview reliability

1) Deriving indicators from the guideline

Two authors (S.H.J.K., M.J.N.) transformed guideline recommendations into a set of potentially eligible quality indicators. Next, these authors independently selected acceptable and measurable potential indicators from this total set. In case of disagreement, a third author (M.M.) was asked to facilitate reaching consensus.

2) Prioritization of indicators by an expert panel

Eight physiotherapists were invited to participate in an expert panel (see acknowledgements) and asked to rate potential indicators on their relevance for quality of care. Four of these physiotherapists were members of the guideline development group and the other four were experienced PD physiotherapists.

Members rated the relevance of each indicator for quality of care (effectiveness, efficiency, acceptability and measurability) on a four point scale (very relevant, relevant, some relevance, no relevance). Potential indicators which were rated 'very relevant' or 'relevant' by all members of the expert panel were included in the final set of quality indicators.

3) Operationalization of prioritized quality indicators

We operationalized the set of process-quality indicators into a questionnaire called the 'Quality Indicator for Physiotherapy in Parkinson's disease' (QIP-PD). Items within the QIP-PD represented diagnostic and therapeutic process-indicators (see Table 3A, B) and physiotherapists were asked to score how frequently they followed that specific process on a five point scale (0 = never; 1 = seldom; 2 = sometimes; 3 = generally; 4 = always).

4) Testing the initial QIP-PD

We piloted a first version of the QIP-PD among 19 PD expert physiotherapists and 86 general physiotherapists. Completeness of answers were checked and considered poor if this percentage exceeded 10%. This pilot was also performed to determine whether items measured the intended content or redefinition of items was necessary.

5) Applying the adjusted QIP-PD

The adjusted version of the QIP-PD was sent by mail to a large cohort of physiotherapists in The Netherlands. We invited 46 PD expert physiotherapists and 795 general physiotherapists to complete the QIP-PD. Reminders were sent after four weeks to physiotherapists who had not responded.

Completeness of answers was evaluated by calculating the proportion of complete answers for each item of the QIP-PD. To evaluate response distribution, item scores were dichotomized into 'frequently following the indicator' (item score 3 or 4) or 'frequently not following the indicator' (item score 0, 1or 2). Proportions for 'frequently following indicator' were calculated for each item and the criterion for acceptable guideline adherence was set at > 75% of the physiotherapists frequently following an item.

Discriminative power between PD experts and general physiotherapists was determined for the total QIP-PD score and for the proportion 'frequently following the indicator' for each item.

Differences between the two groups were calculated using Mann-Whitney U test for numeric data with a skewed distribution and the Chi Square test for proportions.

Incomplete items (> 10% of answers missing), items showing acceptable adherence in both groups of physiotherapists (> 75%), or items lacking significant discriminative power ($P \leq 0.05$) were excluded for the calculation of the final total QIP-PD score. The final total QIP-PD score was calculated using the sum of all included items. Finally, internal consistency for the QIP-PD score of all physiotherapists was calculated using Crohnbach's alpha.

6) Reliability of the QIP-PD

To investigate the reliability of the final total QIP-PD, a random sample of 64 physiotherapists (32 PD experts and 32 general physiotherapists) was invited for a structured interview within four weeks after completion of the QIP-PD. Physiotherapists were instructed not to consult the guideline or guideline-related literature before the interview. In addition, they were instructed not to provide information about their status (PD expert physiotherapist or general physiotherapist) during the interview. Three experienced PD physiotherapists (see acknowledgements) each performed 20 interviews. During this interview, physiotherapists were structurally asked about the diagnostic and therapeutic process for their most recently treated PD patients (maximum five). At the end of the interview, the interviewer rated all indicators of the QIP-PD for each physiotherapist. Each interview was scored three times. The first scoring took place during the recording of the interview. Then, H.E. checked the recording for blinding and removed the non-blinded parts if necessary. Afterwards, interviews were scored independently by the two other interviewers. Physiotherapist-interviewer correlations were analyzed using the Intraclass Correlation Coefficient (ICC). The level of significance was set at $P \leq 0.05$ for all analysis performed in this study.

Results

1) Deriving indicators out of the guideline

The evidence-based guideline for physiotherapy in PD consists of 39 recommendations for practice. These 39 practice recommendations were transformed into 56 potential indicators, of which 19 potential indicators were "acceptable" (e.g. relevant for a large group of PD patients) and measurable. Disagreement for five other potential indicators was discussed and both authors reached consensus for two indicators, leaving a final set of 21 potential indicators.

Table 4.1.2. Characteristics for PD expert and general physiotherapists. Values are numbers (%), mean ± SD and P-values.

General characteristics	PD expert physiotherapists (n=41)	General physiotherapists (n=245)	P
Gender			
Males	20 (49%)	120 (49%)	0.94
Working hours per week	35.3 ± 10.1	34.2 ± 9.9	0.49
Work experience in years	20.7 ± 8.8	19.4 ± 9.6	0.44
PD patients treated per year	11.7 ± 7.5	4.1 ± 4.5	0.01[a]
Setting [b]			
Primary care	31 (76%)	224 (91%)	0.03[a]
Hospital	5 (12%)	2 (1%)	0.01[a]
Rehabilitation centre	1 (2%)	4 (2%)	0.72
Nursing home	7 (17%)	25 (10%)	0.20

[a] *significant ($P \leq 0.05$);* [b] *can work in more settings*

2) Prioritization and operationalization of indicators

All eight members of the expert panel rated 16 out of the 21 potential indicators as 'very relevant' or 'relevant' for quality of care. The authors subsequently transformed these 16 quality-indicators into a 16-item questionnaire (QIP-PD).

3) Testing the initial QIP-PD

The measurability of all items turned out to be good (96-100% complete answers). Five items were specified in more detail based on remarks of the responding physiotherapists. One item concerning the generic use of PD outcome measures was split into three separate items concerning gait, balance and transfers. One item on the application of an active exercise program was split into four separate indicators of which three items covered active exercise for physical capacity and one item for gait related exercises. Four items were removed because they not measured the intended content.

4) Applying the adjusted QIP-PD

The adjusted QIP-PD consisted of 17 items, and was sent to 46 PD expert physiotherapists and to 795 general physiotherapists. Forty-one (89%) PD expert physiotherapists and 465 (58%) general physiotherapists returned the QIP-PD. Two-hundred and twenty general physiotherapists had not treated PD patients over the last year, and were therefore excluded from further analyses. General characteristics of the 41 PD expert therapists and the remaining 245 general physiotherapists are presented in Table 4.1.2.

The completeness of answers for each item ranged from 95% to 98%. The proportion of both PD expert and general physiotherapists that frequently adhered to the indicators is presented in Table 4.1.3. Five of the 17 items were excluded as physiotherapists in both groups scored an acceptable adherence of >75%. In addition, one item lacking significant discriminative power was excluded.

The differences between PD expert and general physiotherapists were mainly found for the domains of gait, balance and transfers. Furthermore, differences were found for treatment of patients at home, for PD-specific compensatory strategies such as cues to improve gait and cognitive movement strategies to improve transfers, and for evaluation of treatment goals and informing the referring physician.

For the final QIP-PD consisting of eleven items, the internal consistency of the QIP-PD was good (Crohnbach's alpha 0.84) and PD expert physiotherapists scored significantly higher on the total QIP-PD score compared to general physiotherapists (35.1 ± 4.2 versus 22.2 ± 7.7).

5) Reliability of the QIP-PD

All physiotherapists who were approached completed the interview, except for one PD expert and two general physiotherapists. For five of the 61 interviews, the recording of the interview had failed and these interviews were therefore examined only once. The ICC's for physiotherapist-interview reliability are presented in Table 4.1.4 and ranged from 0.63 to 0.75. These ICC's values fell within an acceptable range.

Table 4.1.3A. Proportion of PD expert physiotherapists and general physiotherapists frequently following quality indicators for the diagnostic process.

Quality process-indicators of the QIP-PD (n=6)	Level of evidence	PD Expert physiotherapists (n=41)	General physiotherapists (n=245)	P
I. Diagnostic process				
Asking for patients main complaints [b]	4 [5;136]	100% (41)	91% (224)	0.11
Inventory of freezing of gait using the Freezing of Gait Questionnaire during history taking when freezing is suspected	4 [5;136]	93% (38)	16% (40)	0.01[a]
Assessing gait using the Parkinson's Activity Scale, Timed Up and Go test, Freezing of Gait Questionnaire or Ten-meter walk test	4 [5;136]	95% (39)	31% (75)	0.01[a]
Assessing fall risk using Questionnaire History of Falling and the Falls Diary	4 [5;136]	83% (34)	26% (63)	0.01[a]
Assessing balance using Retropulsion test, Questionnaire History of Falling, Falls Diary or (Modified) Falls Efficacy Scale	4 [5;136]	95% (39)	24% (59)	0.01[a]
Assessing transfers using Parkinson's Activity Scale or Timed Up or Go test	4 [5;136]	98% (40)	27% (65)	0.01[a]

[a] significant ($P \leq 0.05$); [b] Excluded because adherence in both groups > 75%

Table 4.1.3B. Proportion of PD expert physiotherapists and general physiotherapists frequently following quality indicators for the therapeutic process.

Quality process-indicators of the QIP-PD (n=11)	Level of evidence	PD Expert physio-therapists (n=41)	General physiothera-pists	P
II. Therapeutic process				
Treating patients with limitations in activities at least one time in their home environment	4 [5;136]	76% (31)	39% (96)	0.01[a]
Providing information concerning arm swing, step length, heel support or turning when gait is limited [b]	2 [22;23;52]	98% (40)	89% (217)	0.20
Application of cueing strategies when gait is limited	2 [22;26;49]	73% (30)	54% (132)	0.05[a]
Providing information about avoiding double tasking when balance is limited [b]	4 [5;136]	98% (40)	86% (210)	0.09
Application of balance exercises and strength training of the lower extremities when balance is limited [b]	2 [28;30]	83% (34)	89% (217)	0.07
Application of cueing strategies when the initiation of transfers are limited [c]	3 [25]	66% (27)	52% (128)	0.21
Application of cognitive movement strategies when transfers are limited	2 [23;26]	98% (40)	65% (159)	0.01[a]
Application of an at least 8 weeks lasting active exercise program when inactivity is present	3 [23;49;139;140]	73% (30)	56% (137)	0.05[a]
Application of an home exercise program which is evaluated with a low frequency when physical capacity is limited [b]	3 [23;49;139;140]	88% (36)	90% (220)	0.27
Evaluating treatment goals for physical capacity after 8 weeks	4 [5;136]	78% (32)	52% (127)	0.01[a]
Informing referring physician about treat-ment goals and outcome when the patients is discharged	4 [5;136]	85% (35)	61% (150)	0.01[a]

[a] *significant ($P \leq 0.05$);* [b] *Excluded because adherence in both groups > 75%;* [c] *Excluded because significant discriminative power is lacking*

Table 4.1.4. Physiotherapists-interviewer reliability for QIP-PD scores.

QIP-PD scores	ICC	95% Confidence Interval
Physiotherapists versus Interviewer I	0.63	0.36 - 0.78
Physiotherapists versus Interviewer II	0.69	0.48 - 0.82
Physiotherapists versus Interviewer III	0.72	0.52 - 0.84
Physiotherapists versus Interviewers II-III	0.75	0.57 - 0.85
Physiotherapists versus Interviewers I-II-III	0.73	0.54 - 0.84

ICC; Intraclass Correlation Coefficient

Discussion

The purpose of this study was to develop process quality indicators to estimate the quality of physiotherapy in PD. According to international standards for the development of quality indicators[128;138], we derived indicators out of an evidence-based guideline for physiotherapy in PD.[5] This Dutch guideline recently became available in English and was adapted by the Association of Physiotherapists in Parkinson's Disease Europe (APPDE).[5]

An expert panel was asked to rate indicators for several quality criteria before the authors transformed indicators into the questionnaire 'Quality Indicators for Physiotherapy in Parkinson´s Disease' (QIP-PD). We applied the QIP-PD between two groups of physiotherapists to assess several clinimetric aspects. Eleven process quality indicators were included in the final QIP-PD as these indicators were found relevant, measurable, discriminative and reliable.

This is the first publication that describes the development of quality indicators for physiotherapy in PD. Cheng et al. also developed quality indicators for PD treatment but these indicators were more general and included only one indicator for a referral for physiotherapy when daily activities of PD patients are limited.[114] Also different from our study, Cheng et al. based their indicators on a literature search instead of a guideline.

Quality indicators intend to measure how frequently professionals are following relevant and important health care processes to provide a high quality of care. Probably the most reliable source to evaluate whether professionals frequently follow such processes is to make use of existing patient records. The latter is recommended in literature[138], but often not feasible in practice. The documentation in patient records by physiotherapists is often poor or serves a different purpose (e.g. financial registration).[141] Therefore, we developed a *questionnaire* consisting 11 quality indicators. In the QIP-PD, physiotherapists are asked to judge their adherence to these 11 indicators. The reliability of a questionnaire can be questioned as physiotherapists may give social desirable answers and we therefore introduced a validation step. QIP-PD scores of physiotherapists were compared to results of a structured interview and the ICC´s for this validation process were found acceptable.

The QIP-PD was able to distinguish between PD experts and general physiotherapists. The observed differences were mainly found for the use of PD-specific outcome measures (e.g. Freezing of Gait Questionnaire, Parkinson Activity Scale or Timed Up and Go test) and for PD-specific interventions (e.g. cueing or cognitive movement strategies). The findings for cueing and cognitive movement strategies are quite remarkable as most evidence for the efficacy of physiotherapy in PD has been found for these interventions.[23;48]

We derived indicators out of the evidence-based guideline for physiotherapy in PD which is based on literature up to 2003. Physiotherapy research in PD is evolving rapidly and the recommendations (based on the guidelines) have recently been updated with literature up to December 2007.[31;48] New evidence was mainly found for cueing strategies to improve several aspects of gait and transfers, but did not have any consequences for the existing QIP-PD items.[48;142;143] We therefore believe that the content of the QIP-PD remains relevant for the upcoming period.

Although our primary aim was to develop set of valid quality indicators for physiotherapy in PD, this study also provided insight current adherence of physiotherapists to the PD guideline. In line with the physiotherapy guidelines for low back pain[144], whiplash[145], and ankle injuries[146], we found that adherence to the guideline was not optimal. However, more room for improvement was found for the PD guideline compared to the three guidelines mentioned above. Implementation strategies may be useful to increase adherence of physiotherapists to the guideline in PD. Such strategies were successfully implemented for low back pain and whiplash, and adherence for both these guidelines increased.[144;145]

The physiotherapy guideline in PD may benefit from active implementation strategies as well. For this purpose we recently designed a professional PD network called ParkinsonNet.[147] Within ParkinsonNet, only a selected group of physiotherapists is trained in the correct use of the PD guideline. Furthermore, neurologists are instructed to refer their PD patients to network physiotherapists. We piloted this concept in the area of Nijmegen and found that these network physiotherapists more frequently followed guideline recommendations compared to general physiotherapists.

We developed a valid set of quality of quality indicators for physiotherapy in PD that are evaluated in a questionnaire. The QIP-PD was shown to be relevant, measurable, discriminative and reliable. Subsequently, we found that adherence to the PD guideline was suboptimal and implementation strategies are needed. One of these strategies, the ParkinsonNet concept, is currently being evaluated in a large cluster randomized trial.[112] In this trial, the QIP-PD is used as an outcome measure for the quality of physiotherapy care.

Acknowledgments

We would like to thank the following persons for their participation in the expert panel: C.J.T. de Goede (VU University Medical Center, Amsterdam), M. van Haaren (Rehabilitation Centre Breda, Breda), M. Jaspers (Physiotherapy Ludinge, Zuidlaren), Y.P.T. Kamsma (University Medical Center Groningen, Groningen), B.Y. de Wolff (Medical Center De Vecht, Groningen), L.J.A. Nijhuis (Physiotherapy Weezenhof, Nijmegen), WG.M. Oerlemans (Physiotherapy Maasstaete, Druten), S. Ross (Physiotherapy Ross, Elst), and H.WH.A. Arts (Physiotherapy Ter Horst, Velp). We would like to thank the following persons for the data acquisition of the questionnaires: A.J. Fijen and S. Lanson (School of Exercise Therapy Amsterdam, Amsterdam). We would like to thank the following persons for the data acquisition of the interviews: G.C. Wind, C.S. Steeg (Radboud University Nijmegen Medical Centre, Nijmegen), and J.M. Timmermans (Leiden University Medical Center, Leiden).

The Netherlands Organisation for Health Research and Development (947-04-357) and the Royal Dutch Society for Physical Therapy (WCF 2006) funded this research. A grant (016.076.352) from the Netherlands Organisation for Health Research and Development supported B.R. Bloem.

4.2 Patient-Specific Index for physiotherapy in Parkinson's disease

Published as: Nijkrake MJ, Keus SH, Quist-Anholts GW, Overeem S, De Roode MH, Lindeboom R, Mulleners W, Bloem BR, Munneke M: Evaluation of a Patient-Specific Index as an outcome measure for physiotherapy in Parkinson's disease. Eur J Phys Rehabil Med 2009;45:507-512.

Summary:

We developed and evaluated a patient-specific index for physiotherapy in Parkinson's disease (PSI-PD). In the PSI-PD, patients (a) select problematic activities out of a predefined list, with one self-report item; (b) rank selected items in order of importance; and (c) rate severity for each ranked item. To examine test-retest reliability, a cohort of patients was asked to complete the PSI-PD twice. Afterwards, validity was evaluated using a telephone interview. The PSI-PD was completed twice by 81 patients. Test-retest agreement for the selection of activity limitations was 73% to 94%. Items ranked by patients were categorized into domains, of which gait, transfers and dexterity were rated most frequently (41%-70%). Test-retest agreement for ranked domains ranged from 74% to 82%. Interviews confirmed that the PSI-PD reliably identified problem areas. The PSI-PD is a relevant, reliable and valid instrument to identify limitations in everyday activities that are important for both PD patients and physiotherapists.

Introduction

There is mounting evidence that physiotherapy can provide therapeutic relief in patients with Parkinson's disease (PD). Studies in gait and balance laboratories yielded a rationale for physiotherapy strategies, and application of these strategies in clinical trials is beginning to provide evidence for therapeutic efficacy.[46;48;148;149] With research moving towards large trials[48;55] and translated into evidence-based guidelines for physiotherapy practice[5], there remains a need for a better outcome measures.[150]

Outcome measures for physiotherapy in PD such as the PDQ-39[151] and UPDRS[152] both have their background in pharmacology trials. Although these measures have been evaluated and proved to be relevant, valid and reliable in this context, they have limitations for physiotherapy interventions in PD. These instruments all have a fixed number of predefined items that are relevant to pharmacological interventions but which may not automatically generalize to physiotherapy interventions. The Berg Balance Scale[153]and the Tinetti Mobility Test[154] were originally developed to evaluate physiotherapy interventions in other populations such as elderly or stroke patients. An advantage of these instruments is that they are more focused on relevant physiotherapy areas in PD such as gait and balance. Despite their focus, these measures still lack accuracy. For instance, both the Tinetti Mobility Test and the Berg Balance Scale do not have PD specific items on freezing of gait. It is known that freezing of gait is present in many PD patients[155] and that cueing strategies are an effective physiotherapy intervention.[48]

Because the intended effect of physiotherapy in PD is difficult to capture with the current outcome measures, a patient-specific instrument may counteract the problems mentioned above. The general idea behind patient-specific instruments is to let persons themselves identify items relevant to their particular situation. Furthermore, a patient-specific instrument can help to adequately tailor physiotherapy interventions in PD. This is important because of the broad range of symptoms and the different expression of these symptoms among PD patients.

Currently, there is no validated patient-specific instrument for PD, to evaluate the effectiveness for physiotherapy. The recently published evidence-based Dutch Guideline for Physiotherapy in Parkinson's Disease recommends using the Patient-specific Instrument (PSI) for this purpose.[5] This recommendation was mainly based on previous experience with the PSI evaluating physiotherapy interventions for low back pain, where it was found to be feasible and responsive to change.[156;157] However, the PSI was originally not developed for PD.[157] Furthermore, the PSI was developed for use during an interview with a professional. Application of the PSI in clinical practice as well as in large-scale studies would be facilitated if it could be self-completed by patients.

We therefore constructed a PD-specific version of the PSI (PSI-PD), taking into account the above issues. Here, we evaluate the use of the PSI-PD to select patient-relevant problems, the test-retest reliability of the instrument, and the validity compared to a telephone interview.

Methods

Study design

After constructing a Parkinson-specific version of the PSI, the scale was sent twice to PD patients within a period of two weeks, in order to evaluate content validity and test-retest reliability. Within two weeks after completing the second PSI-PD, patients were approached by telephone for a structured interview. The local medical ethics committee approved the study.

Subjects

We screened 300 patient records from the neurology outpatient clinic of a large general hospital (Canisius Wilhelmina Ziekenhuis in Nijmegen) for 'probable idiopathic PD' according to the Gelb criteria.[119] Other inclusion criteria were: Hoehn and Yahr disease stage between I and IV[120], no severe co-morbidity, and living independently within the community. A total of 122 PD patients met these criteria and were invited by mail to participate.

PSI-PD: construction and evaluation

The PSI-PD consists of three parts. In (a), patients select their relevant limitations in activities and body functions relevant for physiotherapy, based on an extended predefined list as well as one self-report item. In (b), patients rank their selected items in order of importance. In (c), patients rate the severity of the ranked items.

1) Selection of patient-relevant limitations

We first created a predefined list of items consisting of frequently reported limited activities and body functions by PD patients. In part, this list was based on the results of a recent survey among 217 PD patients.[125] The Dutch evidence based guidelines for physiotherapy in PD were used to determine whether frequently reported limitations belong to the core areas of physiotherapy in PD: gait, transfers, posture, dexterity and physical capacity (see Table 4.2.1.).[5] In order to make the definition of balance as an activity more clear to patients, we decided not to form a separate balance category but assign balance either to the domain 'gait' (e.g. instability during turning while walking) or the domain 'transfers' (e.g. instability while getting in or out of chair). Patients were asked to select activities that were limited. In addition, a free text item gave patients the opportunity to add a troublesome activity that was not predefined in the list.

To evaluate whether the predefined items were relevant for PD patients, frequencies of self-reported limited items were calculated. In order to evaluate reliability, agreement between the first

and the second questionnaire was assessed for all 26 predefined items separately. We calculated the agreement as the percentage of identical responses and obtained Cohen's Kappa as a measure of chance-corrected agreement.

2) Ranking of limited activities and body functions

After the selection of limited items (pre-defined list or one free item) by patients themselves, patients were asked to rank these items by choosing their "top five" of items that they wish to improve most. However, during data analysis we noticed that many patients did not use the exact name of the selected predefined item, but their own terminology instead. For instance, both the pre-defined items 'starting when walking' and 'turning while walking' were selected as limited by one patient. However, this patient used the term 'freezing' by the ranking process. Because of the different terminology used by a large proportion of patients, we were not able to measure test-re-test agreement and validity for the ranked items separately. In order to evaluate the ranking process of the PSI-PD, we therefore categorized ranked items that were related to each other into the domains of gait, transfers, posture, dexterity and physical capacity. We scored how often problems in these domains were ranked by patients. Agreement between the first and the second questionnaire was assessed for the ranked domains, calculating the percentages of identical responses as well as Cohen's Kappa scores. All patients who returned the PSI-PD twice were contacted by telephone for history taking using a structured interview During this interview, patients were specifically asked if the items ranked by themselves in the PSI-PD were indeed the most troublesome to them.

3) Severity rating of ranked activities and body functions

Patients were asked to rate the severity of ranked items on a Numeric Rating Scale (0 = executable without effort; 10 = impossible to execute). Median severity scores were calculated for the ranked items.

Results

Ninety-six patients (79%) returned the first PSI-PD, and 81 of these completed the second within a mean time-span of 15 days. Sixty-nine patients could be contacted by telephone for a further structured interview.

Patient characteristics

The average age of respondents to the first mailing (n=96) was 69.9 (SD 8.6) years, and disease duration was 7.1 (SD 5.4) years. Fifty-nine percent of respondents were men and 58% of subjects received physiotherapy at the time of completing the questionnaire. No significant differences were found for gender, age and disease duration between the full responders and the patients who did not complete the second PSI-PD or interview.

Evaluation of the selection of limited activities and body functions

Table I provides an overview of the self-reported limitations in activities and body functions of the 96 PD patients. All patients reported at least one limitation. More than 70% of the patients reported limitations in posture during walking, turning around in bed, getting in or out of bed, and in manipulating an object. Releasing an object (25%) and instability when stopping walking (23%) were the least reported limitations by patients. The proportion of subjects with 'test-retest agreement' varied from 73% to 94%, whereas Cohen's Kappa ranged from 0.39 to 0.83 (Table 4.2.1).

Evaluation of the ranked domains

During data analysis we found that agreement scores improved with 5-10% when we calculated agreement for the "top three" of ranked items instead of the "top five". Therefore, we present data of the first three ranked items. At least one selected limitation was ranked by 87 (90%) patients, 81 (84%) patients ranked at least two and 74 (77%) ranked three problems.

Patients most often mentioned items within the domains of gait, transfers and dexterity (range 41%-70%). Items within the domains of physical capacity (21%) or posture (23%) were least ranked. The agreement between the domains that were ranked during either the first or second questionnaire ranged from 74% to 82%, whereas Cohen's Kappa ranged from 0.43 to 0.60 (Table 4.2.2.).

The median severity scores on the Numeric Rating Scale for the first to third ranked problem turned out to be almost identical and were respectively 7.0 (IQR 6-8), 7.0 (IQR 5-8) and 7.0 (IQR 5-8).

During the structured interview, 65 of the 69 patients (94%) indicated that they were satisfied with the list of predefined activities and body functions in the PSI-PD from which they could select their own limited items. The agreement between the ranked domains of the completed PSI-PD and the most troublesome activities and body functions named in the interview was high (96%). Four patients mentioned an additional activity (free text item) that was not predefined in the list of PSI-PD items. These activities included cycling and writing and both activities were also named during the interview.

Table 4.2.1. Self-reported problems in the predefined activities and body functions of PD patients (n=96) and test-retest reliability for these predefined items.

Domains	Predefined items	Self-reported problems (n)	Test-retest agreement[a]	Cohen's Kappa
Gait	posture during walking	79% (76)	85%	0.55
	walking outside	63% (60)	81%	0.59
	instability while turning	62% (59)	73%	0.45
	instability when starting walking	51% (49)	85%	0.71
	walking inside the house	48% (46)	79%	0.58
	climbing and descending stairs	48% (46)	79%	0.57
	instability when performing dual tasks	41% (39)	80%	0.60
	instability due to negotiating passages	33% (32)	78%	0.53
	instability when stopping walking	23% (22)	90%	0.71
Transfers	turning around in bed	79% (76)	94%	0.83
	getting in or out of bed	75% (72)	86%	0.64
	getting in or out a car	70% (67)	78%	0.52
	(instability while) getting in or out of a chair	66% (63)	90%	0.75
	picking up an object from the ground	58% (56)	81%	0.63
	getting up from a floor	54% (52)	75%	0.51
	getting on or off a bicycle	46% (44)	74%	0.48
	getting in or out of a bath	38% (36)	78%	0.54
Dexterity	manipulating an object	72% (69)	93%	0.82
	grasping an object	42% (40)	90%	0.80
	moving an object	38% (36)	91%	0.82
	releasing an object	25% (24)	91%	0.76
Physical Capacity	insufficient muscle strength	69% (66)	77%	0.44
	quickly tired	65% (62)	84%	0.64
Posture	posture while standing	54% (52)	73%	0.45
	posture while sitting	46% (44)	79%	0.58
	posture while lying in bed	32% (31)	75%	0.39

[a] *% of patients with the same answer in the first and second questionnaire*

Discussion

We describe the development and evaluation of a patient-specific measure for physiotherapy in PD. Our results show that the PSI-PD is a feasible, reliable and valid instrument to identify self-reported limitations in activities and body functions of PD patients that are relevant for both patients and the field of physiotherapy.

Table 4.2.2. Ranking for different domains and test-retest reliability (n=87).

Domain	Ranked domain [a]	Agreement for ranked domains [b]	Cohen's Kappa
Gait	70% (61)	78%	0.43
Transfers	61% (53)	74%	0.44
Posture	23% (20)	80%	0.43
Dexterity	41% (36)	80%	0.60
Physical Capacity	21% (18)	82%	0.49

[a] *Defined as the percentage of patients ranking this domain in their 'top three'.*
[b] *Defined as self-reported problems within a domain that were ranked during both the first and second questionnaire, or not ranked during both the first and second questionnaire*

We derived the PSI-PD from the PSI that was used in patients with low back pain.[157] Caution should be raised when applying patient-specific measures in other patient groups as the concept should include content that is considered to be important for the target patient population.[158] We used a survey study[125] and the ICF model of Kamsma, which is incorporated in the evidence-based guideline for physiotherapy in PD[136], to generate relevant items for the PSI-PD. The model by Kamsma mainly describes physiotherapy interventions for limitations in activities such as gait, transfers, maintaining and changing body position, and reaching and grasping. In this study, we found among a representative group of PD patients that limitations were frequently reported for most of the predefined PSI-PD items. In addition we found that only a small proportion of patients reported items that were not predefined in the list. These results show that the content of the PSI-PD is very relevant for both PD patients and the focus of physiotherapy in PD. Although a small proportion of patient reported items that were not predefined, we believe that having a free text item is useful to tailor physiotherapy to the individual needs of PD patients.

The test-retest reliability of the PSI-PD was good, because between 73 to 94% of patients gave identical answers with respect to their self-reported limitations in activity and body functions for both questionnaires. Although agreement was high, some Kappa values were modest. These Kappa values need to be interpreted with caution especially when positive outcomes (e.g. when the patient prioritized an item) and negative outcomes (e.g. when the patient did not prioritize that item) are not equally distributed. In this case the value of Kappa is lower than expected by the amount of

agreement.[159] Discrepancies between the first and second questionnaires may be explained by differences found between subjective and objective reports of functioning in PD patients, perhaps due to lack of insight, a response shift or cognitive problems.[14;160]

Cognitive problems, which can be present in early stages of PD, may also be responsible for the fact that ranking was not performed as intended.[14] Earlier studies evaluating self-reported patient-specific instruments reported few problems with the ranking of limitations, but were all in patients without cognitive problems.[161;162] Therefore, assistance by an interviewer may be necessary for a better completion of the ranking process of the PSI-PD.

There are three main subtypes of validity: content, criterion and construct validity. Content validity of the PSI-PD, already mentioned above in our discussion, appeared to be very good. However, to determine both criterion and construct validity, preferably objective and standardized measures with good psychometric properties are needed. Such measures are unavailable yet for physiotherapy in PD[150], but also for many other patient reported outcome measures.[163] To tackle the lack of a gold standard as much as possible, we introduced a structured telephone interview. Based on these interviews, answers to the PSI-PD questionnaire appeared to be valid. Specifically, for most of the patients, the 'ranked domains' were confirmed first during a structured telephone interview.

Another relevant psychometric property is responsiveness to change. It is known that 'ceiling effects' can be present in patient-specific measures as patients only rate their ranked items and those are most troublesome.[158] The IQR (5-8) of the Numeric Rating Scale in our study leaves room for changes, nevertheless, the responsiveness of change of the PSI-PD should still be evaluated in future studies.

We think that the PSI-PD is a promising outcome measure for both physiotherapy research and every day clinical practice in PD. The PSI-PD was able to detect relevant self-reported limitations by PD patients. Selection of patient-relevant problems was performed well in the self-report questionnaire. However, the ranking of selected items was not performed as intended and therefore may require the assistance of an interviewer, especially when cognitive impairment is present. Currently, the PSI-PD is used as an outcome measure in a large multicentre randomized clinical trial, evaluating evidence-based physiotherapy in PD.[123]

Acknowledgments
This study was supported by the Netherlands Organisation for Health Research and Development (grant number 945-04-357). Dr. B.R. Bloem was supported by the Netherlands Organisation for Health Research and Development (grant number 016.076.352).

Chapter 5
The ParkinsonNet trial to evaluate the efficacy of ParkinsonNet

5

5.1 The ParkinsonNet trial: design and baseline characteristics

Published as: Keus SH, Nijkrake MJ, Borm GF, Kwakkel G, Roos RA, Berendse HW, Adang EM, Overeem S, Bloem BR, Munneke M: The ParkinsonNet trial: design and baseline characteristics. Mov Disord 2010;25:830-837.

Summary:

Chapter 3 describes how implementation of professional networks (ParkinsonNet) may improve the quality and efficiency of allied health care in Parkinson's disease (PD). We designed a cluster randomized controlled trial to evaluate this ParkinsonNet concept for one allied health discipline, namely physical therapy. Here we describe the study design and baseline characteristics. The design fully complies with the CONSORT criteria. Sixteen regions in the Netherlands were randomly divided into eight experimental regions where a ParkinsonNet was implemented, and eight control regions where the organization of care was left unchanged (usual care). Participating patients were followed for 6 months to evaluate the implementation process, health benefits and costs of the intervention. In the ParkinsonNet regions, 46 therapists were trained and 358 patients were included. In the usual care regions, 341 patients were included. Baseline characteristics of participants in the ParkinsonNet and control clusters were comparable. With 699 participating patients, this is the largest allied health study in PD to date.

Introduction

Recent surveys in the Netherlands show that about 60% of patients with Parkinson's disease (PD) use physical therapy at any given time, and that treatment duration is generally lengthy.[21;125] The efficacy of physical therapy for PD is increasingly supported evidence.[5;164] However, the quality of care is threatened by two processes.[21;125;127] First, referral by neurologists is inadequate, because clear indications for referral are missing. Second, most therapists lack PD-specific expertise, treat only few patients (low treatment volume), and do not provide evidence-based care.

To improve the quality of allied health care (including physical therapy), we developed an innovative health care organization called ParkinsonNet (see *Chapter 3)*[†]. ParkinsonNet aims to boost the quality and efficiency of care by improving: (1) PD-specific expertise, by training a selected number of participating therapists according to evidence-based guidelines; (2) the accuracy of referrals by neurologists; (3) the patient volume per therapist, via preferred referral to these selected therapists; and (4) collaboration between therapists, neurologists, and patients.

We subsequently designed the ParkinsonNet trial to determine whether implementation of this ParkinsonNet concept improves the quality and efficiency of physical therapy for PD patients. Our primary goals were to examine the quality of care, health benefits for patients, and costs. Here, we describe the trial design and baseline characteristics, taking into account the CONSORT statement adjusted for cluster trials.[165]

Methods

Design

Randomization could not be carried out at the patient level, because this would create a risk of avoid contamination within a given region (e.g., patients allocated to usual care visiting a ParkinsonNet therapist). We therefore randomized at a cluster level, making the ParkinsonNet trial a cluster randomized controlled trial (RCT). Specifically, eight experimental clusters with a ParkinsonNet were compared with eight clusters without a ParkinsonNet (usual care). Each cluster represented one or two community hospitals and their catchment area (patients as well as therapists).

Clusters and randomization

The trial was initiated from the Radboud University Nijmegen Medical Centre (RUNMC), in collaboration with the university medical centers in Leiden (LUMC) and Amsterdam (VUmc). Eligibility criteria for the participating community hospitals were: (1) located in the vicinity of one of the coordinating university medical centers; (2) a neurology department with at least four neurologists; (3) no specific organization of physical therapy for PD patients within the hospital catchment area. This was determined by contacting the local neurologists, the Royal Dutch Society for Physical Therapy, and the Parkinson's Disease Society. Hospitals were selected to have as little overlap as possible regarding their catchment area, to avoid contamination.

Random allocation of clusters was performed by a biostatistician (GB) who was not involved in patient inclusion. The random allocation was based on the minimum variance minimization method, with factors 'research area' (Nijmegen, Leiden, and Amsterdam), 'size' (number of patients in the hospital catchment area), and 'teaching status' (whether or not a hospital had a status to train neurology consultants).

In daily practice, participating hospitals in different clusters may be in contact with each other. The hospitals randomized to 'usual care' were therefore specifically requested not to implement any changes in their care for PD patients in their region for the following two years. In addition, the names of ParkinsonNet therapists were not made public, but only given to the neurologists and family physicians in the intervention clusters.

The Medical Ethics Committees of all participating hospitals approved the study. The study is registered at clinicaltrials.gov (nr NCT00330694).

Patients

Eligibility criteria for patients were: (1) idiopathic PD according to the UK PDS Brain Bank criteria for PD; (2) living independently in the community; (3) able to complete the questionnaires; (4) no severe cognitive impairment (MMSE>23); and (5) no severe co-morbidity unrelated to PD that interfered with daily functioning.

Patient registrations of the participating hospitals were screened to identify all PD patients who visited the outpatient clinic in 2005. Medical records of these patients were screened to identify eligible patients. If the catchment areas of hospitals overlapped (as determined by the patients' postal codes), patients living within overlapping areas were excluded.

To keep patients blinded to allocation of their cluster, we invited patients, in writing, to participate in 'a study evaluating differences in physical therapy care in the Netherlands'. Responders were visited at home by a trained assessor in the week prior to their routine follow-up consultation with their neurologist. During this home visit, the inclusion criteria were reassessed and eligible patients who decided to participate signed informed consent.

Intervention

A detailed description of the ParkinsonNet concept can be found in chapter 3.[1] Briefly, the selected therapists increased their PD-specific expertise according to the evidence-based guideline through an extensive baseline training, as well as continuous follow-up education (physical meetings, a decision-supporting electronic patient record and web-based e-learning). In addition, referrals were

structured using referral forms and patient information brochures. The resultant rise in patient volume per ParkinsonNet therapist further ascertained an increase in expertise. Finally, collaboration between therapists and referring neurologists was optimized through joint ParkinsonNet meetings.

Referral and patient allocation

In the ParkinsonNet clusters, neurologists were informed about the indications for referral to physical therapy.[5;136] They were asked to preferentially refer their patients with such an indication to a ParkinsonNet physical therapist. However, patients were always free to choose a physical therapist of their own preference. Therefore, in these clusters, patients were either: (1) referred to a ParkinsonNet physical therapist; (2) referred to a general physical therapist (if the patient preferred this); or (3) not referred to physical therapy at all (if there was no indication for referral).

In the usual care clusters, patients were either: (1) not referred to physical therapy; or (2) referred to a general physical therapist, without specific expertise in PD (in both cases, irrespective of whether or not a patient had an indication for referral to physical therapy).

Evaluation of the implementation process

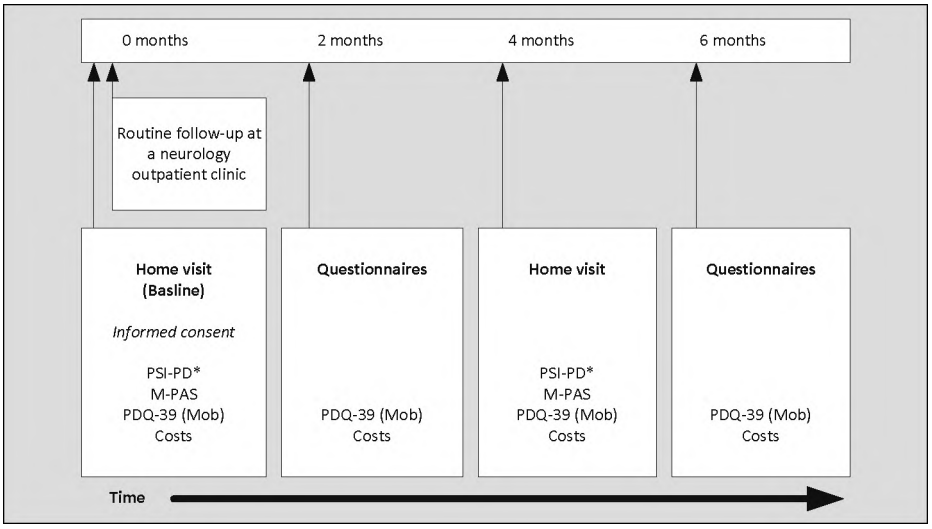
To evaluate the quality of physical therapy, we used the Quality Indicators for Physical Therapy in Parkinson's disease questionnaire (QIP-PD).[127] The QIP-PD was sent to all physical therapists that treated participating patients during the study period.

Patient satisfaction with the physical therapist and the perceived quality of physical therapy care were evaluated using the MedRisk questionnaire at 6 months.[166]

Assessment of outcome

Patients and their partners were followed for six months to assess quality of care, health benefits (including quality of life), and costs (Figure 5.1.1). Assessments were carried out by seven specifically trained assessors (graduated in physical therapy, occupational therapy or human movement science). Before and just after start of the assessment period, two calibration days were organized for these assessors.

Figure 5.1.1. Timeline for patient assessments (primary and secondary outcome measures).



*PSI-PD, Patient Specific Index for Parkinson's disease; M-PAS, Modified Parkinson Activity Scale; PDQ39 (Mob), mobility domain of Parkinson's disease Questionnaire. * primary outcome measure.*

The primary outcome measure was the Patient Specific Index for Parkinson's Disease (PSI-PD), a preference-based questionnaire.[167] It covers the five core areas for physical therapy in PD: gait, transfers, balance, reaching and grasping, and physical capacity.[5;136]
During a structured interview at baseline, patients were asked to rank their three most important limitations in activities of daily living (ADL), and to provide a score for difficulties experienced in performing each of these three activities. At follow-up, patients were asked to re-score the difficulty they now experienced performing these activities.
Such preference-based questionnaires have shown superior responsiveness compared to various other measures, and are particularly useful for evaluating the effect of complex interventions (e.g. physical therapy), where effects may be expected in multiple domains.[158;162;168]

Three secondary outcome measures were selected: the Modified Parkinson Activity Scale (M-PAS)[169], to evaluate functional mobility; the mobility domain of the 39-item Parkinson's Disease Questionnaire (PDQ-39)[151], to evaluate mobility-related quality of life; and a questionnaire covering direct and indirect costs, inside and outside the healthcare services.[170] This costs questionnaire covered the preceding eight weeks, and contained questions related to physical therapy, medication, specialist consultation, homecare, productivity loss (we also asked the spouse about this), day hospital rehabilitation, and admission to a hospital, nursing home, or home for the elderly.
In addition, a range of tertiary outcome measures was selected covering all five domains for physical therapy in PD, emotional functions, caregiver burden, as well as dopaminergic treatment (measured in Levodopa Equivalent Doses[171]).

Blinding

In order to keep assessors blinded, patients were instructed not to discuss their physical therapy with the assessors. Moreover, the questionnaires concerning physical therapy care (required for the costs analysis) were returned in separate, closed envelopes. To evaluate whether patients had been unblinded, we explained at 6 months to the patients that regions with usual care had been compared to regions with a changed organization of physiotherapy care. Patients were asked to indicate to which trial arm their region had been allocated.

Sample size

In a prior feasibility study, we found that physical therapy according to a concept version of the evidence-based guideline, yielded an effect size of 0.74 on a Patient Specific Index.[116] However, this study was small (n=27). Therefore, we used a more conservative effect size estimate in the power calculation (0.4 based on standardized Z-scores). We derived this score from a systematic review on the effects of physical therapy on ADL in PD.[172]

Sixteen clusters with 40 evaluable patients each (640 in total), an intra-class correlation of 0.05, and two-sided testing at a significance level of 0.05 would lead to a power of slightly over 80% for a test on the follow-up results. Because we will also include the baseline values as a covariate in the analyses, the power will even be higher.[173] To compensate for dropouts and incomplete follow-up, an enrolment of 700 patients was planned.

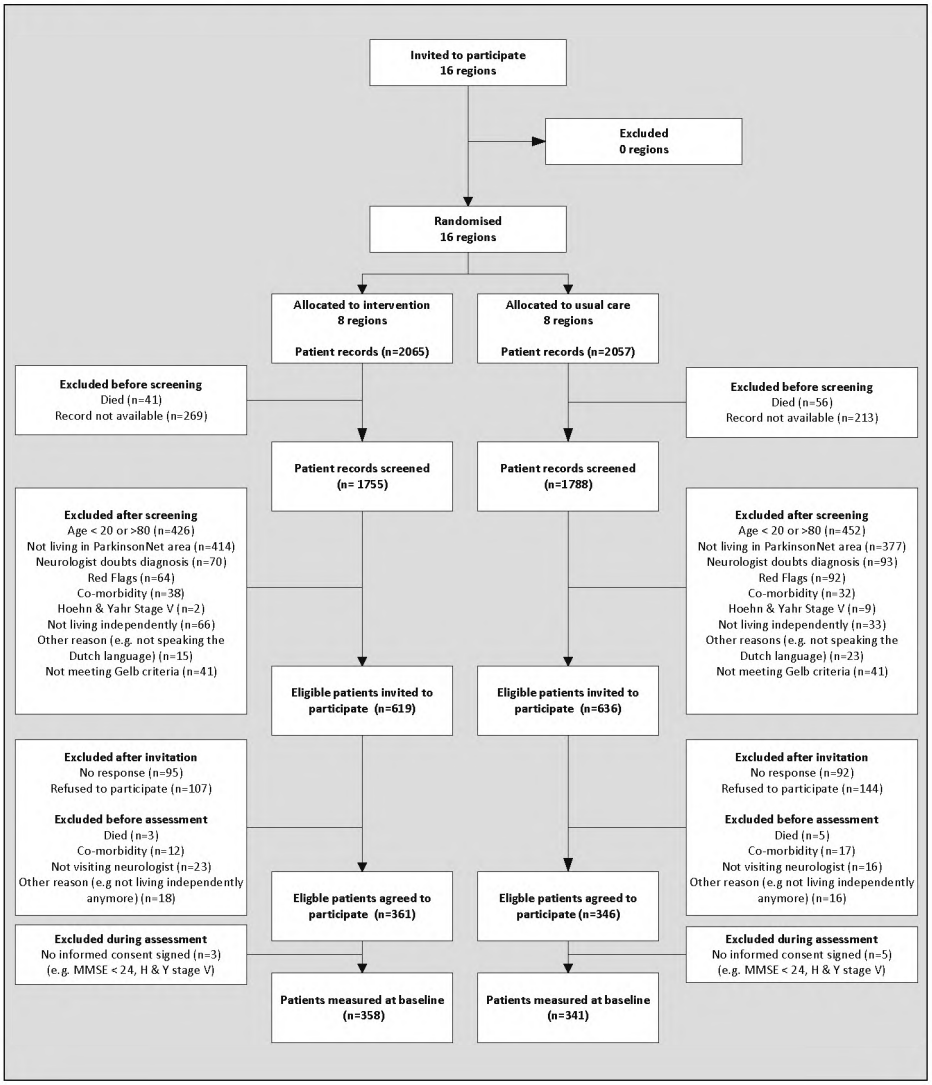
Endpoints and analysis

The primary endpoint of the study was the PSI-PD score at 4 months. The secondary endpoints were: (1) the M-PAS at 4 months; (2) the PDQ-39 mobility at 2, 4, and 6 months (mean); and (3) the health care costs during 6 months.

In a pilot study, we found that the average duration of physical therapy according to the guideline, was about 9 weeks.[116] To allow for waiting times around the start of actual therapy, we decided to assess the main endpoint at 16 weeks. The primary outcome was determined by an assessor at the patients' home. We deemed it not feasible to perform another home visit for the long term follow up, so these assessments were only secondary and by postal questionnaires.

Continuous variables, including costs, will be analyzed using a random effects model with random factor cluster and fixed variables baseline value, size and research area. When a variable is measured several times (e.g. PDQ-39 mobility), an additional random factor, patient, will be included. Binary variables will be analyzed in a similar model with Bernouilly distribution and linear link function. A sensitivity analysis will be carried out to estimate the possible impact of missing values, using multiple imputation.[173] Patients without any available information during follow-up will be excluded.

Figure 5.1.2. Flowchart of hospital and patient inclusion.



Productivity gains and losses can be consequences of the intervention, and must be included in the analyses. However, it has been argued that productivity losses or gains of patients are already reflected by their Quality of Life ratings.[170;174] Therefore, only productivity losses of the spouses was measured. For those in paid jobs, productivity losses will be evaluated using the Friction Cost Method.[175] The friction time is estimated to be 22 weeks for the Netherlands.[174] To evaluate the robustness of the results, we will perform additional scenarios, including the patients' productivity gains and losses.[176] To estimate costs, standardized cost prices in the Netherlands will be used.[170;174] Costs will be compared with changes in utilities within a cost-utility analysis in which utility will be assessed with the EQ-5D.

Results

Clusters

Hospitals were included between November 2004 and February 2005. All approached hospitals participated (Figure 5.1.2). Random allocation of clusters was performed in May 2005. Baseline characteristics for clusters were comparable (Table 5.1.1).

The selection of therapists started in June 2005. In the eight ParkinsonNet regions, a total of 493 practices and departments for physical therapy received information about ParkinsonNet. Of these, 108 (21.9%) were interested to participate. Finally, 46 therapists of different practices and departments were selected (range 4 to 9 per network). All therapists followed the baseline training before May 2006, when patient enrolment started. Thereafter, up to the end of the study period, all networks organized five educational meetings. Participation rates for these meetings ranged from 78% to 100%.

Patients

Of the 4122 medical records screened between February and April 2006, 699 patients (n=358 ParkinsonNet, and n=341 Usual Care) signed informed consent and were included (Figure 5.1.2). Enrolment of patients was completed in January 2007. Baseline characteristics of participants in ParkinsonNet clusters and Usual Care clusters were comparable (Table 5.1.1). The main daily limitations reported by patients, concerned gait, transfers and dexterity.

Discussion

The ParkinsonNet trial is designed to evaluate ParkinsonNet as a novel intervention to improve the quality and efficiency of physical therapy for patients with PD. Most prior trials in this field were relatively small or showed methodological limitations (e.g. inadequate methods of randomization, inappropriate outcome measures, and short follow-up).[31;150] With 699 participating patients and a rigorous trial design according to the CONSORT criteria, the ParkinsonNet trial is the largest trial ever performed on physical therapy in PD.

Table 5.1.1. Baseline characteristics of clusters and patients.

		ParkinsonNet	Usual Care
Clusters			
N		8	8
Mean number of citizens in hospital catchment area (x1,000)		143 (133-171)	148 (118-191)
Neurologists in general hospital		7 (5-9)	5 (5-7)
Medical teaching hospitals (n over all clusters)		1	2
Physical therapy practices		49 (42-75)	47 (30-52)
Participating patients		45 (38-47)	45 (33-49)
Patients – general characteristics			
N		358 [a]	341 [a]
Age (years)		68.8 ± 7.9	68.4 ± 7.5
Men		215 (60.1)	194 (56.9)
Living status	Alone	67 (18.7)	63 (18.5)
	Together with main caretaker	268 (74.9)	254 (74.5)
	Other situation	4 (1.2)	0 (0.0)
Paid work		32 (8.9)	29 (8.5)
Patients - PD specific data			
Years since diagnosis (years)		5.2 ± 4.5	5.4 ± 5.0
Hoehn & Yahr stage	1	47 (13.5)	30 (9.0)
	2	156 (44.7)	171 (51.5)
	3	131 (37.5)	112 (33.7)
	4	15 (4.3)	19 (5.7)
UPDRS III, motor function (score between 0-108)		28.0 ± 10.3	28.8 ± 11.9
MMSE, cognition (score between 0-30)		27.8 ± 2.1	27.4 ± 2.6
CIRS-G, comorbidity (score between 0-56)		6.1 ± 3.8	5.6 ± 3.7
HADS-A, anxiety (score between 0-21)		5.8 ± 3.7	5.9 ± 3.9
HADS-D, depression (score between 0-21)		5.3 ± 3.7	5.4 ± 3.8
Patients – treatment			
Medication	Levodopa	224 (75.2)	217 (77.0)
	Dopamine agonists	170 (57.0)	156 (55.3)
	Glutamate	48 (16.1)	38 (13.5)
	COMT inhibitors	21 (7.0)	21 (7.4)
	MAO-B inhibitors	19 (6.4)	13 (4.6)
	Anticholinergics	16 (5.4)	23 (8.2)
Use of physical therapy		200 (55.8)	194 (56.9)

Data are mean ± sd, n (%), or median (25% - 75% interquartile range); [a] missing data as some patients (<10%) were unaware of years since diagnosis or treatment details, or refused test.

The design of the trial, with a cluster randomization, allows for comparison across two different types of regional care. This is important, because the trial primarily addresses the impact of an optimized *organization* of physical therapy care, and not the efficacy of a specific physical therapy intervention. A benefit of such a strategy is that improvements in care are addressed at several levels at the same time. For example, in ParkinsonNet, this concerns the neurologists (e.g. structured referral), the therapists (e.g. increased patient volume, guideline adherence), but also the patients (e.g. empowerment through improved goal setting). A drawback is that –when any effects are found- it will be hard or impossible to identify the specific element responsible.

Like other RCTs on physical therapy in PD[55;116], we encountered several problems in patient recruitment: of the 4122 PD patients whose records were screened, 3423 patients could not be included in the trial. The majority of these patients was excluded because of age (25.7%) and living outside the study area (23.1%). Obviously, when it comes to interpreting the eventual findings of our study, the age range of the included patients should be taken into account. This also applies to the potential generalization of our results in terms of broader implementation, efficacy or costs.

It generally takes time to properly implement a change in the organization of care, so a longer study period might have been needed to see the full effects of the new ParkinsonNet concept.[35] However, we decided against a longer evaluation period, because contamination across clusters might develop and thus preclude evaluation of health benefits. We considered a trial length of six months to be an optimal compromise. With this design, we were able to fully exclude contamination (not a single patient in the Usual Care regions inadvertently visited a ParkinsonNet therapist).

Physical therapy in PD is not the not the only discipline where health care delivery is threatened by inadequate organization and insufficient expertise.[21] A comparable situation is seen in other areas of allied health care, such as occupational therapy and speech therapy.[125] If implementation of the ParkinsonNet concept proves successful, a valuable environment is created for the implementation of optimally organized, guideline-based multidisciplinary care. In addition, the design of the ParkinsonNet trial might provide a good infrastructure for future evaluation of other complex interventions.

Acknowledgements
This research was supported by grants from the RUNMC and the Netherlands Organisation for Health Research and Development (947-04-357). Prof. BR Bloem was supported by a VIDI research grant (016.076.352) from the Netherlands Organisation for Health Research and Development.

We like to thank JW Custers and PJ van der Wees (Royal Dutch Society for Physiotherapy), RAB Oostendorp (RUNMC), TPM Vliet-Vlieland, and J Verhoef (both LUMC) for their participation in the ParkinsonNet trial advisory board; M Wester, P van Keeken (both RUNMC), A Nieuwboer (Katholieke Universiteit Leuven), YPT Kamsma (University Medical Center Groningen), and CJT de Goede (both VUmc) for their educational support; and MAC van Rossum, E van Rossum, MJE Likumahwa, H Ewalds, MA Houweling (all RUNMC), N Hazelhof, M de Jong (both LUMC), CJT de Goede, and E Westerveld (both VUmc) for their contribution during the data collection.

Members of the ParkinsonNet Trial Study Group are as follows, in alphabetical order: *Investigators*: EM Adang, HW Berendse, BR Bloem, GF Borm, SHJ Keus, G Kwakkel, LIIK Lim, M Munneke, MJ Nijkrake, S Overeem, RAC Roos.

Local coordinators of the participating hospitals: M Aramideh (Medisch Centrum Alkmaar), JP ter Bruggen (Jeroen Bosch Ziekenhuis), C Jansen (Ziekenhuis Gelderse Vallei), Kamphuis (Reinier de Graaf Groep locatie Delft), K Keizer (Catharina Ziekenhuis), M Kleijer ('t Lange Land Ziekenhuis), B van Kooten (Tergooiziekenhuizen), JMJ Krul (Tergooiziekenhuizen locatie Blaricum); PM Laboyrie (Tergooiziekenhuizen locatie Hilversum), Lemmen (Slingeland Ziekenhuis), MACJ de Letter (Ziekenhuis Bernhoven), GA van Meer (Groene Hart Ziekenhuis), FWJ Opstelten (VieCuri Medisch Centrum voor Noord-Limburg locatie Venlo), MF Roesdi (Kennemer Gasthuis), R Rundervoort (Medisch Centrum Haaglanden locatie Westeinde), HM Schrijver (Westfries Gasthuis), FE Strijks (Gelre Ziekenhuizen), GJ Tissingh (Deventer Ziekenhuis), and A Valkenburg (Maxima Medisch Centrum locatie Veldhoven).

5.2 The ParkinsonNet trial: efficacy results

Published as: Munneke M, Nijkrake MJ, Keus SH, Kwakkel G, Berendse HW, Roos RA, Borm GF, Adang EM, Overeem S, Bloem BR: Efficacy of community-based physiotherapy networks for patients with Parkinson's disease: a cluster-randomised trial. Lancet Neurol 2010;9:46-54.

Summary:

Many patients with Parkinson's disease (PD) use physiotherapy. We have developed a community-based professional network (ParkinsonNet) that involves training of a selected number of expert physiotherapists to work according to evidence-based recommendations, and structured referrals to these trained physiotherapists to increase the numbers of patients they treat. We aimed to assess the efficacy of this approach for improving health-care outcomes. Between February, 2005, and August, 2007, we did a cluster-randomised trial with 16 clusters (defined as community hospitals and their catchment area). Clusters were randomly allocated by use of a variance minimization algorithm to ParkinsonNet care (n=8) or usual care (n=8). Patients were assessed at baseline and at 8, 16, and 24 weeks of follow-up. The primary outcome was a patient preference disability score, the patient-specific index score, at 16 weeks. Health secondary outcomes were functional mobility, mobility-related quality of life, and total societal costs over 24 weeks. Analysis was by intention to treat. This trial is registered, number NCT00330694. We included 699 patients. Baseline characteristics of the patients were comparable between the ParkinsonNet clusters (n=358) and usual care clusters (n=341). The primary endpoint was similar for patients within the ParkinsonNet clusters (mean 47.7, SD 21.9) and control clusters (48.3, 22.4). Health secondary endpoints were also similar for patients in both study groups. Total costs over 24 weeks were lower in ParkinsonNet clusters compared with usual care clusters (difference €727; 95% CI 56–1399). Implementation of ParkinsonNet networks did not change health outcomes for patients living in ParkinsonNet clusters. However, health-care costs were reduced in ParkinsonNet clusters compared with usual care clusters.

Introduction

Parkinson's disease is a neurodegenerative disorder that has a severe impact on patients' daily lives.[11;177] Although pharmacotherapy and deep brain stimulation can provide partial symptomatic relief, many patients remain incapacitated.[13] Evidence suggests that allied health interventions provide additional symptomatic relief for patients.[115] Use of physiotherapy in patients with Parkinson's disease has been studied in detail in clinical trials[48;55;164] that have led to evidence-based recommendations for the use of physiotherapy in Parkinson's disease,[5] with gait, balance, transfers (e.g. rolling over in bed or rising from a chair), reaching and grasping, and physical capacity as the main treatment areas.

In the Netherlands and the UK around 54–60% of patients with Parkinson's disease have received physiotherapy at some point during their treatment.[21;178] However, the quality of current physiotherapy care for patients with Parkinson's disease is insufficient:[125] clear indications for referral are missing; physiotherapists often have little or no Parkinson's disease-specific expertise; each therapist treats only a few patients each year, which is not enough to reach a sufficient degree of expertise; and evidence-based recommendations are poorly implemented in clinical practice. We introduced the ParkinsonNet system of care in the Netherlands with the aim of improving the quality of physiotherapy for patients with Parkinson's disease.[1] ParkinsonNet consists of regional community networks, each with a small number of physiotherapists trained to treat Parkinson's disease according to evidence-based recommendations.[5] Physicians within a ParkinsonNet area are encouraged to refer patients to a physiotherapist if they show difficulty with transfers, posture (including neck and back problems), reaching and grasping, balance and falls (including fear of falling), gait, or physical capacity and (in)activity.[5] ParkinsonNet supports collaboration and communication between the participating health professionals. Our initial experience in the first regional network in the Netherlands suggested that the ParkinsonNet intervention leads to better knowledge and use of evidence based recommendations.[1]

In this trial we aimed to evaluate the implementation of ParkinsonNet networks across the Netherlands and to investigate the effects of ParkinsonNet on health-care costs and health outcomes of patients with Parkinson's disease.

Methods

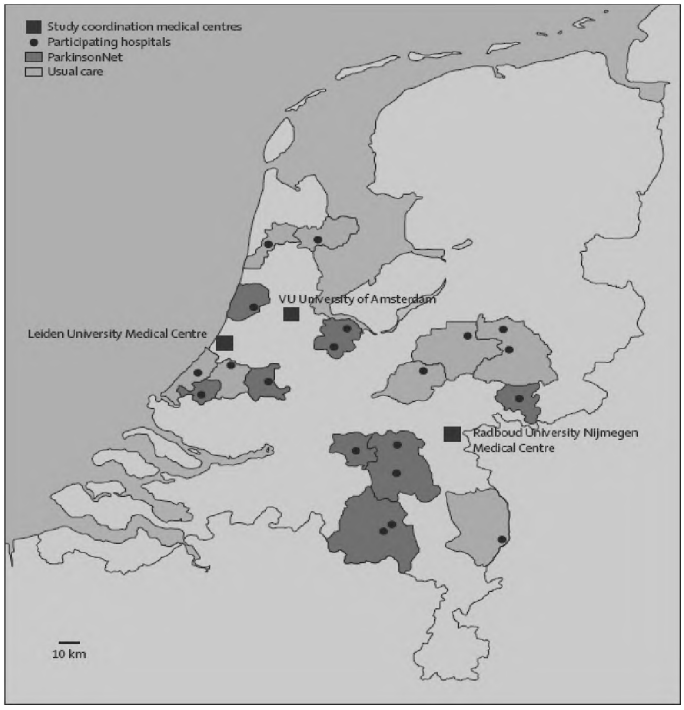
Participants

The methods of the ParkinsonNet trial have been described in detail elsewhere.[135] We did a cluster randomised trial in the Netherlands including 16 clusters. A cluster design was chosen because it allowed us to assess the complete health-care process, including referral patterns, and it reduced the risk of contamination between groups in the trial. Our pilot investigations[1] were done in a region geographically separate from all clusters in the current trial; thus, patients and physiotherapists had

no pre-existing knowledge of ParkinsonNet or a system similar to ParkinsonNet in the 16 clusters. Study coordination took place at three university medical centres (Radboud University Nijmegen Medical Centre, VU University of Amsterdam, and Leiden University Medical Centre). Clusters were randomly selected from the clusters in the vicinity of the three participating university medical centres. Hospitals were invited to participate by MM and BRB. All invited hospitals agreed to participate. Some of the invited hospitals also suggested inclusion of their neighbouring hospital because neurologists were working in both hospitals, or because both hospitals served the same catchment area (figure 5.2.1).

Figure 5.2.1: Geographic distribution of the participating clusters in the trial.

In the participating hospitals, health records of all patients with Parkinson's disease were screened to identify eligible candidates. Inclusion criteria were diagnosis of idiopathic Parkinson's disease by



a neurologist on the basis of the UK Brain Bank criteria,[179] living independently in the community, ability to complete the questionnaires, and absence of comorbidity that interfered with daily functioning (verified at baseline using the cumulative illness rating scale questionnaire).[180;181] Exclusion criteria were severe cognitive impairment (mini-mental state examination score <24) and presence of major psychiatric disorders.

Eligible patients received a written invitation to participate in a study evaluating two different systems of physiotherapy in the Netherlands. The specific differences between the two systems

of care were not explained in the invitations. We could withhold this information from patients because the intervention affected all patients in that cluster (even if they were not enrolled in the study) and therefore there was very little opportunity for patients to receive care that was different to the care assigned to that cluster. Participants did not know which cluster they were in, and there was minimum risk of contamination.

Within the participating regions, we sent invitations to participate in ParkinsonNet to all physiotherapists from the Dutch Online phone book. On the basis of our pilot experience in the first ParkinsonNet region[1], we calculated the required number of physiotherapists for each region from: the estimated number of patients within that region (to get a sufficient increase in caseload per therapist); the geographical distribution of physiotherapists within the selected region; and a maximum travel time of about 15 min by car for both patients (to the therapist's office) and physiotherapists (for optional home visits). Enough physiotherapists volunteered in all regions. If there were too many interested physiotherapists in a particular location within the cluster, selection was made on the basis of discussions among the physiotherapists who volunteered or by our project team (MM, MJN, and SHJK) on the basis of motivation of physiotherapists expressed in their response letters.

All patients provided signed informed consent before the baseline assessment. The trial had no independent monitor or monitoring committee. The Medical Ethics Committees of all participating hospitals approved the study.

Randomisation and masking

An independent biostatistician (GFB) who was not involved in recruitment randomly allocated clusters by use of a variance minimisation algorithm with the factors research area (Nijmegen, Leiden, and Amsterdam), area size (number of patients in the hospital catchment area), and teaching status (presence of teaching facilities for neurology residents). Participants were instructed not to discuss the nature of their physiotherapy with the research assistants who did the assessments. Questionnaires were returned from participants to the assessors in separate, closed envelopes and were opened by a member of the study group (MJE Likumahwa).

Procedures

The active components of the ParkinsonNet intervention have been described.[1] Key elements include the specific training of physiotherapists, structuring of the referral process (to increase the number of patients with Parkinson's disease seen by participating physiotherapists), and optimisation of communication between the participating health professionals (panel 5.2.1).

Panel 5.2.1. Elements of the ParkinsonNet Intervention.[1]

1. **Selection of a restricted number of motivated physiotherapists:**
   - Include a limited number of therapists within in a circumscribed region, to increase number of patients per therapist [a]
   - But include a sufficient number to ascertain geographical coverage of entire cluster

2. **Improving the expertise of the selected physiotherapists:**
   - Baseline training (4 days)
     - Plenary lectures to improve knowledge of Parkinson's disease [b]
     - Focused workshop to improve specific skills [c]
     - Discussion of case reports to improve clinical reasoning
   - Provision of a web-based electronic patient record, with decision support to improve clinical reasoning and adherence to evidence-based recommendations

3. **Stimulating communication and collaboration with referring physicians**
   - Structuring of the referral process by providing physicians with standardised referral forms, including objective referral criteria [c]
   - Organisation of joint seminars for referring physicians and ParkinsonNet therapists
   - Facilitating development of a regional communication plan (e.g. agreement about preferred media for interdisciplinary communication)

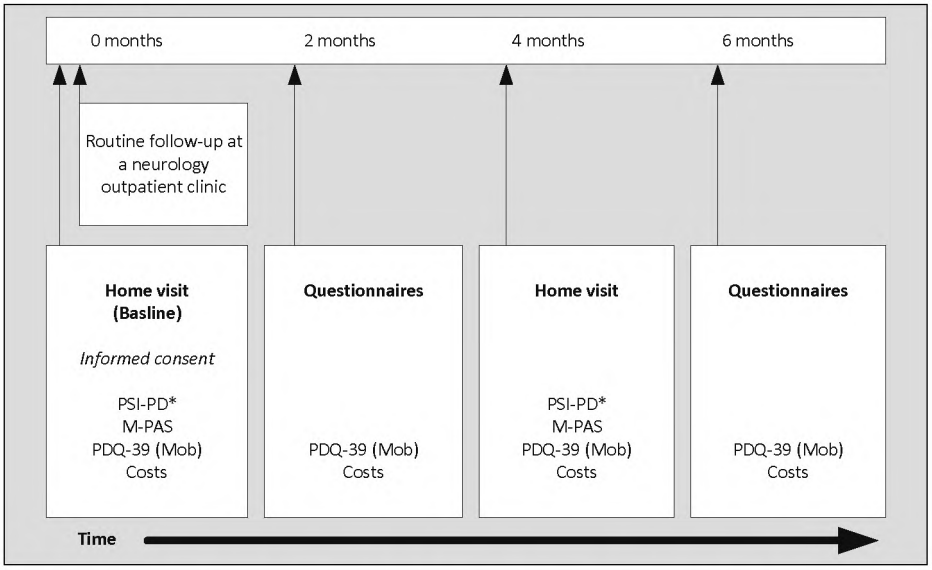
4. **Promoting visibility of the available expertise for both patients and professionals**
   - Printed brochures with background information about the ParkinsonNet approach, including names and addresses of all regional ParkinsonNet therapists
   - Website with the same information as the printed brochures (www.parkinsonnet.nl) [d]

[a] Attracting more patients helps to improve and maintain experience among the selected physiotherapists. [b] For example, to explain the rationale behind motor compensatory strategies. [c] According to the Dutch evidence-based recommendations for physiotherapy in PD.[5] Since 2004, all physiotherapists in the Netherlands have had free online access to these recommendations. [d] This website became available only after completion of the trial, to avoid contamination.

All physiotherapists followed the basic training programme[1], and attended at least four of five follow-up educational seminars over the next year. 46 physiotherapists participated in the ParkinsonNet networks (range 4–9 per network). The remaining physiotherapists, referred to here as generic physiotherapists, provided patients with usual care, and did not receive any of the components of the ParkinsonNet intervention (panel 5.2.1).

Outcome was assessed at four time points (figure 5.2.2). At baseline and at 16 weeks participants were assessed at home by one of seven trained assessors who were blinded to cluster allocation. Questionnaires were completed by patients at baseline and at 8, 16, and 24 weeks.

Figure 5.2.2. Length of follow-up and ascertainment methods for the various endpoints used in this study.



** primary outcome measure; PSI-PD, Patient Specific Index for Parkinson's disease; M-PAS, Modified Parkinson Activity Scale; PDQ39 (Mob), mobility domain of Parkinson's disease Questionnaire.*

The efficacy of the ParkinsonNet intervention was evaluated in two main areas: health outcomes for patients and costs. The primary outcome was the patient-specific index for Parkinson's disease (PSI-PD) at 16 weeks compared with baseline.[167] The PSI-PD covers the five main treatment areas of physiotherapy in Parkinson's disease: gait, balance, transfers, reaching and grasping, and physical capacity.[5] Preference-based questionnaires such as the PSI-PD have shown higher response rates than some other measures[158;162;168] and they are particularly useful for assessing complex interventions such as physiotherapy, for which effects are expected in multiple domains.[158;162;168] Secondary health outcomes were functional mobility measured with the modified Parkinson activity scale[169] at 16 weeks, mobility-related quality of life measured with the mobility domain of the 39-item

Parkinson's disease questionnaire mobility subscale at 8, 16, and 24 weeks,[151] and costs. Costs were measured with a detailed questionnaire based on microcosting completed by patients and their partners at baseline and at weeks 8, 16, and 24. In microcosting, a unit cost is calculated for each component of a resource to give detailed cost information. The questionnaire included questions about medication, physiotherapy, specialist consultation, and costs of care at home over the preceding 8 weeks. To measure indirect costs, productivity loss was estimated for partners of patients. Total costs were calculated in euros on the basis of standardised cost prices for the Netherlands. Indirect costs were calculated with the friction cost method.[175]

Tertiary endpoints were: unified Parkinson's disease rating scale motor section score, timed up and go test score, 4×3 m walk test score, nine hole peg board test score, and nine hole peg board test counting task added score at 16 weeks; the self-assessment Parkinson's disease disability scale score, Academic Medical Center linear disability score, European quality of life 5 dimensions score, and freezing of gait questionnaire at 8, 16, and 24 weeks; the longitudinal aging study Amsterdam physical activity questionnaire at 16 and 24 weeks; and the number and incidence of falls during 24 weeks (monitored with a falls calculator).

We also asked physiotherapists who had treated the participating patients how many Parkinson's disease patients they had treated in 2006. These physiotherapists also completed the quality indicators for physiotherapy in Parkinson's disease questionnaire, a self-reported measure that assesses adherence to 11 quality indicators.[127]

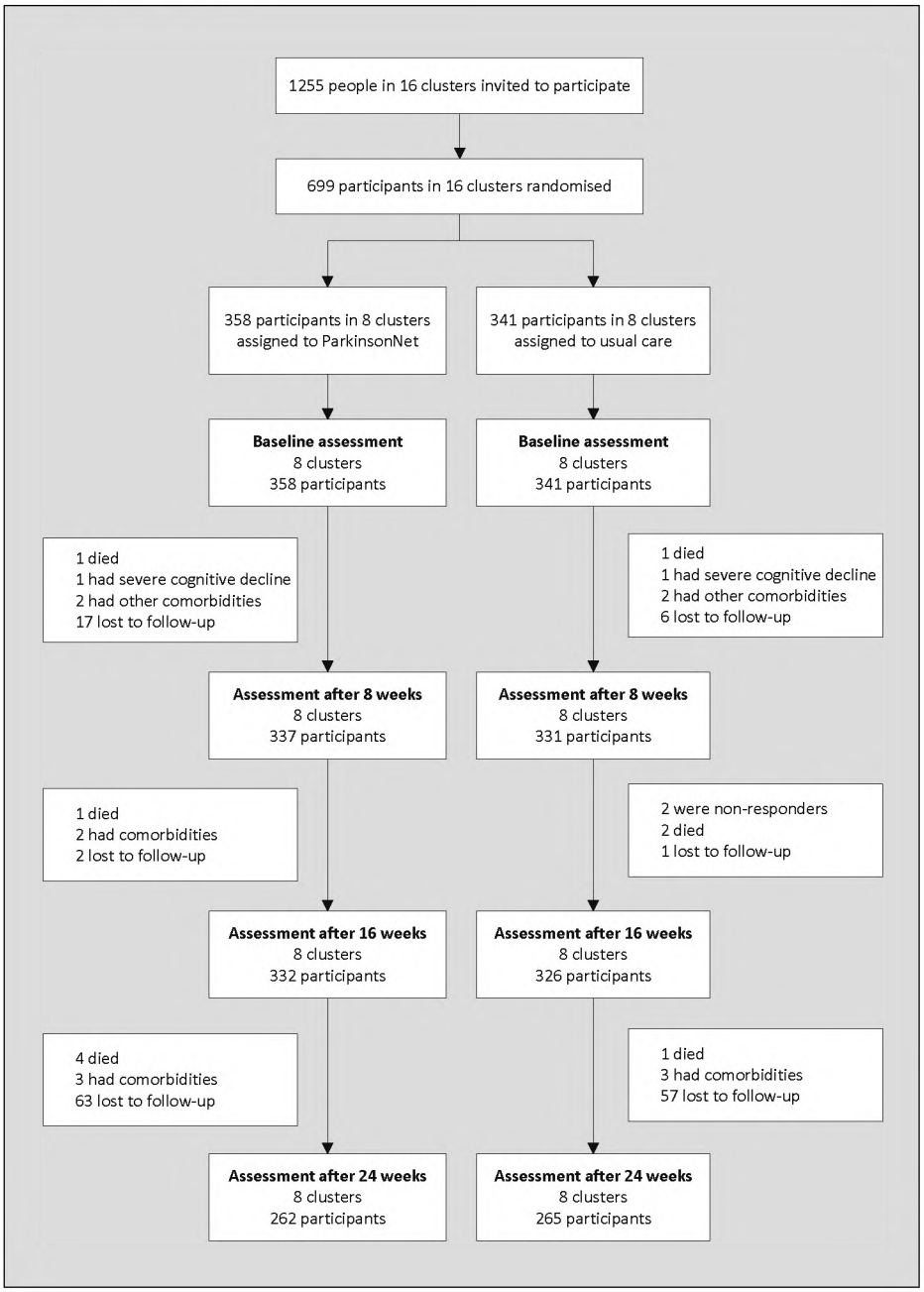
Because of the type of intervention (change in the organisation of physiotherapy care), we did not expect to see a change in incidence of adverse events, and thus information about adverse events was not collected systematically.

Statistical analysis

Power calculations were based on a meta-analysis[172] and on a pilot study of evidence-based physiotherapy for Parkinson's disease,[116] in which we found a standardized effect size (Cohen's *d*) of 0.4 for the primary outcome measure. An effect size of 0.4 can be regarded as medium sized[182;183] and was thus believed to be adequate for this trial. 16 clusters with 40 evaluable patients each (i.e., 640 patients in total), with an intraclass correlation of 0.05, and two-sided testing at a significance level of 0.05 would lead to a power of slightly over 80%. Therefore, to compensate for participants not completing the study, we aimed to include 700 patients.

Continuous variables were analysed by use of a random effects model with random factor (cluster) and fixed variables (baseline value) and cluster size (number of citizens). When a variable was measured several times (e.g., Parkinson's disease questionnaire mobility subscale), participant was added as an additional random factor and time as a fixed factor. Analysis was by intention to treat.

Figure 5.2.3. Trial profile.



Binary variables were analysed in a similar model, with Bernouilli distribution and linear link function. A sensitivity analysis with multiple imputation was done to estimate the possible effect of missing values. Patients without any available information during follow-up were excluded. We used SAS 8.2 for statistical analysis.

Continuous variables were analysed by use of a random effects model with random factor (cluster) and fixed variables (baseline value) and cluster size (number of citizens). When a variable was measured several times (e.g., Parkinson's disease questionnaire mobility subscale), participant was added as an additional random factor and time as a fixed factor. Analysis was by intention to treat. Binary variables were analysed in a similar model, with Bernouilli distribution and linear link function. A sensitivity analysis with multiple imputation was done to estimate the possible effect of missing values. Patients without any available information during follow-up were excluded. We used SAS 8.2 for statistical analysis.

Role of the funding source
The sponsor had no role in the study design, data collection, data analysis, data interpretation, or writing of this report. MM and BRB had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

In February, 2005, eight clusters were randomly assigned to ParkinsonNet and eight to usual care; the clusters comprised 20 hospitals. 1255 patients with Parkinson's disease were invited and 699 agreed to participate (figure 5.2.3).[135] 60 neurologists (4–12 per cluster) and 46 physiotherapists (4–9 per cluster) participated. Each cluster had 25–65 participants. Baseline characteristics, including the number of participants, physiotherapists, and neurologists, were comparable between the ParkinsonNet and usual care clusters (table 5.2.1).[135]

262 of 358 participants in the ParkinsonNet clusters and 265 of 341 participants in the usual care clusters were followed up for the duration of the trial. No adverse events or side-effects were reported in any of the participants.

ParkinsonNet physiotherapists had more than twice as many patients per physiotherapist than did either generic physiotherapists in usual care clusters or generic physiotherapists in the ParkinsonNet clusters (table 5.2.2). A higher proportion of ParkinsonNet physiotherapists (26 of 29) than generic physiotherapists (56 of 165) intended to apply the treatment recommendations on a regular basis.

Table 5.2.1. Participants characteristics at baseline

		ParkinsonNet Clusters (n= 358)	Usual care Clusters (n= 341)
General			
Age (years)		68.8 ± 7.9	68.4 ± 7.5
Men		215 (60.1)	194 (56.9)
Time since diagnosis (years)		5.2 ± 4.5	5.4 ± 5.0
Hoehn & Yahr stage	1[a]	47 (13.5)	30 (9.0)
	2[a]	156 (44.7)	171 (51.5)
	3[a]	131 (37.5)	112 (33.7)
	4[a]	15 (4.3)	19 (5.7)
Daily Levodopa Equivalent Dose (LED)		408 ± 375	422 ± 348
Health measures			
PSI-PD (0-100)		54.2 ± 20.9	53.4 ± 22.2
M-PAS (0-56)		47.2 ± 7.6	46.9 ± 8.5
PDQ-39 Mobility (0-100)		36.5 ± 24.7	38.2 ± 25.3
UPDRS III, motor function (0-108)		28.4 ± 12.3	28.8 ± 11.9
TUG (s)		10.6 ± 12.3	10.2 ± 8.6
4X3m Walk Test (s)		18.4 ± 9.2	18.6 ± 11.8
NHPB test (s)		33.0 ± 10.9	34.6 ± 17.1
NHPB test, CT (s)		50.8 ± 37.5	49.0 ± 27.5
SPDSS (24-120)		40.8 ± 12.7	40.6 ± 13.3
ALDS (0-100)		80.5 ± 12.0	80.5 ± 12.0
EQ-5D (0-1)		0.65 ± 0.20	0.65 ± 0.22
FOGQ (0-20)		7.0 ± 5.4	7.4 ± 5.6
LAPAQ (MET)		63.2 ± 58.0	70.4 ± 67.9
Costs			
Parkinson Care Costs (€)[b]		1228 ± 2071	1460 ± 2194

Data are mean ± SD or number (%). PSI-PD, Patient-Specific Index for Physiotherapy in PD; M-PAS, Modified Parkinson Activity Scale; PDQ-39 Mobility, Parkinson's Disease Questionnaire subscale Mobility; UPDRS III, Unified Parkinson's Disease Rating Scale Motor Section; TUG, Timed Up and Go Test; NHPB Nine Hole Peg Board Test; CT, Counting Task added; SPDSS, Self-assessment Parkinson's Disease Disability Scale; ALDS, AMC Linear Disability Score; EQ-5D, European Quality of Life-5 Dimensions; FOGQ, Freezing Of Gait Questionnaire; LAPAQ, LASA Physical Activity Questionnaire; MET, Metabolic Equivalent of Task.

[a] *Nine patients from each group refused a home visit and so were assessed by telephone interview.*

[b] *Over 8 weeks preceding enrolment.*

Physiotherapy was used by 252 (74%) of 341 patients in the usual care clusters and 265 (74%) of 358 patients in the ParkinsonNet clusters. In the usual care clusters, none of the patients consulted a ParkinsonNet therapist. Of the patients receiving physiotherapy in the ParkinsonNet clusters, 74 (28%) were treated by specialised ParkinsonNet therapists. The remaining 191 (72%) in the ParkinsonNet clusters were treated by generic therapists.

In both groups, most patients were treated by physiotherapists who were aware of the existence of evidence-based physiotherapy recommendations (table 5.2.2). However, the proportion of patients treated by physiotherapists who used the recommendations in daily practice was higher for the ParkinsonNet clusters (95 of 146 patients for whom data were available) than for the usual care clusters (40 of 118). Total contact time between patients and physiotherapists over 6 months was similar in the ParkinsonNet clusters (mean 15.5 [13.3] sessions of mean 29.3 [16.6] min per patient) and usual care clusters (15.7 [12.5] sessions; 26.9 [17.3] min per patient).

At 16 weeks there was no difference in primary, secondary, or tertiary health endpoints between the ParkinsonNet clusters and control clusters (table 5.2.3). Dopaminergic treatment (measured in levodopa equivalent doses)[171] did not differ between patients in the ParkinsonNet clusters (mean levodopa equivalent dose at 24 weeks 403 mg, SD 320 mg) and usual care clusters (450 mg, 364 mg).

Total costs per person over 24 weeks were €727 lower in the ParkinsonNet clusters than in the usual care clusters (table 5.2.4). The greatest differences in costs were for informal care (€313 difference) and day-hospital rehabilitation (€123 difference).

Table 5.2.2. Characteristics of the participating physiotherapists.

	ParkinsonNet Clusters		Usual care Clusters
	ParkinsonNet physiotherapists (n=29)[a]	Generic physiotherapists (n=75)	Generic physiotherapists (n=90)
QIP-PD (0-44)	35.3 ± 4.3	22.4 ± 10.1	22.6 ± 7.9
Patient volume [a]	13.6 ± 7.5	4.2 ± 6.1	6.0 ± 6.2
Knows existence of guideline	29 (100%)	61 (81%)	86 (96%)
Applies recommendations	26 (90%)	26 (35%)	30 (33%)

Values are mean ± SD or number (%). QIP-PD=quality indicators for physiotherapy in Parkinson's disease. [a] 17 of the 46 ParkinsonNet physiotherapists were not involved in treatment of patients enrolled in the trial. [b] Physiotherapists who deliver usual care, and who have not received any of the components of the ParkinsonNet training programme (panel 5.2.1).

In a post-hoc analysis of patients who were treated by ParkinsonNet physiotherapists versus those who received standard physiotherapy, mean PSI-PD scores for patients who received standard physiotherapy were 49.9 (SD 22.5) in the usual care clusters, 48.1 (22.6) in the ParkinsonNet clusters, and 48.9 (20.9) for patients who received ParkinsonNet physiotherapy.

Discussion

The ParkinsonNet system of care was not associated with a change in health outcome over 6 months for patients living in ParkinsonNet clusters. ParkinsonNet was successfully implemented in eight regions in the Netherlands and was associated with indicators of improved quality of care. Specifically, number of patients per therapist was more than two times higher for ParkinsonNet physiotherapists than for generic physiotherapists in usual care clusters or ParkinsonNet clusters. The proportion of patients who were treated by a trained physiotherapist who worked according to evidence-based recommendations was higher in ParkinsonNet clusters than in usual care clusters. We also noted an increase in self-reported adherence of physiotherapists to evidence-based recommendations. However, quality of care involves more than these elements, and other features of the quality of care could have been investigated by monitoring the delivery of care by the participating physiotherapists. We decided against this because monitoring might have influenced the behaviour of physiotherapists in both groups.

Table 5.2.3 Health outcomes.

	ParkinsonNet clusters		usual care clusters		Estimated difference	95% confidence interval
	N	mean ± SD	N	mean ± SD		
Primary outcome						
PSI-PD (0-100)						
16 weeks	313	47.7 ± 21.9	302	48.3 ± 22.4	-0.7	(-3.6; 2.3)
Secondary outcomes						
M-PAS (0-56)						
16 weeks	317	48.3 ± 7.4	303	47.5 ± 8.4	0.4	(-0.4; 1.2)
PDQ-39 Mobility (0-100)						
8 weeks	225	36.6 ± 24.7	268	34.4 ± 24.2	1.7	(-0.9; 4.4)
16 weeks	300	34.6 ± 24.0	294	35.3 ± 26.1	-0.6	(-2.7; 1.6)
24 weeks	262	34.4 ± 24.3	265	35.9 ± 25.5	0.1	(-2.5; 2.6)
Tertiary outcomes						
UPDRS III, motor function (0-108)						
16 weeks	320	30.0 ± 10.7	314	30.5 ± 12.0	-0.4	(-2.2; 1.4)
TUG (s)						
16 weeks	317	9.9 ± 8.4	310	10.0 ± 7.7	-0.4	(-1.4; 0.7)
4X3m Walk Test (s)						
16 weeks	317	18.2 ± 12.8	304	18.1 ± 8.8	-0.4	(-2.0; 1.2)
NHPB test (s)						
16 weeks	323	34.3 ± 15.7	313	33.8 ± 14.4	1.1	(-1.0; 3.2)
NHPB test, CT (s)						
16 weeks	318	47.0 ± 23.0	306	46.3 ± 22.0	-0.1	(-3.1; 3.0)
SPDSS (24-120)						
8 weeks	222	41.9 ± 13.2	269	41.0 ± 13.6	-0.5	(-2.1; 1.1)
16 weeks	302	41.1 ± 12.8	296	40.9 ± 13.9	-0.4	(-1.7; 1.0)
24 weeks	262	41.6 ± 13.1	265	42.7 ± 15.3	-1.0	(-2.7; 0.7)

ALDS (0-100)						
8 weeks	227	80.1 ± 12.6	269	81.3 ± 11.1	0.0	(-1.3; 1.2)
16 weeks	301	81.1 ± 11.9	297	80.3 ± 12.7	0.8	(-0.3; 2.0)
24 weeks	262	80.6 ± 12.7	265	80.2 ± 12.8	0.3	(-0.3; 2.0)
EQ-5D (0-1)						
8 weeks	221	0.66 ± 0.22	260	0.67 ± 0.20	-0.01	(-0.04; 0.02)
16 weeks	295	0.66 ± 0.20	294	0.65 ± 0.23	0.01	(-0.02; 0.04)
24 weeks	262	0.68 ± 0.21	259	0.66 ± 0.23	0.02	(-0.01; 0.05)
FOGQ (0-20)						
8 weeks	221	7.2 ± 5.3	265	7.4 ± 5.3	-0.1	(-0.6; 0.4)
16 weeks	302	7.0 ± 5.3	295	7.4 ± 5.4	-0.2	(-0.8; 0.4)
24 weeks	262	7.0 ± 4.9	264	7.5 ± 5.5	0.2	(-0.5; 0.8)
LAPAQ (MET)						
16 weeks	301	60.3 ± 55.7	293	65.4 ± 64.9	-1.0	(-15.5; 13.6)
24 weeks	262	73.4 ± 91.9	265	74.9 ± 86.4	4.7	(-12.5; 22.0)
Falls						
24 weeks	329	0.71[a]	312	0.65[a]	0.02	(-0.07; 0.12)

PSI-PD, Patient-Specific Index for Physiotherapy in PD; M-PAS, Modified Parkinson Activity Scale; PDQ-39 Mobility, Parkinson's Disease Questionnaire subscale Mobility; UPDRS III, Unified Parkinson's Disease Rating Scale Motor Section; TUG, Timed Up and Go Test; NHPB, Nine Hole Peg Board Test; CT, Counting Task added; SPDSS, Self-assessment Parkinson's Disease Disability Scale; ALDS, AMC Linear Disability Score; EQ-5D, European Quality of Life-5 Dimensions; FOGQ, Freezing Of Gait Questionnaire; LAPAQ, LASA Physical Activity Questionnaire; MET, Metabolic Equivalent of Task. [a] *Incidence.*

The ParkinsonNet system of care could be easily implemented and was also associated with reduced costs compared with usual care. However, implementation of ParkinsonNet was not completely successful. Within the ParkinsonNet clusters, only 28% of patients referred for physiotherapy were treated by a ParkinsonNet therapist. Both the referring physicians and the patients chose their therapist. At the start of the trial, many patients were already being treated by a physiotherapist, and not all patients agreed to change to a ParkinsonNet physiotherapist. There were no signs to suggest that variations across centres (e.g., differences in organization or local preferences) affected the referral rates to ParkinsonNet physiotherapists. Furthermore, low referral rates were not due to inability of the ParkinsonNet physiotherapists to cope with increased demand. Likely explanations are increased travel distance (patients might need to travel further to find a ParkinsonNet therapist) or unawareness of ParkinsonNet availability. To reduce the risk of contamination,

we limited the promotion of the ParkinsonNet system of care. Nevertheless, the change in referral pattern for one third of patients is substantial. Our experience in the pilot region[1] shows that implementation continues as the network grows, with a steady increase in referral to ParkinsonNet physiotherapists (by about three additional patients per year) after the first year.

Table 5.2.4. Cost components and total costs.

	ParkinsonNet clusters		usual care clusters		Estimated diffe-rence	95% confidence interval
	N	mean ± SD	N	mean ± SD		
Total costs						
24 weeks	326	3007 ± 3452	325	3799 ± 5335	-727	(-1399; -56)
Costs components						
Physiotherapy	347	297 ± 325	334	310 ± 306	-2	(-38; 34)
Medication	350	921 ± 1319	340	1018 ± 1808	-30	(-265; 205)
Consultation	344	104 ± 101	332	102 ± 92	7	(-13; 27)
Day hospital rehabilitation	343	195 ± 730	332	345 ± 1258	-123	(-263; 17)
Admission	344	340 ± 1455	332	376 ± 1554	-16	(-255; 224)
Home care (paid services)	343	699 ± 1888	332	863 ± 2512	-85	(-395; 225)
Informal care	343	400 ± 1020	332	696 ± 2169	-313	(-554; -71)
Productivity loss partner	344	15 ± 99	334	24 ± 119	-10	(-25; 6)

All values in Euros. For each component, the number of patients is shown for whom cost data were collected. For the total costs, the number of patients is shown that had cost data collected for all components.

We expected that improved quality of care of patients in ParkinsonNet clusters would be reflected by better health outcomes for patients living in these regions. However, there were no differences in self-perceived disability, functional mobility, and mobility-related quality of life of patients living in ParkinsonNet clusters compared with patients in usual care clusters.

Several factors might explain the absence of health benefits for patients. One possibility is that therapy delivered by physiotherapists trained to follow the guidelines used in this study[5] is not more effective than treatment delivered by generic physiotherapists. Most ParkinsonNet physiotherapists in this trial worked according to evidence-based recommendations, but perhaps more intensive training or longer exposure to large numbers of patients is needed to improve the use of interventions such as cueing[184;185] and cognitive movement strategies.[26] Also, only a third of patients in ParkinsonNet clusters were treated by a ParkinsonNet physiotherapist; thus there was limited contrast

between study groups. Post-hoc analyses for the subgroup of patients treated by ParkinsonNet physiotherapists also did not show significantly improved health outcomes compared with patients treated by generic physiotherapy. However, the validity and power of this analysis is limited because it was non-randomised, relied on behaviour of participants after random assignment, and might be subject to bias because it compared a subgroup of patients in the treatment group with an unselected group in the usual care clusters.

Another explanation for the absence of health benefits could be the short interval between implementation and analysis of ParkinsonNet. We started enrolling patients for the trial immediately after the baseline training of physiotherapists to become ParkinsonNet physiotherapists. This interval might not have allowed enough time for the ParkinsonNet physiotherapists to reach adequate specialisation or to treat enough patients to gain a lasting improvement in skills. Finally, Parkinson's disease progression might have attenuated physiotherapy outcomes. Disease progression might necessitate changes in medication, and possible health benefits in ParkinsonNet clusters could have been masked because the effects of physiotherapy reduced the need to increase the dose of antiparkinsonian drugs. However, our analyses showed no differences in levodopa equivalent doses between ParkinsonNet and usual care.

This trial gives no insight into the possible effectiveness of physiotherapy for patients with Parkinson's disease, because similarly large proportions of patients received physiotherapy in both groups. This finding shows that ParkinsonNet does not promote the use of physiotherapy per se; however, it does create system that offers patients the possibility of referral to an expert therapist.

Health-care costs were lower for patients in the ParkinsonNet clusters than for those in usual care clusters. However, independent confirmation with a trial focusing on costs is necessary to validate these findings. Although the wide confidence intervals suggest that actual cost savings might have been smaller, we believe that some of the cost reduction is real, because we observed savings for most of the different areas of health-care costs.

Most cost savings were from a reduced need for home care and day-hospital rehabilitation. The improved quality of care delivered by community physiotherapists might have removed the need for home and day-hospital rehabilitation, but this needs further study. ParkinsonNet might shift the emphasis of care to the community setting, such that comparable clinical effects can be achieved but with cheaper forms of care. Thus individual patients might have reached the same clinical level but with cheaper methods and better trained health personnel.

We believe further research should be done on the ParkinsonNet system. Since completion of the trial, we have implemented more than 50 additional regional ParkinsonNet networks in the Netherlands, which shows how ParkinsonNet has been accepted. ParkinsonNet could also be used

in other countries where the organisation of health care is different and where other funding models are in place. The ParkinsonNet approach is probably most feasible in densely populated areas, because referral to ParkinsonNet physiotherapists could be unacceptable in rural areas because of long travel times. The amount of funding for allied health care might also prevent implementation, for example if patients must pay for part of the costs themselves.

Another potential way to extend the network is by inclusion of other health-care disciplines. All ParkinsonNet networks in the Netherlands now have a selection of trained occupational therapists and speech-language therapists. ParkinsonNet could also be used as a model for the development of networks for patients with other chronic disorders. Interventions that aim to improve the quality of care for patients with chronic diseases, for example new approaches to management of diabetes[186] and the chronic care model,[187] have been assessed. However, we are not aware of comparable studies with a controlled design that investigated the implementation of networks of specialised health professionals. Finally, the availability of ParkinsonNet networks also has scientific potential, for example to assess the benefits of specific health-care interventions for Parkinson's disease.

Acknowledgements

We thank all contributors and participants for their contribution to this study. We thank Wim Lemmens for his contribution to the data analyses. We thank Lars Oude Nijhuis for his support in preparing the figures for this paper. We thank ZonMw (947-04-357), the Netherlands Organisation for Scientific Research, the Dutch Parkinson's Disease Society, the National Parkinson Foundation, and De Stichting Robuust for their financial support.

Contributors

MM and BRB wrote the grant application and supervised all project staff . MM, MJN, SHJK, GK, HWB, RACR, GFB, and BRB contributed to the research design. MM, SHJK, GK, GFB, SO, and BRB selected health outcome measures. MM and MJN monitored study conduct. MJN contributed to implementation of the ParkinsonNet intervention, took responsibility for the education for physiotherapists, and prepared the data. MJN and SHJK supervised research assistants for data collection and managed and developed databases. SHJK contributed to inclusion of participants. SHJK and GK trained research assistants. MM, MJN, SHJK, and BRB trained physiotherapists. GFB did sample-size calculations and cluster randomisation and devised statistical analyses and presentation of the results. EMA contributed to the selection of economic outcome measures, made economic calculations, and devised presentation of economic results. SO did the data analysis. BRB was responsible for the education of neurologists. MM and BRB contributed to writing of the discussion, MJN and SO to the introduction, methods, and results, and SHJK to the methods. MM, MJN, SHJK, and SO reviewed drafts of the article. MM, MJN, GFB, GK, HWB, RACR, EMA, and BRB reviewed the final draft of the article.

ParkinsonNet Trial Study Group

Advisory board—JW Custers, PJ van der Wees, RAB Oostendorp, TPM Vliet-Vlieland, J Verhoef. *Local coordinators*—K Keizer, GJ Tissingh, B van Kooten, FE Strijks, GA van Meer, JP ter Bruggen, MF Roesdi, M Kleijer, A Valkenburg, M Aramideh, R Rundervoort, DJ Kamphuis, K Lemmen, JMJ Krul, PM Laboyrie, FWJ Opstelten, HM Schrijver, MACJ de Letter, C Jansen. *Physiotherapist training*—E Westerveld, P van Keeken, A Nieuwboer, Y Kamsma, LIIK Lim, CJT de Goede. *Recruitment and data collection*—MAC van Rossum, E van Rossum, MJE Likumahwa, H Ewalds, MA Houweling, M de Jong, N Hazelhof, E Westerveld.

Conflicts of interest

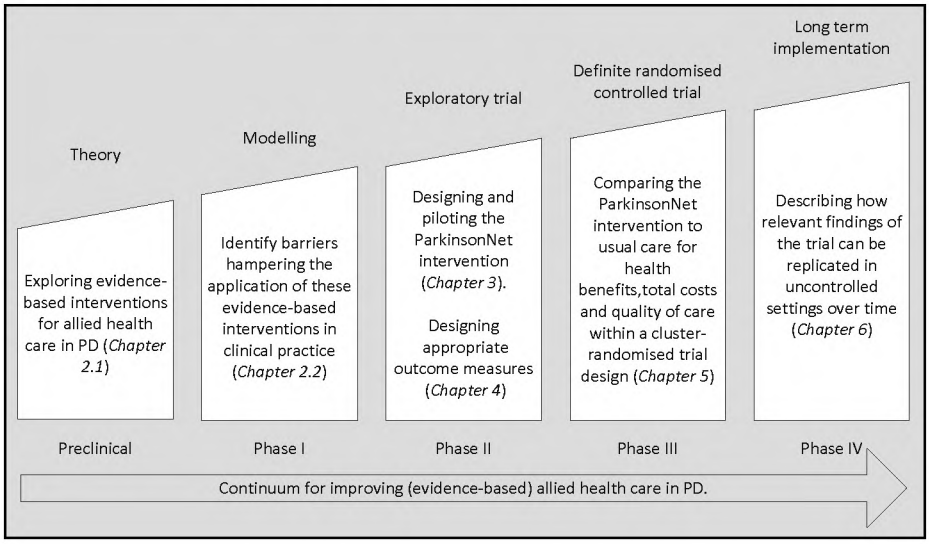
MM has received grants from the Netherlands Organisation for Health Research and Development (ZonMw), the National Parkinson Foundation, the Michael J Fox Foundation, and Stichting Robuust. MJN has received grants from ZonMw, the Royal Dutch Society for Physical Therapy, and Stichting Robuust. SHJK has received grants from ZonMw and the National Parkinson Foundation. GK has received grants from ZonMw, the Royal Dutch Society for Physical Therapy, and the International Parkinson Fund. HWB has received grants from ZonMw, the International Parkinson Foundation, and the Van Alkemade-Keuls Foundation. EMA has received grants from ZonMw. SO is a consultant for and has received speaker's fees and travel expenses from UCB. BRB has received grants from ZonMw, the National Parkinson Foundation, and the Michael J Fox Foundation, and is a consultant for GlaxoSmithKline, Boehringer Ingelheim, TEVA, UCB, and Novartis. RACR and GFB have no conflicts of interest.

Chapter 6
Summary and general discussion

Improving health care in PD

Increasing health care costs due to ageing and suboptimal quality of care for chronic patients call for a change in the organisation of health care.[4;6] This thesis focused on improving allied health care in PD using a stepwise approach (see box 1.3, *Chapter 1*). Two earlier approaches also recommended a stepwise approach to improve aspects of health care.[188;189] Differences between these two methods include the number of steps taken, as each was developed for a specific purpose (e.g. targeted at a service, organisation or professional) and context. The similar and most essential steps are best illustrated in the six phase framework for the design and evaluation of complex interventions of the Medical Research Council's (MRC) (Box 6.1).[188] Our method (see box 1.3) fully complies with the phases of the MRC framework. The continuum for improving allied health care in PD is graphically illustrated within the MRC framework in box 6.1. Below, we briefly summarize and discuss the findings for each phase of the framework.

Box 6.1 Continuum for improving allied health care in PD.



Preclinical phase: exploring evidence-based interventions for allied health care in PD

Summary

The effectiveness for allied health interventions in PD was explored in *Chapter 2.1* by conducting a systematic review. This review identified moderate to strong evidence for physiotherapy and speech therapy. The effectiveness of occupational therapy in PD is unknown.

Within the field of physiotherapy, exercise therapy and motor compensatory strategies (cueing and cognitive movement strategies) are effective in improving balance, gait and transfers in PD patients.[5] Compensatory strategies supervised by speech therapists are effective to improve speech

(Lee Silverman Voice Treatment[85] and Pitch Limiting Voice Treatment[86]). For occupational therapy, the effectiveness is difficult to determine as trials for occupational interventions in PD are simply lacking. Therefore, only best-practice recommendations are provided for occupational therapy interventions that have proven to be effective for other conditions (e.g. dementia[77]).

Discussion

In the meanwhile, three systematic reviews of allied health care interventions in PD[2;31;190] and a meta-analysis for exercise interventions in PD[164] have become available. Especially for the field of physiotherapy, the number of controlled studies has increased rapidly (17 physiotherapy studies in 2001 to 37 physiotherapy studies in 2007).[31] This also resulted in more supporting evidence for both exercise therapy to improve both gait and physical capacity[164;191-193], and for the application of cueing strategies to improve gait-related activities[142;143]. However, an update of the Cochrane review for occupational therapy in PD showed no new evidence.[190]

Recommendations

Although the number of randomized controlled trials has increased rapidly, in particular for the field of physiotherapy, these studies still deal with methodological shortcomings. Many allied health studies show limitations such as a biased design, under powering, inappropriate blinding or follow up that is too short.[20;150;190] Therefore, the use of CONSORT guidelines[194] are strongly recommended for future research in this field. The seminal RESCUE trial conducted by Nieuwboer *et al.*[48] is a good example of how to conduct a trial for allied heath in PD.

We should also draw more attention to the fact that the effectiveness of occupational therapy in PD is still unknown.[190] The reason for this finding is that trials are simply lacking (but at least two large trials are now underway, including one in the United Kingdom, and one in The Netherlands). Because the principle behind motor compensatory strategies in PD is generic, and while being applied initially only in the field of physiotherapy, this approach may also be useful for the field of occupational therapy. For example, allied health personnel most often receive requests from patients to improve dexterity; future research should therefore address the use of compensatory strategies to improve dexterity.[125]

Phase I: identifying barriers hampering the practical application of evidence-based allied health interventions

Summary

A survey among 260 PD patients and 297 allied health professionals is described in *Chapter 2.1*. The survey aimed to identify barriers hampering the practical application of evidence-based interventions. The results show that the quality of both referrals and consultations of allied health care in PD is suboptimal. Most patients with an indication for allied health care do not consult an allied health professional. This is particularly the case for occupational therapy (>80% not consulting)

and to a lesser extent for speech therapy (60-80% not consulting) and physiotherapy (30-40% not consulting). If patients are referred for allied health care, they are often treated by allied health professionals who themselves expressed to have a lack of PD-specific expertise. In addition, most of these allied health professionals were also not aware of the treatment options that could be delivered by other involved professionals.

Discussion

A lack of PD-specific expertise among physiotherapists was already identified in a previous survey among PD patients,[21] but was now confirmed by allied health professionals themselves. Another important finding is that even PD 'experts' typically have a low patient volume (<10 patients/year per therapist). This may explain why educational programs are scarce, why only a small number of professionals are participating in these programs and why only a small number of professionals are aware of the possibilities of other disciplines involved in the care of PD patients. Furthermore, unawareness about the (im)possibilities of allied health care among PD patients and referring physicians may result from absence of guidelines or standards for allied health care in PD.

Recommendations

The barriers for both the referral and consultation process for allied health care in PD need to be targeted by a quality improvement intervention. The first step should be the development of evidence-based guidelines or best practice standards for allied health care, as they will provide clear recommendations for treatment but also clear criteria for referral. After the survey in 2004, such a guideline has become available for physiotherapy in PD.[5] In 2008, guidelines for occupational and speech therapy have become available as well.[44;45] However, the existence of guidelines is not enough as guidelines often do not implement themselves.[144-146] For physiotherapy it is known that guideline adherence improves significantly when a multifaceted implementation strategy is used.[137;144;145] For rheumatoid arthritis, almost similar barriers existed in the Netherlands and these have been targeted by a local community network of rheumatologists and physiotherapists.[124] Within this community network, physiotherapists are trained by rheumatologists to treat this patient population according to standards, and rheumatologists are trained to refer patients with an indication to these trained specialists. This approach appeared to be feasible in daily practice and seems therefore promising for allied health care in PD as well. An important finding of this concept has been that the number of patients remained relative low. For PD, a substantial increase in the number of patient treated yearly by each professional is desired as a larger case load appeared to be associated with a higher level of expertise in this survey.[125]

Phase II: Designing and piloting a quality improvement intervention for allied health care in PD.

Summary

The design of a new quality improvement intervention for allied health care in PD called ParkinsonNet is described in *Chapter 3*. ParkinsonNet is a community network for neurologists and allied health professionals aiming to: (1) improve PD-specific expertise by training a selected number of allied health professionals according to evidence-based guidelines; (2) enhance the accuracy of referrals by neurologists; (3) boost patient volumes per professional, by stimulating preferred referral to ParkinsonNet professionals; and (4) stimulate collaboration between allied health, neurologists, and PD patients. The ParkinsonNet concept was first implemented on a small scale and was successfully adapted by all involved professionals. For physiotherapy, the number of participating professionals has been sufficient to evaluate changes in the PD expertise and patient volume. Both these aspects of quality of care increased significantly.

Expertise increased immediately after the basic course and remained at a high level over time, whereas patient volume steadily increased over the years (from eight PD patients yearly in 2003 to 18 patients in 2007).

Discussion

The ParkinsonNet concept appeared to be a promising strategy to improve the quality of allied health as it was rapidly adapted by the involved professionals. Moreover, quality indicators such as PD-specific expertise and patient volume changed significantly in the desired directions. No scientific articles are available that precisely describe how to improve allied health care in PD. However, many studies describe quality improvement interventions for different health conditions.[35;137;195] Several elements of which we thought had the potential to counteract barriers have been incorporated in the ParkinsonNet intervention, and therefore may explain these initial effects. For example, the concept of a community network worked successfully for rheumatoid arthritis in the Netherlands, and only needed to be tailored for PD.[124] Furthermore, educational components of a quality improvement intervention have proven to be effective, and were even more effective when integrated within a multi-faceted strategy.[137;195] The increase in PD-specific expertise immediately after the basic course shows that this component of the intervention is very successful. Finally, the finding of a steadily rising patient volume is an indication that the network matures over time and this is also in line with previous findings.[35] Although the initial experience with ParkinsonNet is promising, this study is a pilot that was not without methodological shortcomings. However, this initial network is delivered as a proof of principle, which is crucial before starting a formal trial.[188]

Recommendations

After the successful completion of the exploratory phase, we prepared a randomised controlled trial evaluating ParkinsonNet according to quality standards in terms of the CONSORT guidelines.[188;194] This trial aimed to address the question whether implementation of ParkinsonNet leads

to higher quality of care delivered by ParkinsonNet therapists, whether PD patients benefit from the concept in terms of health status, and what the consequences might be for the total health care costs. With respect to outcome measures, we included not only measures for the disease or condition. ParkinsonNet has a much wider relevance to the health care system (e.g. quality of care).[188] Outcome measures that are able to measure changes in health status of patients and in the quality of are due to ParkinsonNet therapy are currently lacking and therefore need to be developed and evaluated first. From a feasibility perspective, we decided to start evaluating the ParkinsonNet physiotherapy component first. Reasons for this choice are that PD patients have more relevant problems in the domains of physiotherapy,[125] the level of evidence for physiotherapy is higher[115] suggesting a larger contrast between groups, and that evidence-based guidelines for physiotherapy[136] are already available. The latter makes it easier to standardize treatment and possible to evaluate guideline adherence with quality indicators that are systematically derived out of this guideline.[128]

Phase II: Designing appropriate outcome measures to detect changes due to the quality improvement intervention.

The development and evaluation of an outcome measure for quality of physiotherapy in PD *(Chapter 4.1)*

Summary

To evaluate whether the implementation of the physiotherapy component of ParkinsonNet improves the quality of care delivered by ParkinsonNet physiotherapists, quality indicators have been derived systematically out of the evidence-based guideline for physiotherapy in PD.[5;128;136] Indicators which have been rated as relevant by an expert panel have been incorporated into a questionnaire termed 'Quality Indicators for Physiotherapy in PD' (QIP-PD). Face validity has been tested first, and then 41 ParkinsonNet physiotherapists and 286 general physiotherapists completed an adjusted the 17 item QIP-PD. Completeness of item scores ranged from 95-98% and six items showed either a ceiling effect or lack of discrimination. After excluding these six items, the 11 items QIP-PD showed a good internal consistency (Crohnbach's alpha 0.84). Interviews among a randomly selected cohort of 32 PD experts and 32 general physiotherapists showed that the QIP-PD is also reliable (Intraclass Correlations Coefficients ranged from 0.63 to 0.75). The total QIP-PD score appeared to be significantly higher for ParkinsonNet physiotherapists (35.1 ± 4.2) compared to general physiotherapists (22.2 ± 7.7; P = 0.01).

Discussion

Beside the development of a relevant, feasible, valid, discriminative and reliable outcome measure for the quality of physiotherapy in PD, this study provided insight in guideline adherence of both trained ParkinsonNet physiotherapists and 'generic' physiotherapists. The results show that physiotherapy guidelines do not implement themselves automatically, and that a multifaceted implemen-

tation strategy can significantly improve guideline adherence. These findings are in line with the literature for other physiotherapy guidelines.[128;137;144-146] The results also show that PD is a complex disease for physiotherapists. Particularly the application of PD-specific interventions (such as cueing and cognitive movement strategies) was significantly lower for physiotherapists without PD-specific expertise compared to ParkinsonNet physiotherapists. This finding is striking as cueing and cognitive movement strategies are among the effective physiotherapy interventions, and patients treated by inexperienced 'generic' therapists are thus withheld an effective treatment.[5;23;26;31;48]

Five quality indicators for speech therapy in PD have recently been derived from the new evidence-based guideline for speech therapy in PD in a similar way.[45;196] Different from our study, young members of ParkinsonNet were compared with older members of ParkinsonNet. The group of speech therapist that were more seasoned members of ParkinsonNet scored significantly higher than the younger members and were treating significantly more patients. This finding supports our earlier suggestion that ParkinsonNet matures with time, and this success speaks for its broad acceptance by the field.

Recommendations

The QIP-PD is a relevant, feasible, valid, discriminative and reliable outcome measure for the quality of physiotherapy delivered to PD patients. For those reasons, the QIP-PD is found eligible as an outcome measure for quality of physiotherapy in PD for a randomised trial design evaluating the physiotherapy component of ParkinsonNet.

Development and evaluation of a patient specific index to measure changes in health status of PD patients (*Chapter 4.2*)

Summary

To evaluate whether the implementation of the physiotherapy component of ParkinsonNet results in health benefits for PD patients, an instrument that captures the whole domain of physiotherapy in PD is needed. Such an instrument was lacking, and we therefore developed a patient-specific index for physiotherapy in Parkinson's disease (PSI-PD). In the PSI-PD, patients (a) select problematic activities out of a predefined list, with one self-report item; (b) rank selected items in order of importance; and (c) rate severity for each ranked item. Test-retest reliability was examined by asking a cohort of patients to complete the PSI-PD twice. Eighty-one patients completed the PSI-PD twice. Test-retest agreement for the selection of activity limitations ranged from 73% to 94%. Patients did not rank the items as intended and therefore items have been ranked into domains of which agreement ranged from 74% to 82%. Telephone interviews confirmed that the PSI-PD reliably identified problem areas.

Discussion

The ultimate outcome measure for physiotherapy in PD has not yet been found, as there are several limitations in the currently available methods.[150] The first problem is that different patients can experience a widely diverse nature of activity limitations. To capture relevant improvements for all these patients, multiple 'primary' outcomes had to be selected in previous studies. A disadvantage to this approach is the risk of an accidental positive finding. A second problem is that many selected instruments do not capture the aim of a physiotherapy intervention, thereby decreasing responsiveness to change (e.g. speech and swallowing items of the UPDRS ADL section). We aimed to tackle these problems with the development of a patient specific index as the PSI-PD can bypass this problem by evaluating the specific activity limitations that are most bothersome to each individual patient. The PSI-PD seems promising as it is a feasible, reliable and valid instrument to identify self-reported limitations in activities of PD patients. However, the limitation of the PSI-PP is the fact that patients do not rank their items as intended. Therefore the responsiveness remains unknown.

Recommendations

For future physiotherapy trials in PD, consensus should be reached about the choice of outcome measures. One scenario could be that outcome measures are defined for each core area: gait, transfers, balance, posture and physical capacity. Depending on the aim of the physiotherapy intervention, the best matching measure is selected. Other food for thought is whether a patient-reported measure should be used in addition with an objective physiologic measure (e.g. activity monitoring).

For our penultimate purpose (evaluation of the physiotherapy component of ParkinsonNet), the PSI-PD is a good primary outcome measure under two conditions. The first condition is assistance by an interviewer or professional during the ranking process, especially when cognitive impairment is present. Second, we recommend the inclusion of 'secondary' outcomes for each core area of physiotherapy.

Phase III: The ParkinsonNet trial: efficacy of the ParkinsonNet physiotherapy component

Summary

With the availability of appropriate measures it became possible to evaluate the physiotherapy component of ParkinsonNet within a randomized trial setting. *Chapter 5* describes the ParkinsonNet trial, a randomised controlled trial in which the physiotherapy component of ParkinsonNet was compared with usual care physiotherapy. Both groups were compared for health benefits for PD patients (primary outcome PSI-PD; secondary outcomes M-PAS and PDQ39 Mob), quality of care as delivered by physiotherapists (QIP-PD), and total health care costs. If randomisation would have taken place at the patient level, a substantial risk of contamination would have been introduced (e.g., patients allocated to usual care physiotherapy visiting a ParkinsonNet therapist). Therefore, we decided to randomise at the level of regions (clusters), effectively making this trial

a cluster-randomised trial. A sample size calculation showed that at least sixteen regions with each 40 valuable patients were needed. To compensate for drop outs, a number of approximately 700 patients needed to be enrolled to ascertain sufficient power. Sixteen regions were thus divided randomly into eight experimental regions with a ParkinsonNet and eight control regions where the organization of care remained unchanged. Forty-six therapists in the ParkinsonNet regions received a dedicated baseline training to increase their PD-specific expertise. Subsequently we included 358 patients in ParkinsonNet regions and 341 patients in the usual care regions.

The proportion of patients who were treated by a physiotherapist who worked according to evidence-based recommendations (QIP-PD) was higher than in the usual care clusters. In the usual care clusters, 252 (74%) of 341 patients used physiotherapy compared to 265 (74%) of 358 patients in the ParkinsonNet clusters. In the usual care clusters, none of the patients consulted a ParkinsonNet therapist. Of the patients receiving physiotherapy in the ParkinsonNet clusters, 74 (28%) consulted a specialised ParkinsonNet therapist. The remaining 191 patients (72%) in the ParkinsonNet clusters consulted a generic therapist. After 16 weeks, no differences were found for the primary (PSI-PD) and secondary health endpoints between the ParkinsonNet clusters and control clusters. Total costs per patient over 24 weeks were €727 lower in the ParkinsonNet clusters than in the usual care clusters. Informal care (€313 difference) and day-hospital rehabilitation (€123 difference) contributed most to the differences in total health care costs. The results of this large RCT thus demonstrated that the ParkinsonNet system of care was not associated with a change in health outcome over 6 months for patients living in ParkinsonNet clusters, but it provided a higher quality of care at reduced costs compared with usual care.

Discussion

Most prior trials in the field of physiotherapy in PD dealt with serious methodological problems such as bias in the design, the use of multiple outcome measures, lack of assessor blinding, inadequate placebo, lack of power or insufficient contrast between groups.[31;164;172;197;198] The ParkinsonNet trial has tackled most of these problems as it fully complies with the CONSORT criteria that were mentioned earlier.[165]

The design of the ParkinsonNet trial is different from most other randomized controlled trials in the field of physiotherapy. This trial captured the total delivery of physiotherapy including its referral by physicians, thereby evaluating physiotherapy in a more 'real world' setting. A consequence of this design is that most o patients in the usual care group also received physiotherapy, and this may lead to less contrast between both groups. This cluster-controlled design is therefore suboptimal when the aim is to evaluate health benefits for a specific physiotherapy interventions (e.g., auditory cueing to improve rising from a chair). A lack of contrast between both groups is one of the likely explanations for the absence of health benefits for PD patients in this trial. This is supported by the fact that only one third of patients in the ParkinsonNet clusters that received

physiotherapy visited a ParkinsonNet therapist. Explanations for this relatively low proportion of patients that consulted a ParkinsonNet physiotherapist include the fact that promotion of ParkinsonNet was limited, to avoid the risk of contamination. Another explanation is that patient already had physiotherapy[21] and did not agree to change to another therapist. Further explanations for the lack of health benefits for patients could be that the intensity of physiotherapy was not intensive enough,[26;184;185] or that the time between implementation of ParkinsonNet and enrolment of patients was still too short. Within the ParkinsonNet trial, patients enrolled the study immediately after physiotherapists had followed their baseline training. Therefore, therapists may have still been too inexperienced immediately after this baseline training, since they had not yet been able to implement the newly acquired skills in clinical practice. Moreover, the ParkinsonNet trial commenced immediately after neurologists had been instructed about the referral criteria for physiotherapy, and presumably they also needed to get used to the new system of care. This assumption about immaturity of the network is supported by the results of our pilot study[1] and comparable literature,[35] both showing that 'shared care' interventions need to time to season (i.e. the effects steadily increase over time).

Looking at health care costs in more detail, the wide confidence intervals leave open the possibility that the actual cost saving might have been smaller. However, we believe that at least some of the reduction is real as savings were observed for most of the different costs components. A reduced need for home care and day hospital rehabilitation explained most of the costs savings, implying that patients might have reached the same clinical level in the hands of ParkinsonNet therapists, but now with cheaper forms of care and better quality physiotherapy.

Recommendations

One limitation of the current ParkinsonNet is that the role of PD patients within ParkinsonNet is minimal. So far, we have limited promotion of ParkinsonNet among patients to avoid that patients allocated to the usual care went travelling to a relatively nearby ParkinsonNet therapist during our study. Now that the trial is finished, we have increased awareness among PD patients and referring physicians with a search tool on the website (www.parkinsonnet.nl) and by publishing several relevant papers for both target groups.[196;199;200] However, next to increasing awareness, we also aim to strengthen the role of patients as an active member of the ParkinsonNet network. This is in line with other chronic conditions where self-management or patient empowerment has shown positive outcomes concerning health status and cost savings.[201] A first step to be taken is to inquire which role PD patients and their caregivers want to play by means of a survey or focus group interviews. This project is currently underway.[202]

Phase IV: external validity of the ParkinsonNet concept

Of course the findings of the ParkinsonNet trial make it relevant to explore the broader implications of the ParkinsonNet concept. Questions that need to be answered are whether such an approach will also 'work' for other professionals involved with PD patients, for other regions and countries with different health care systems, or for other (chronic) conditions. Such extrapolations need to be made with care because many determinants (including ones that are unrelated to the innovation itself (e.g. change in insurance policy)) may play an important role in the implementation and dissemination of health innovations.[203] Here, we discuss the external validity in more detail and provide recommendations for the dissemination of the ParkinsonNet concept.

Recommendations for other professionals working with PD patients

Whether other professionals working with PD patients may also benefit from the ParkinsonNet concept is no longer a question. Similar clinical barriers existed for speech-language and occupational therapists, and for these two disciplines participation in ParkinsonNet has proved to be feasible as well. Following completion of the ParkinsonNet trial in 2007, we have begun disseminating ParkinsonNet throughout the Netherlands for physiotherapy, occupational therapy and speech-language therapy. We expect to cover the entire country by the end of 2010. Recently we have also inquired about the needs of psycho-social workers and dieticians, and have piloted the inclusion of these disciplines on a small scale. If positive, these allied health professionals will also join the existing networks at a nationwide level by the end of 2010. The dissemination of ParkinsonNet is illustrated in more detail in box 6.2.

Recommendations for other regions and countries

Whether ParkinsonNet can be extrapolated to other countries largely depends on the organization of health care, the local insurance policy and the geographical features of each county or region. ParkinsonNet fits well into the existing rules, regulations and legislations of the Dutch health care system. This system is a 'single payer' system guaranteeing that every citizen has a health insurance with an option for a private (additional) insurance. Furthermore, allied health care for PD is still covered for most PD patients by insurance companies. We therefore believe that the ParkinsonNet concept may also work for countries with an almost comparable system such as the United Kingdom, Germany and Canada. Furthermore, note that the Netherlands are a densely populated with a relative good infrastructure for health services and transportation. In less densely populated areas, an increased patient volume for a professional cannot be expected as travel distance between patient and professionals may become too far. For those areas, the ParkinsonNet intervention should be adjusted, perhaps using telemedicine which is already used in thinly populated areas in e.g. Australia or Finland.[204] Perhaps existing health care resources within communities (e.g. allied health professionals, sport instructors, social workers or caregivers) can be involved to carry out parts of evidence-based practice by using a 'train the trainer' strategy. [205]

Recommendations for other conditions

Whether ParkinsonNet is suitable for other (chronic) conditions depends on the extent to which the procedures/guidelines for this condition are clear, on the extent to which it is perceived as being advantageous by users (both patients and professionals) and on the extent to which 'ownership' by the health professional is perceived. As mentioned earlier in this thesis, the existence of evidence-based standards makes it easier to design a transparent intervention with clear communication and collaboration plans. Furthermore, note that ParkinsonNet has advantages for many different types of users. Thus, patients will receive a higher quality of care, physicians know better where to find expert allied health professionals for their patients, and allied health personnel receives the skills to improve their expertise. In addition, the selection process (which is necessary to increase patient volumes) is another important determinant. The increased patient volume for participating professionals is of course also financially attractive for participating professionals. In contrast, ParkinsonNet can be a threat to non-participating professionals, who sustain the risk of losing part of their already small volume of patients (during the trial on average of three PD patients on a yearly basis).[125] Indeed, the results of the ParkinsonNet trial showed that generic therapists in the ParkinsonNet clusters treated slightly fewer patients compared to generic therapists in the usual care clusters, because the ParkinsonNet therapists now attracted more patients. However, the ParkinsonNet organization of care may also offer advantages for these generic therapists, because this provides them the opportunity to refer their relatively 'complex' patients to an expert colleague. All these aspects mentioned above should be taken into consideration when extrapolating the ParkinsonNet concept to other conditions. Therefore, we recommend to first enquire about the current strengths and limitations in practice (see *Chapter 2)* so that the concept can be tailored to this specific condition (*Chapter 3*).

Dissemination on a larger scale

Finally, dissemination on a large scale and maintaining the existing networks requires central coordination and support. Currently, a small project team has been installed to set up new networks and to support the existing networks. Financial support for this project team is currently provided by the Dutch Parkinson Patient Society ('Parkinson Vereniging', www.parkinson-vereniging.nl/). Furthermore, the following societies for professionals have adopted the concept: Nederlandse Werkgroep voor Bewegingsstoornissen, Koninklijk Nederlands Genootschap voor Fysiotherapie, Vereniging voor Oefentherapeuten Cesar en Mensendieck, Ergotherapie Nederland en Nederlandse Vereniging voor Logopedie en Foniatrie. Furthermore, maintenance of the existing networks is established by a yearly financial contribution ('membership fee') by the participating professionals. The installation of new ParkinsonNet networks is financially supported by both governmental (the Netherlands Organisation for Health Research and Development, ZonMw) and non-governmental (National Parkinson's disease Foundation, Stichting Robuust, Parkinson Vereniging) organizations.

Box 6.2 Dissemination of ParkinsonNet throughout the Netherlands.

Currently, 65 ParkinsonNet networks have been installed throughout the entire country. Within these ParkinsonNet networks, a number of 748 physiotherapists, 289 speech therapists, 265 occupational therapists, 82 dieticians and 54 psycho-social workers are participating.

1. Steenwijk
2. Friesland
3. Groningen
4. Drenthe
5. Noord-Oostpolder
6. Zwolle
7. Hardenberg - Ommen
8. Twente
9. Deventer
10. Harderwijk
11. Lelystad
12. Noord-Holland Noord
13. Alkmaar
14. Hoorn
15. Purmerend
16. Zaanstad
17. Beverwijk
18. Haarlem
19. Amsterdam West
20. Haarlemmermeer
21. Amsterdam Centrum-Oost-Zuid Oost
22. Amsterdam Zuid
23. 't Gooi
24. Almere
25. Utrecht Stad
26. Utrecht Zuid-Oost
27. Eemland
28. Ede-Wageningen-Veenendaal
29. Apeldoorn
30. Arnhem
31. Zutphen
32. Doetinchem
33. Arnhem
34. Nijmegen-Boxmeer
35. Tiel
36. Utrecht Zuid-West
37. Woerden
38. Leiden
39. Den Haag
40. Zoetermeer
41. Delft
42. Schiedam
43. Rotterdam Noord
44. Rotterdam Zuid
45. Drechtsteden
46. Gorinchem
47. Waalwijk
48. Oss-Uden-Veghel
49. Helmond-Geldrop
50. Venlo
51. Weert
52. Roermond
53. Sittard-Geleen
54. Heerlen-Kerkrade
55. Maastricht
56. Eindhoven
57. Tilburg
58. Breda
59. Roosendaal
60. Bergen op Zoom
61. Zeeland-Noord
62. Zuid-Hollandse Eilanden
63. Zeeuws Vlaanderen
64. Gouda
65. Amsterdam-Noord

The 'Parkinson Zorgzoeker' is a search engine on the ParkinsonNet website (www.parkinsonnet.nl) that makes it possible to easily find nearby ParkinsonNet professionals.

Overall conclusion

The aim of this thesis was to improve allied health care in PD. ParkinsonNet appears to be a promising health concept as it has been implemented relatively easily, it improved the quality of physiotherapy care and it reduced total health care costs, but without changes in the health status of PD patients. With the current economic crisis and ageing of our population, there is an urgent need for such cost-saving health care programs.

When the reduced costs for the physiotherapy component (yearly €1450 per patient) are extrapolated roughly to the population of 50.000 PD patients in the Netherlands, an estimated amount of €73 million is saved.[206] We acknowledge that this is a rough first estimate, but these findings do underscore that an initially small investment in strategies such as ParkinsonNet is perhaps a better way to save money than cutting on the health care budget for patients with a chronic or age-related condition. The latter approach is almost inevitably followed by lower levels of quality of care, whereas ParkinsonNet improved the quality of care. The positive findings of ParkinsonNet have led to a rapid dissemination of ParkinsonNet throughout the entire country. Finally, the question remains whether the multidisciplinary component of ParkinsonNet is also efficient. This is currently being investigated in a new trial (the IMPACT study[36]) of which the results are expected by the end of 2011.

References

(1) Nijkrake MJ, Keus SH, Overeem S, Oostendorp RA, Vlieland TP, Mulleners W et al. The ParkinsonNet concept: development, implementation and initial experience. Mov Disord 2010; 25(7):823-829.

(2) van der Marck MA, Kalf JG, Sturkenboom IH, Nijkrake MJ, Munneke M, Bloem BR. Multidisciplinary care for patients with Parkinson's disease. Parkinsonism Relat Disord 2009; 15 Suppl 3:S219-S223.

(3) Wynia K, Middel B, Van Dijk JP, De RH, Lok W, Ha De KJ et al. Broadening the scope on health problems among the chronically neurologically ill with the International Classification of Functioning (ICF). Disabil Rehabil 2006; 28(23):1445-1454.

(4) Algemene Rekenkamer. Nog weinig afstemming in de zorg voor chronisch zieken. Persbericht 2006.

(5) Keus SH, Bloem BR, Hendriks EJ, Bredero-Cohen AB, Munneke M. Evidence-based analysis of physical therapy in Parkinson's disease with recommendations for practice and research. Mov Disord 2007; 22(4):451-460.

(6) Hargreaves S. Burden of ageing population may be greater than anticipated. Lancet 2000; 355(9221):2146.

(7) Dorsey ER, Constantinescu R, Thompson JP, Biglan KM, Holloway RG, Kieburtz K et al. Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030. Neurology 2007; 68(5):384-386.

(8) Klink A, Bussemaker J. Programmatische aanpak van chronische ziekten. Ministerie van Volksgezondheid, Welzijn en Sport 2008.

(9) von Campenhausen S, Bornschein B, Wick R, Botzel K, Sampaio C, Poewe W et al. Prevalence and incidence of Parkinson's disease in Europe. Eur Neuropsychopharmacol 2005; 15(4):473-490.

(10) Schrag A, Jahanshahi M, Quinn N. What contributes to quality of life in patients with Parkinson's disease? J Neurol Neurosurg Psychiatry 2000; 69(3):308-312.

(11) Gage H, Hendricks A, Zhang S, Kazis L. The relative health related quality of life of veterans with Parkinson's disease. J Neurol Neurosurg Psychiatry 2003; 74(2):163-169.

(12) Findley LJ. The economic impact of Parkinson's disease. Parkinsonism Relat Disord 2007; 13 Suppl:S8-S12.

(13) Lees AJ, Hardy J, Revesz T. Parkinson's disease. Lancet 2009; 373(9680):2055-2066.

(14) Hanna-Pladdy B. Dysexecutive syndromes in neurologic disease. J Neurol Phys Ther 2007; 31(3):119-127.

(15) Morris ME, Iansek R, Galna B. Gait festination and freezing in Parkinson's disease: pathogenesis and rehabilitation. Mov Disord 2008; 23 Suppl 2:S451-S460.

(16) World Health Organization (WHO). International Classification of Functioning, Disability and Health, ICF. Geneva: 2001.

(17) Fahn S, Oakes D, Shoulson I, Kieburtz K, Rudolph A, Lang A et al. Levodopa and the progression of Parkinson's disease. N Engl J Med 2004; 351(24):2498-2508.

(18) Limousin P, Martinez-Torres I. Deep brain stimulation for Parkinson's disease. Neurotherapeutics 2008; 5(2):309-319.

(19) Deuschl G, Schade-Brittinger C, Krack P, Volkmann J, Schafer H, Botzel K et al. A randomized trial of deep-brain stimulation for Parkinson's disease. N Engl J Med 2006; 355(9):896-908.

(20) Deane KH, Ellis-Hill C, Jones D, Whurr R, Ben-Shlomo Y, Playford ED et al. Systematic review of paramedical therapies for Parkinson's disease. Mov Disord 2002; 17(5):984-991.

(21) Keus SH, Bloem BR, Verbaan D, de Jonge PA, Hofman M, van Hilten BJ et al. Physiotherapy in Parkinson's disease: utilisation and patient satisfaction. J Neurol 2004; 251(6):680-687.

(22) Behrman AL, Teitelbaum P, Cauraugh JH. Verbal instructional sets to normalise the temporal and spatial gait variables in Parkinson's disease. J Neurol Neurosurg Psychiatry 1998; 65(4):580-582.

(23) Kamsma YPT, Brouwer WH, Lakke JPW Training of compensational strategies for impaired gross motor skills in Parkinson's disease. Physiother Theory Pract 1992; 11:209-229.

(24) Mak MK, Hui-Chan CW Audiovisual cues can enhance sit-to-stand in patients with Parkinson's disease. Mov Disord 2004; 19(9):1012-1019.

(25) Muller V, Mohr B, Rosin R, Pulvermuller F, Muller F, Birbaumer N. Short-term effects of behavioral treatment on movement initiation and postural control in Parkinson's disease: a controlled clinical study. Mov Disord 1997; 12(3):306-314.

(26) Nieuwboer A, De WW, Dom R, Truyen M, Janssens L, Kamsma Y. The effect of a home physiotherapy program for persons with Parkinson's disease. J Rehabil Med 2001; 33(6):266-272.

(27) Gillespie LD, Gillespie WJ, Robertson MC, Lamb SE, Cumming RG, Rowe BH. Interventions for preventing falls in elderly people. Cochrane Database Syst Rev 2003;(4):CD000340.

(28) Hirsch MA, Toole T, Maitland CG, Rider RA. The effects of balance training and high-intensity resistance training on persons with idiopathic Parkinson's disease. Arch Phys Med Rehabil 2003; 84(8):1109-1117.

(29) Scandalis TA, Bosak A, Berliner JC, Helman LL, Wells MR. Resistance training and gait function in patients with Parkinson's disease. Am J Phys Med Rehabil 2001; 80(1):38-43.

(30) Toole T, Hirsch MA, Forkink A, Lehman DA, Maitland CG. The effects of a balance and strength training program on equilibrium in Parkinsonism: A preliminary study. NeuroRehabilitation 2000; 14:165-174.

(31) Keus SH, Munneke M, Nijkrake MJ, Kwakkel G, Bloem BR. Physical therapy in Parkinson's disease: evolution and future challenges. Mov Disord 2009; 24(1):1-14.

(32) Sheriff JN, Chenoweth L. Challenges in conducting research to improve the health of people with Parkinson's disease and the well-being of their family carers. Int J Rehabil Res 2003; 26(3):201-205.

(33) Sitzia J, Haddrell V, Rice-Oxley M. Evaluation of a nurse-led multidisciplinary neurological rehabilitation programme using the Nottingham Health Profile. Clin Rehabil 1998; 12(5):389-394.

(34) Wade DT, Gage H, Owen C, Trend P, Grossmith C, Kaye J. Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study. J Neurol Neurosurg Psychiatry 2003; 74(2):158-162.

(35) Smith SM, Allwright S, O'Dowd T. Effectiveness of shared care across the interface between primary and specialty care in chronic disease management. Cochrane Database Syst Rev 2007;(3):CD004910.

(36) van der Marck MA, Bloem BR, Mulleners W, Hoogerwaard EM, Overeem S, Adang EM et al. Rationale and design of the IMPACT study: a cluster controlled trial to evaluate cost-effectiveness of multidisciplinary care in Parkinson's disease. Mov Disord 2010; Suplement to volume 25(7):S290-S291.

(37) de Buck PD, van Amstel RJ, Buijs PC, Maasen JH, van Dijk FJ, Hazes JM et al. Communication between Dutch rheumatologists and occupational physicians in the occupational rehabilitation of patients with rheumatic diseases. Ann Rheum Dis 2002; 61(1):62-65.

(38) Lindgren P Economic evidence in Parkinson's disease: a review. Eur J Health Econ 2004; 5 Suppl 1:S63-S66.

(39) Stewart DA. NICE guideline for Parkinson's disease. Age Ageing 2007; 36(3):240-242.

(40) Horstink M, Tolosa E, Bonuccelli U, Deuschl G, Friedman A, Kanovsky P et al. Review of the therapeutic management of Parkinson's disease. Report of a joint task force of the European Federation of Neurological Societies (EFNS) and the Movement Disorder Society-European Section (MDS-ES). Part II: late (complicated) Parkinson's disease. Eur J Neurol 2006; 13(11):1186-1202.

(41) Ferry P, Johnson M, Wallis P Use of complementary therapies and non-prescribed medication in patients with Parkinson's disease. Postgrad Med J 2002; 78(924):612-614.

(42) Montgomery EB, Jr. Rehabilitative approaches to Parkinson's disease. Parkinsonism Relat Disord 2004; 10 Suppl 1:S43-S47.

(43) Rajendran PR, Thompson RE, Reich SG. The use of alternative therapies by patients with Parkinson's disease. Neurology 2001; 57(5):790-794.

(44) Sturkenboom IH, Thijssen M, Gons-van Eslacker J, Janssen I, Maasdam A, Schulten M et al. Ergotherapie bij de ziekte van Parkinson. Woerden: LEMMA; 2008.

(45) Kalf JG, de Swart BJ, Bonnier-Baars M, Kanters J, Hofman M, Kocken J et al. Logopedie bij de ziekte van Parkinson. Woerden: LEMMA; 2008.

(46) Morris ME. Locomotor training in people with Parkinson disease. Phys Ther 2006; 86(10):1426-1435.

(47) Snijders AH, van de Warrenburg BP, Giladi N, Bloem BR. Neurological gait disorders in elderly people: clinical approach and classification. Lancet Neurol 2007; 6(1):63-74.

(48) Nieuwboer A, Kwakkel G, Rochester L, Jones D, van WE, Willems AM et al. Cueing training in the home improves gait-related mobility in Parkinson's disease: the RESCUE trial. J Neurol Neurosurg Psychiatry 2007; 78(2):134-140.

(49) Thaut MH, McIntosh GC, Rice RR, Miller RA, Rathbun J, Brault JM. Rhythmic auditory stimulation in gait training for Parkinson's disease patients. Mov Disord 1996; 11(2):193-200.

(50) de Goede CJ, Ellis T, Wagenaar RC, Feldman R, Wolters E. De effecten van een fysiotherapie groepsbehandeling voor Parkinson: een cross-over trial. Ned Tijdschrift Fysiother 2004; 114:78-82.

(51) Miyai I, Fujimoto Y, Ueda Y, Yamamoto H, Nozaki S, Saito T et al. Treadmill training with body weight support: its effect on Parkinson's disease. Arch Phys Med Rehabil 2000; 81(7):849-852.

(52) Formisano R, Pratesi L, Modarelli FT, Bonifati V, Meco G. Rehabilitation and Parkinson's disease. Scand J Rehabil Med 1992; 24(3):157-160.

(53) Robinson K, Dennison A, Roalf D, Noorigian J, Cianci H, Bunting-Perry L et al. Falling risk factors in Parkinson's disease. NeuroRehabilitation 2005; 20(3):169-182.

(54) Grimbergen YA, Munneke M, Bloem BR. Falls in Parkinson's disease. Curr Opin Neurol 2004; 17(4):405-415.

(55) Ashburn A, Fazakarley L, Ballinger C, Pickering R, McLellan LD, Fitton C. A randomised controlled trial of a home based exercise programme to reduce the risk of falling among people with Parkinson's disease. J Neurol Neurosurg Psychiatry 2007; 78(7):678-684.

(56) Constantinescu R, Leonard C, Deeley C, Kurlan R. Assistive devices for gait in Parkinson's disease. Parkinsonism Relat Disord 2007; 13(3):133-138.

(57) Cubo E, Moore CG, Leurgans S, Goetz CG. Wheeled and standard walkers in Parkinson's disease patients with gait freezing. Parkinsonism Relat Disord 2003; 10(1):9-14.

(58) Ten Harkel AD, van Lieshout JJ, Wieling W Effects of leg muscle pumping and tensing on orthostatic arterial pressure: a study in normal subjects and patients with autonomic failure. Clin Sci (Lond) 1994; 87(5):553-558.

(59) Schenkman M, Cutson TM, Kuchibhatla M, Chandler J, Pieper CF, Ray L et al. Exercise to improve spinal flexibility and function for people with Parkinson's disease: a randomized, controlled trial. J Am Geriatr Soc 1998; 46(10):1207-1216.

(60) Stallibrass C, Sissons P, Chalmers C. Randomized controlled trial of the Alexander technique for idiopathic Parkinson's disease. Clin Rehabil 2002; 16(7):695-708.

(61) Morris ME. Movement disorders in people with Parkinson disease: a model for physical therapy. Phys Ther 2000; 80:578-597.

(62) Fertl E, Doppelbauer A, Auff E. Physical activity and sports in patients suffering from Parkinson's disease in comparison with healthy seniors. J Neural Transm Park Dis Dement Sect 1993; 5(2):157-161.

(63) Crizzle AM, Newhouse IJ. Is physical exercise beneficial for persons with Parkinson's disease? Clin J Sport Med 2006; 16(5):422-425.

(64) Smidt N, de Vet HC, Bouter LM, Dekker J, Arendzen JH, de Bie RA et al. Effectiveness of exercise therapy: a best-evidence summary of systematic reviews. Aust J Physiother 2005; 51(2):71-85.

(65) Deane KH, Ellis-Hill C, Dekker K, Davies P, Clarke CE. A Delphi survey of best practice occupational therapy for Parkinson's disease in the United Kingdom. Occup Ther 2003; 66:247-254.

(66) Morris ME, Iansek R, Matyas TA, Summers JJ. Stride length regulation in Parkinson's disease. Normalization strategies and underlying mechanisms. Brain 1996; 119 (Pt 2):551-568.

(67) Oliveira RM, Gurd JM, Nixon P, Marshall JC, Passingham RE. Micrographia in Parkinson's disease: the effect of providing external cues. J Neurol Neurosurg Psychiatry 1997; 63(4):429-433.

(68) Kirkwood B. Occupational therapy for Parkinson's Disease. In: Morris ME, Iansek R, editors. Parkinson's Disease: a team approach. Blackburn: Buscombe Vicprint Ltd.; 1997. 83-104.

(69) O' Shea S, Morris ME, Iansek R. Dual task interference during gait in people with Parkinson disease: effects of motor versus cognitive secondary tasks. Phys Ther 2002; 82:888-897.

(70) Ma HI, Trombly CA, Tickle-Degnen L, Wagenaar RC. Effect of one single auditory cue on movement kinematics in patients with Parkinson's disease. Am J Phys Med Rehabil 2004; 83(7):530-536.

(71) Lim I, van WE, de GC, Deutekom M, Nieuwboer A, Willems A et al. Effects of external rhythmical cueing on gait in patients with Parkinson's disease: a systematic review. Clin Rehabil 2005; 19(7):695-713.

(72) Landes AM, Sperry SD, Strauss ME, Geldmacher DS. Apathy in Alzheimer's disease. J Am Geriatr Soc 2001; 49(12):1700-1707.

(73) Matuska K, Mathiowetz V, Finlayson M. Use and perceived effectiveness of energy conservation strategies for managing multiple sclerosis fatigue. Am J Occup Ther 2007; 61:62-69.

(74) Mann WC, Ottenbacher KJ, Fraas L, Tomita M, Granger CV. Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly. A randomized controlled trial. Arch Fam Med 1999; 8(3):210-217.

(75) Gitlin LN, Winter L, Corcoran M, Dennis MP, Schinfeld S, Hauck WW. Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH Initiative. Gerontologist 2003; 43(4):532-546.

(76) Gitlin LN, Hauck WW, Dennis MP, Winter L. Maintenance of effects of the home environmental skill-building program for family caregivers and individuals with Alzheimer's disease and related disorders. J Gerontol A Biol Sci Med Sci 2005; 60(3):368-374.

(77) Graff MJ, Vernooij-Dassen MJ, Thijssen M, Dekker J, Hoefnagels WH, Rikkert MG. Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. BMJ 2006; 333(7580):1196.

(78) Simons G, Thompson SB, Smith Pasqualini MC. An innovative education programme for people with Parkinson's disease and their carers. Parkinsonism Relat Disord 2006; 12(8):478-485.

(79) Sutter D, Curdt T, Neufeld P Promoting community participation among persons with Parkinson's disease and their caregivers: occupational therapy practitioners can facilitate persons with Parkinson's disease finding ways to continue to participate in valued occupations. OT-Practice 2006; 11:19-22.

(80) Deane KH, Whurr R, Clarke CE, Playford ED, Ben-Shlomo Y. Non-pharmacological therapies for dysphagia in Parkinson's disease. Cochrane Database Syst Rev 2001;(1):CD002816.

(81) Deane KH, Whurr R, Playford ED, Ben-Shlomo Y, Clarke CE. Speech and language therapy for dysarthria in Parkinson's disease. Cochrane Database Syst Rev 2001;(2):CD002812.

(82) Pinto S, Ozsancak C, Tripoliti E, Thobois S, Limousin-Dowsey P, Auzou P. Treatments for dysarthria in Parkinson's disease. Lancet Neurol 2004; 3(9):547-556.

(83) Marigliani C, Gates S, Jacks D. Speech Pathology and Parkinson's Disease. In: Morris ME, Iansek R, editors. Parkinson's Disease: a team approach. Melbourne: Buscombe Vicprint Ltd.; 1997.

(84) Ho AK, Bradshaw JL, Iansek T. Volume perception in parkinsonian speech. Mov Disord 2000; 15(6):1125-1131.

(85) Ramig LO, Countryman S, Thompson LL, Horii Y Comparison of two forms of intensive speech treatment for Parkinson disease. J Speech Hear Res 1995; 38:1231-1251.

(86) de Swart BJ, Willemse SC, Maassen BA, Horstink MW. Improvement of voicing in patients with Parkinson's disease by speech therapy. Neurology 2003; 60(3):498-500.

(87) Kalf JG, de Swart BJ, Bloem BR, Munneke M. Guidelines for speech-language therapy in Parkinson's disease. XVIIth WFN World Congress on Parkinson's Disease and Related Disorders 2007; (submitted abstract).

(88) Pfeiffer RF. Gastrointestinal dysfunction in Parkinson's disease. Lancet Neurol 2003; 2(2):107-116.

(89) El SA, Ramig L, Logemann JA, Pauloski BR, Rademaker AW, Smith CH et al. Swallowing and voice effects of Lee Silverman Voice Treatment (LSVT): a pilot study. J Neurol Neurosurg Psychiatry 2002; 72(1):31-36.

(90) Nagaya M, Kachi T, Yamada T. Effect of swallowing training on swallowing disorders in Parkinson's disease. Scand J Rehabil Med 2000; 32(1):11-15.

(91) Huckabee ML, Pelletier CA. Management of Adult Neurogenic Dysphagia. San Diego: Singular Publishing Group; 1999.

(92) Siddiqui MF, Rast S, Lynn MJ, Auchus AP, Pfeiffer RF. Autonomic dysfunction in Parkinson's disease: a comprehensive symptom survey. Parkinsonism Relat Disord 2002; 8(4):277-284.

(93) Kalf JG, Smit AM, Bloem BR, Zwarts MJ, Munneke M. Impact of drooling in Parkinson's disease. J Neurol 2007; 254(9):1227-1232.

(94) Molloy L. Treatment of sialorrhoea in patients with Parkinson's disease: best current evidence. Curr Opin Neurol 2007; 20(4):493-498.

(95) Marks L, Weinreich J. Drooling in Parkinson's disease: a novel tool for assessment of swallow frequency. Int J Lang Commun Disord 2001; 36 Suppl:288-291.

(96) Cushing ML, Traviss KA, Calne SM. Parkinson's disease: implications for nutritional care. Can J Diet Pract Res 2002; 63(2):81-87.

(97) Evatt ML. Nutritional therapies in Parkinson's disease. Curr Treat Options Neurol 2007; 9(3):198-204.

(98) Wolfrath SC, Borenstein AR, Schwartz S, Hauser RA, Sullivan KL, Zesiewicz TA. Use of nutritional supplements in Parkinson's disease patients. Mov Disord 2006; 21(8):1098-1101.

(99) Barichella M, Marczewska A, De NR, Vairo A, Baldo C, Mauri A et al. Special low-protein foods ameliorate postprandial off in patients with advanced Parkinson's disease. Mov Disord 2006; 21(10):1682-1687.

(100) Ueki A, Otsuka M. Life style risks of Parkinson's disease: association between decreased water intake and constipation. J Neurol 2004; 251 Suppl 7:vII18-vII23.

(101) Taal E, Bobietinska E, Lloyd J, Veehof M, Rasker WJ, Oosterveld FG et al. Successfully living with chronic arthritis. The role of the allied health professionals. Clin Rheumatol 2006; 25(2):189-197.

(102) Bronner G. Sexual dysfunction and Parkinson's disease: a need for further understanding. Eur J Neurol 2008; 15(11):1146-1147.

(103) Rees PM, Fowler CJ, Maas CP. Sexual function in men and women with neurological disorders. Lancet 2007; 369(9560):512-525.

(104) Tan LC, Lau PN, Jamora RD, Chan ES. Use of complementary therapies in patients with Parkinson's disease in Singapore. Mov Disord 2006; 21(1):86-89.

(105) Venglar M. Case report: Tai Chi and Parkinsonism. Physiother Res Int 2005; 10(2):116-121.

(106) Schmitz-Hubsch T, Pyfer D, Kielwein K, Fimmers R, Klockgether T, Wullner U. Qigong exercise for the symptoms of Parkinson's disease: a randomized, controlled pilot study. Mov Disord 2006; 21(4):543-548.

(107) Paterson C, Allen JA, Browning M, Barlow G, Ewings P. A pilot study of therapeutic massage for people with Parkinson's disease: the added value of user involvement. Complement Ther Clin Pract 2005; 11(3):161-171.

(108) Eng ML, Lyons KE, Greene MS, Pahwa R. Open-label trial regarding the use of acupuncture and yin tui na in Parkinson's disease outpatients: a pilot study on efficacy, tolerability, and quality of life. J Altern Complement Med 2006; 12(4):395-399.

(109) Lee H, Park HJ, Park J, Kim MJ, Hong M, Yang J et al. Acupuncture application for neurological disorders. Neurol Res 2007; 29 Suppl 1:S49-S54.

(110) Shulman LM, Wen X, Weiner WJ, Bateman D, Minagar A, Duncan R et al. Acupuncture therapy for the symptoms of Parkinson's disease. Mov Disord 2002; 17(4):799-802.

(111) Diaz N, Bronstein JM. Parkinson's Disease Research Education and Clinical Centers (PADRECC): background and overview. NeuroRehabilitation 2005; 20(3):153-160.

(112) Munneke M, Keus SH, Nijkrake M, Lim NG, Roos RA, Kwakkel G et al. The ParkNet trial; Implementation of an Evidence Based guideline for Physical Therapy in Parkinson's Disease. Mov Disorders 2006; 20:pl40 (abstract).

(113) Ouwens M, Wollersheim H, Hermens R, Hulscher M, Grol R. Integrated care programmes for chronically ill patients: a review of systematic reviews. Int J Qual Health Care 2005; 17(2):141-146.

(114) Cheng EM, Siderowf A, Swarztrauber K, Eisa M, Lee M, Vickrey BG. Development of quality of care indicators for Parkinson's disease. Mov Disord 2004; 19(2):136-150.

(115) Nijkrake MJ, Keus SH, Kalf JG, Sturkenboom IH, Munneke M, Kappelle AC et al. Allied health care interventions and complementary therapies in Parkinson's disease. Parkinsonism Relat Disord 2007; 13 Suppl 3:S488-S494.

(116) Keus SH, Bloem BR, van Hilten JJ, Ashburn A, Munneke M. Effectiveness of physiotherapy in Parkinson's disease: the feasibility of a randomised controlled trial. Parkinsonism Relat Disord 2007; 13(2):115-121.

(117) Clarke CE, Zobkiw RM, Gullaksen E. Quality of life and care in Parkinson's disease. Br J Clin Pract 1995; 49(6):288-293.

(118) Jaardocument Canisius-Wilhelmina Ziekenhuis (CWZ) 2006. (www cwz nl) 2006;5-139.

(119) Gelb DJ, Oliver E, Gilman S. Diagnostic criteria for Parkinson disease. Arch Neurol 1999; 56(1):33-39.

(120) Hoehn MM, Yahr MD. Parkinsonism: onset, progression and mortality. Neurology 1967; 17(5):427-442.

(121) Deane KH, Whurr R, Playford ED, Ben-Shlomo Y, Clarke CE. A comparison of speech and language therapy techniques for dysarthria in Parkinson's disease. Cochrane Database Syst Rev 2001;(2):CD002814.

(122) Mutch WJ, Strudwick A, Roy SK, Downie AW Parkinson's disease: disability, review, and management. Br Med J (Clin Res Ed) 1986; 293(6548):675-677.

(123) Munneke M, Keus SHJ, Nijkrake MJ, Kwakkel G, Berendse HW, Roos RAC et al. Efficiency of evidence-based physiotherapy for Parkinson's disease: the ParkinsonNet Trial. Mov Disord 2008; 23(S1):S220.

(124) Verhoef J, Oosterveld FG, Hoekman R, Munneke M, Boonman DC, Bakker M et al. A system of networks and continuing education for physical therapists in rheumatology: a feasibility study. Int J Integr Care 2004; 4:e19.

(125) Nijkrake MJ, Keus SH, Oostendorp RA, Overeem S, Mulleners W, Bloem BR et al. Allied health care in Parkinson's disease: referral, consultation, and professional expertise. Mov Disord 2009; 24(2):282-286.

(126) Perera R, Heneghan C, Yudkin P. Graphical method for depicting randomised trials of complex interventions. BMJ 2007; 334(7585):127-129.

(127) Nijkrake MJ, Keus SH, Ewalds H, Overeem S, Braspenning JC, Oostendorp RA et al. Quality indicators for physiotherapy in Parkinson's disease. Eur J Phys Rehabil Med 2009; 45(2):239-245.

(128) Campbell SM, Braspenning J, Hutchinson A, Marshall MN. Research methods used in developing and applying quality indicators in primary care. BMJ 2003; 326(7393):816-819.

(129) Birkmeyer JD, Stukel TA, Siewers AE, Goodney PP, Wennberg DE, Lucas FL. Surgeon volume and operative mortality in the United States. N Engl J Med 2003; 349(22):2117-2127.

(130) Chowdhury MM, Dagash H, Pierro A. A systematic review of the impact of volume of surgery and specialization on patient outcome. Br J Surg 2007; 94(2):145-161.

(131) Davoli M, Amato L, Minozzi S, Bargagli AM, Vecchi S, Perucci CA. [Volume and health outcomes: an overview of systematic reviews]. Epidemiol Prev 2005; 29(3-4 Suppl):3-63.

(132) Francke AL, Smit MC, de Veer AJ, Mistiaen P. Factors influencing the implementation of clinical guidelines for health care professionals: a systematic meta-review. BMC Med Inform Decis Mak 2008; 8:38.

(133) Grol R, Rooijackers-Lemmers N, van KL, Wollersheim H, Mokkink H. Communication at the interface: do better referral letters produce better consultant replies? Br J Gen Pract 2003; 53(488):217-219.

(134) Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 2008; 337:a1655.

(135) Keus SH, Nijkrake MJ, Borm GF, Kwakkel G, Roos RA, Berendse HW et al. The ParkinsonNet trial: design and baseline characteristics. Mov Disord 2010; 25(7):830-837.

(136) Keus SHJ, Hendriks HJM, Bloem BR, Bredero-Cohen A.B., de Goede CJT, van Haaren M et al. KNGF-richtlijn Ziekte van Parkinson (Dutch guideline for physiotherapy in Parkinson's disease). 2004; 114 (suppl) (www.kngf.nl).

(137) van der Wees PJ, Jamtvedt G, Rebbeck T, de Bie RA, Dekker J, Hendriks EJ. Multifaceted strategies may increase implementation of physiotherapy clinical guidelines: a systematic review. Aust J Physiother 2008; 54(4):233-241.

(138) Wollersheim H, Hermens R, Hulscher M, Braspenning J, Ouwens M, Schouten J et al. Clinical indicators: development and applications. Neth J Med 2007; 65(1):15-22.

(139) Comella CL, Stebbins GT, Brown-Toms N, Goetz CG. Physical therapy and Parkinson's disease: a controlled clinical trial. Neurology 1994; 44(3 Pt 1):376-378.

(140) Dam M, Tonin P, Casson S, Bracco F, Piron L, Pizzolato G et al. Effects of conventional and sensory-enhanced physiotherapy on disability of Parkinson's disease patients. Adv Neurol 1996; 69:551-555.

(141) Oostendorp RAB, Pluimers DJ, Nijhuis-van der Sanden MWG, Wensing M. Fysiotherapeutische verslaglegging: de Achilleshiel voor Evidence-based Practice (ebp)? NederlandsTijdschrift voor Fysiotherapie 2006; 116(3):56-61.

(142) Rochester L, Hetherington V, Jones D, Nieuwboer A, Willems AM, Kwakkel G et al. The effect of external rhythmic cues (auditory and visual) on walking during a functional task in homes of people with Parkinson's disease. Arch Phys Med Rehabil 2005; 86(5):999-1006.

(143) Rochester L, Nieuwboer A, Baker K, Hetherington V, Willems AM, Chavret F et al. The attentional cost of external rhythmical cues and their impact on gait in Parkinson's disease: effect of cue modality and task complexity. J Neural Transm 2007; 114(10):1243-1248.

(144) Bekkering GE, Hendriks HJ, van Tulder MW, Knol DL, Hoeijenbos M, Oostendorp RA et al. Effect on the process of care of an active strategy to implement clinical guidelines on physiotherapy for low back pain: a cluster randomised controlled trial. Qual Saf Health Care 2005; 14(2):107-112.

(145) Rebbeck T, Maher CG, Refshauge KM. Evaluating two implementation strategies for whiplash guidelines in physiotherapy: a cluster randomised trial. Aust J Physiother 2006; 52(3):165-174.

(146) van der Wees PJ, Hendriks EJ, Jansen MJ, van BH, de Bie RA, Dekker J. Adherence to physiotherapy clinical guideline acute ankle injury and determinants of adherence: a cohort study. BMC Musculoskelet Disord 2007; 8:45.

(147) Munneke M, Keus SHJ, Nijkrake MJ, Kwakkel G, Berendse HW, Roos R et al. ParkNet: A multifaceted strategy to implement practice guidelines for physiotherapy in Parkinson's disease. Mov Disord 2007; 13(Suppl. 2):S181.

(148) Rubinstein TC, Giladi N, Hausdorff JM. The power of cueing to circumvent dopamine deficits: a review of physical therapy treatment of gait disturbances in Parkinson's disease. Mov Disord 2002; 17(6):1148-1160.

(149) van Wegen EEH, Lim I, de GC, Nieuwboer A, Willems A, Jones D et al. The effects of visual rhythms and optic flow on stride patterns of patients with Parkinson's disease. Parkinsonism Relat Disord 2006; 12(1):21-27.

(150) Kwakkel G, de Goede CJ, van Wegen EEH. Impact of physical therapy for Parkinson's disease: A critical review of literature. Parkinsonism Relat Disord 2007; 13(S3):S478-S487.

(151) Peto V, Jenkinson C, Fitzpatrick R. PDQ-39: a review of the development, validation and application of a Parkinson's disease quality of life questionnaire and its associated measures. J Neurol 1998; 245 Suppl 1:S10-S14.

(152) Siderowf A, McDermott M, Kieburtz K, Blindauer K, Plumb S, Shoulson I. Test-retest reliability of the unified Parkinson's disease rating scale in patients with early Parkinson's disease: results from a multicenter clinical trial. Mov Disord 2002; 17(4):758-763.

(153) Qutubuddin AA, Pegg PO, Cifu DX, Brown R, McNamee S, Carne W Validating the Berg Balance Scale for patients with Parkinson's disease: a key to rehabilitation evaluation. Arch Phys Med Rehabil 2005; 86(4):789-792.

(154) Kegelmeyer DA, Kloos AD, Thomas KM, Kostyk SK. Reliability and validity of the Tinetti Mobility Test for individuals with Parkinson disease. Phys Ther 2007; 87(10):1369-1378.

(155) Okuma Y, Yanagisawa N. The clinical spectrum of freezing of gait in Parkinson's disease. Mov Disord 2008; 23 Suppl 2:S426-S430.

(156) Bekkering GE, Hendriks HJM, Koes BW, Oostendorp RAB, Ostelo RWJG, Thomassen J et al. KNGF-richtlijn Lage-rugpijn (Dutch guideline for physiotherapy in Low Back Pain). 2005; 115 (suppl) (www.kngf.nl).

(157) Beurskens AJ, de Vet HC, Koke AJ, Lindeman E, van der Heijden GJ, Regtop W et al. A patient-specific approach for measuring functional status in low back pain. J Manipulative Physiol Ther 1999; 22(3):144-148.

(158) Jolles BM, Buchbinder R, Beaton DE. A study compared nine patient-specific indices for musculoskeletal disorders. J Clin Epidemiol 2005; 58(8):791-801.

(159) Feinstein AR, Cicchetti DV High agreement but low kappa: I. The problems of two paradoxes. J Clin Epidemiol 1990; 43(6):543-549.

(160) Shulman LM, Pretzer-Aboff I, Anderson KE, Stevenson R, Vaughan CG, Gruber-Baldini AL et al. Subjective report versus objective measurement of activities of daily living in Parkinson's disease. Mov Disord 2006; 21(6):794-799.

(161) Tully M, Cantrill J. The test-retest reliability of the modified Patient Generated Index. J Health Serv Res Policy 2002; 7(2):81-89.

(162) Wright JG, Young NL, Waddell JP. The reliability and validity of the self-reported patient-specific index for total hip arthroplasty. J Bone Joint Surg Am 2000; 82(6):829-837.

(163) Frost MH, Reeve BB, Liepa AM, Stauffer JW, Hays RD. What is sufficient evidence for the reliability and validity of patient-reported outcome measures? Value Health 2007; 10 Suppl 2:S94-S105.

(164) Goodwin VA, Richards SH, Taylor RS, Taylor AH, Campbell JL. The effectiveness of exercise interventions for people with Parkinson's disease: a systematic review and meta-analysis. Mov Disord 2008; 23(5):631-640.

(165) Campbell MK, Elbourne DR, Altman DG. CONSORT statement: extension to cluster randomised trials. BMJ 2004; 328(7441):702-708.

(166) Beattie P, Turner C, Dowda M, Michener L, Nelson R. The MedRisk Instrument for Measuring Patient Satisfaction With Physical Therapy Care: a psychometric analysis. J Orthop Sports Phys Ther 2005; 35(1):24-32.

(167) Nijkrake MJ, Keus SH, Quist-Anholtsg WLQ, Overeem S, De Roode MH, Lindeboom R et al. Evaluation of a Patient-Specific Index as an outcome measure for physiotherapy in Parkinson's disease. Eur J Phys Rehabil Med 2009; 45(4):507-512.

(168) Verhoeven AC, Boers M, van der LS. Validity of the MACTAR questionnaire as a functional index in a rheumatoid arthritis clinical trial. The McMaster Toronto Arthritis. J Rheumatol 2000; 27(12):2801-2809.

(169) Keus SH, Nieuwboer A, Bloem BR, Borm GF, Munneke M. Clinimetric analyses of the Modified Parkinson Activity Scale. Parkinsonism Relat Disord 2009; 15(4):263-269.

(170) Drummond M, Weatherly H, Ferguson B. Economic evaluation of health interventions. BMJ 2008; 337:a1204.

(171) Esselink RA, de Bie RM, de Haan RJ, Lenders MW, Nijssen PC, Staal MJ et al. Unilateral pallidotomy versus bilateral subthalamic nucleus stimulation in PD: a randomized trial. Neurology 2004; 62(2):201-207.

(172) de Goede CJ, Keus SH, Kwakkel G, Wagenaar RC. The effects of physical therapy in Parkinson's disease: a research synthesis. Arch Phys Med Rehabil 2001; 82(4):509-515.

(173) Donders A, van der Heijden G, Stijnen T, Moons K. A gentle introduction to imputation of missing values. Journal of Clinical Epidemiology 2009; 59:1087-1091.

(174) Oostenbrink JB, Bouwmans CAM, Koopmanschap MA, Rutten FFH. Manual for costing research (in Dutch). Amstelveen, the Netherlands: Health Care Insurance Board; 2004.

(175) Brouwer WB, Koopmanschap MA. The friction-cost method : replacement for nothing and leisure for free? Pharmacoeconomics 2005; 23(2):105-111.

(176) Gold MR, Siegel JE, Russel LB, Weinstein MC. Cost-Effectiveness in Health and Medicine. New York: Oxford University press; 1996.

(177) Schrag A, Jahanshahi M, Quinn N. How does Parkinson's disease affect quality of life? A comparison with quality of life in the general population. Mov Disord 2000; 15(6):1112-1118.

(178) Parkinson's Disease Society(PDS). Life with Parkinson's today - room for improvement: results of the UK's largest ever survey of people with Parkinson's and carers. (www parkinsons org uk) [2008 :[1-40]

(179) Hughes AJ, Daniel SE, Kilford L, Lees AJ. Accuracy of clinical diagnosis of idiopathic Parkinson's disease: a clinico-pathological study of 100 cases. J Neurol Neurosurg Psychiatry 1992; 55(3):181-184.

(180) Visser M, Marinus J, van Hilten JJ, Schipper RG, Stiggelbout AM. Assessing comorbidity in patients with Parkinson's disease. Mov Disord 2004; 19(7):824-828.

(181) Miller MD, Paradis CF, Houck PR, Mazumdar S, Stack JA, Rifai AH et al. Rating chronic medical illness burden in geropsychiatric practice and research: application of the Cumulative Illness Rating Scale. Psychiatry Res 1992; 41(3):237-248.

(182) Cohen J. A power primer. Psychol Bull 1992; 112(1):155-159.

(183) Lipsey MW Design sensitivity:statistical power for experimental research. London: Sage Publications; 1990.

(184) Almeida QJ, Wishart LR, Lee TD. Bimanual coordination deficits with Parkinson's disease: the influence of movement speed and external cueing. Mov Disord 2002; 17(1):30-37.

(185) Dibble LE, Nicholson DE, Shultz B, MacWilliams BA, Marcus RL, Moncur C. Sensory cueing effects on maximal speed gait initiation in persons with Parkinson's disease and healthy elders. Gait Posture 2004; 19(3):215-225.

(186) Renders CM, Valk GD, Griffin S, Wagner EH, Eijk JT, Assendelft WJ. Interventions to improve the management of diabetes mellitus in primary care, outpatient and community settings. Cochrane Database Syst Rev 2001;(1):CD001481.

(187) Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the Chronic Care Model in the new millennium. Health Aff (Millwood) 2009; 28(1):75-85.

(188) Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D et al. Framework for design and evaluation of complex interventions to improve health. BMJ 2000; 321(7262):694-696.

(189) Grol R, Wensing M, Eccles M. Improving Patient Care:The Implementation of Change in Clinical Practice. London: Elsevier, 2004.

(190) Dixon L, Duncan D, Johnson P, Kirkby L, O'Connell H, Taylor H et al. Occupational therapy for patients with Parkinson's disease. Cochrane Database Syst Rev 2007;(3):CD002813.

(191) Dibble LE, Hale TF, Marcus RL, Droge J, Gerber JP, LaStayo PC. High-intensity resistance training amplifies muscle hypertrophy and functional gains in persons with Parkinson's disease. Mov Disord 2006; 21(9):1444-1452.

(192) Fisher BE, Wu AD, Salem GJ, Song J, Lin CH, Yip J et al. The effect of exercise training in improving motor performance and corticomotor excitability in people with early Parkinson's disease. Arch Phys Med Rehabil 2008; 89(7):1221-1229.

(193) Kurtais Y, Kutlay S, Tur BS, Gok H, Akbostanci C. Does treadmill training improve lower-extremity tasks in Parkinson disease? A randomized controlled trial. Clin J Sport Med 2008; 18(3):289-291.

(194) Schulz KF, Altman DG, Moher D. CONSORT 2010 statement: updated guidelines for reporting parallel group randomised trials. BMJ 2010; 340:c332.

(195) Grimshaw JM, Thomas RE, MacLennan G, Fraser C, Ramsay CR, Vale L et al. Effectiveness and efficiency of guideline dissemination and implementation strategies. Health Technol Assess 2004; 8(6):iii-72.

(196) Kalf JG, van Doornspeek M, Gesthuysen A, Niessen S, Munneke M. Procesindicatoren voor logopedie bij de ziekte van Parkinson. Logopedie en foniatrie 2010;(3):92-97.

(197) Deane KH, Jones D, Ellis-Hill C, Clarke CE, Playford ED, Ben-Shlomo Y A comparison of physiotherapy techniques for patients with Parkinson's disease. Cochrane Database Syst Rev 2001;(1):CD002815.

(198) Deane KH, Jones D, Playford ED, Ben-Shlomo Y, Clarke CE. Physiotherapy for patients with Parkinson's Disease: a comparison of techniques. Cochrane Database Syst Rev 2001;(3):CD002817.

(199) Nijkrake MJ, Keus SH, Bloem BR, Munneke M. Betere organisatie van oefentherapeutische zorg bij de ziekte van Parkinson bespaart miljoenen. Beweegreden 2010; Jaargang 6(Uitgave 2):8-11.

(200) Tent M. Hogere zorgkwaliteit en lagere kosten dankzij ParkinsonNet. De Neuroloog 2010; 1:10-11.

(201) Chodosh J, Morton SC, Mojica W, Maglione M, Suttorp MJ, Hilton L et al. Meta-analysis: chronic disease self-management programs for older adults. Ann Intern Med 2005; 143(6):427-438.

(202) van der Eijk M, Munneke M, Faber M, Bloem BR. Moving towards patient-centered healthcare for patients with Parkinson's disease. Mov Disord 2010; Suplement to volume 25(7):S423.

(203) Fleuren M, Wiefferink K, Paulussen T. Determinants of innovation within health care organizations: literature review and Delphi study. Int J Qual Health Care 2004; 16(2):107-123.

(204) Nikkanen T, Timonen M, Ylitalo K, Timonen O, Keinanen-Kiukaanniemi S, Rajala U. Quality of diabetes care among patients managed by teleconsultation. J Telemed Telecare 2008; 14(6):295-299.

(205) Orfaly RA, Frances JC, Campbell P, Whittemore B, Joly B, Koh H. Train-the-trainer as an educational model in public health preparedness. J Public Health Manag Pract 2005; Suppl:S123-S127.

(206) ZonMw. Kostenbesparende projecten: Quickscan van ZonMw programma's. (www zonmw nl) 2009;10.

Nederlandse samenvatting

Algemene introductie en doel van het proefschrift

Een groot aantal patiënten met de ziekte van Parkinson maakt gebruik van paramedische zorg in de vorm van fysiotherapie, ergotherapie en logopedie om de uitvoering van dagelijks activiteiten te verbeteren. Het is echter de vraag of de juiste patiënten worden doorverwezen en of paramedici over voldoende kennis en vaardigheden beschikken om patiënten met de ziekte van Parkinson optimaal te kunnen behandelen. In dit proefschrift wordt onderzoek beschreven dat opgezet is om de paramedische zorg bij de ziekte van Parkinson (in het bijzonder fysiotherapie) te verbeteren. Hierbij is gebruik gemaakt van een stappenplan (panel 1).

Panel 1. Stappenplan voor verbetering van paramedische zorg bij de ziekte van Parkinson

Stap 1. In kaart brengen van effectieve paramedische behandelvormen
Stap 2. In kaart brengen van knelpunten binnen de huidige paramedische zorg
Stap 3. Ontwikkeling en implementatie op kleine schaal van een zorgvernieuwing op maat
Stap 4. Ontwikkeling van meetinstrumenten die de effecten van de zorgvernieuwing meten
Stap 5. Uitvoering van een gerandomiseerde en gecontroleerde effectiviteitstudie
Stap 6. Implementatie en disseminatie van de zorgvernieuwing op grote schaal

Stap 1. In kaart brengen van effectieve paramedische behandelvormen

Om de effectiviteit van paramedische zorg te bepalen is een systematisch literatuuronderzoek uitgevoerd (hoofdstuk 1). De gevonden wetenschappelijke bevindingen zijn vertaald naar aanbevelingen voor de praktijk. De studie laat zien dat patiënten met de ziekte van Parkinson baat hebben bij: fysiotherapie om het lopen, de balans, conditie en transfers te verbeteren en bij logopedie om het spreken te verbeteren. Bij zowel de fysiotherapeutische als logopedische behandeling wordt gebruik gemaakt van motorische compensatie strategieën. De meerwaarde van ergotherapie bij de ziekte van Parkinson is nog nauwelijks onderzocht. Meer onderzoek naar ergotherapie, maar ook naar logopedie en fysiotherapie is nodig. Hierbij is het belangrijk dat de methodologische kwaliteit van studies verbeterd wordt.

Stap 2. In kaart brengen van knelpunten binnen de huidige paramedische zorg

Door middel van een enquête onder patiënten en zorgverleners is onderzocht of er knelpunten zijn in de toepassing van paramedische behandeltechnieken. Deze knelpuntenanalyse wordt beschreven in hoofdstuk 2. Aan patiënten met de ziekte van Parkinson en een indicatie voor paramedische zorg is gevraagd of men ook daadwerkelijk behandeld werd door een paramedicus. Daarnaast zijn paramedici gevraagd of zij over voldoende kennis op het gebied van de ziekte van Parkinson beschikken en of ze op de hoogte zijn van de behandelmogelijkheden en onmogelijkheden van andere betrokken zorgverleners. Uit de vragenlijst van patiënten bleek dat het merendeel van de patiënten met een indicatie voor paramedische zorg niet verwezen was. Uit de vragenlijst voor paramedici

bleek dat het merendeel van de paramedici onvoldoende kennis had van de ziekte van Parkinson en dat men niet op de hoogte was van de behandelmogelijkheden van andere zorgverleners die vaak betrokken zijn bij de behandeling van patiënten met de ziekte van Parkinson. Een van de oorzaken van het gebrek aan kennis bij paramedici was dat paramedici maar relatief weinig patiënten met de ziekte van Parkinson behandelden (gemiddeld slechts drie per jaar).

Stap 3. Ontwikkeling en toepassing van de zorgvernieuwing ParkinsonNet
Om een oplossing te vinden voor het gebrek aan specifieke deskundigheid van zorgverleners, beperkte communicatie tussen zorgverleners die betrokken zijn bij de zorg voor Parkinson en het beperkte volume aan Parkinson patiënten bij veel zorgverleners, is het zorgconcept 'ParkinsonNet' ontwikkeld. ParkinsonNet staat voor een regionaal netwerk van zorgverleners. In dit netwerk verwijzen neurologen en parkinsonverpleegkundigen hun patiënten met de ziekte van Parkinson gericht naar een select aantal getrainde paramedici in de regio. Dit concept werd in eerste instantie geïmplementeerd in de regio Nijmegen waarbij neurologen en parkinsonverpleegkundigen gestandaardiseerde verwijsformulieren kregen met de juiste criteria om goed te kunnen verwijzen naar paramedici. Daarnaast werd een selecte groep paramedici uit de regio toegelaten tot het netwerk en getraind in de toepassing van effectieve behandeltechnieken zoals beschreven in hoofdstuk 2. Het bleek dat de deskundigheid met betrekking tot de ziekte van Parkinson onder deelnemende fysiotherapeuten vrijwel direct was toegenomen na de basisscholing en dat deze deskundigheid niet afnam naar verloop van tijd. Verder bleek dat ParkinsonNet fysiotherapeuten in toenemende mate meer patiënten met de ziekte van Parkinson gingen zien door de gerichte verwijzing van neurologen en parkinsonverpleegkundigen. Tot slot waren ParkinsonNet fysiotherapeuten erg tevreden over het ParkinsonNet concept.

Stap 4. Ontwikkeling van betrouwbare meetinstrumenten om de impact van ParkinsonNet op de kwaliteit van zorg en de gezondheidstoestand van patiënten met de ziekte van Parkinson te kunnen meten.
De resultaten van het pilotonderzoek naar de waarde van ParkinsonNet beschreven in hoofdstuk 3 zijn veelbelovend, maar om daadwerkelijk de meerwaarde van ParkinsonNet fysiotherapie bij de ziekte van Parkinson patiënten aan te kunnen tonen, is een kwalitatief goede studie gewenst. Ter voorbereiding hierop zijn twee meetinstrumenten ontwikkeld en beoordeeld op enkele klinimetrische eigenschappen (hoofdstuk 4).

De ontwikkeling en evaluatie van kwaliteitsindicatoren als meetinstrument voor de kwaliteit van fysiotherapeutische zorg bij de ziekte van Parkinson.
Het meetinstrument dat beschreven wordt in hoofdstuk 4.1 richt zich op de kwaliteit van fysiotherapeutische zorg bij de ziekte van Parkinson. Kwaliteit van zorg wordt doorgaans gemeten aan de hand van kwaliteitsindicatoren en deze zijn conform standaard criteria ontwikkeld. Aanbevelingen vanuit de richtlijn fysiotherapie zijn omgezet in potentiële indicatoren en beoordeeld door een ex-

pert panel op relevantie voor de kwaliteit van zorg. De meest relevante indicatoren zijn vervolgens vertaald naar een vragenlijst die onder een klein aantal fysiotherapeuten is getest. Na enkele kleine aanpassingen is de vragenlijst met 17 indicatoren voorgelegd aan een grotere groep van 41 ParkinsonNet therapeuten en een groep van 286 algemene fysiotherapeuten. Zes indicatoren werden uitgesloten, omdat deze of een plafond effect lieten zien of onvoldoende discriminerend waren tussen ParkinsonNet en algemene fysiotherapeuten. De interne consistentie van de uiteindelijke vragenlijst met 11 indicatoren was goed. Verder bleek uit een steekproef van 64 fysiotherapeuten dat de antwoorden die fysiotherapeuten gaven in de vragenlijst goed overeenkwamen met de antwoorden die gegeven waren na een gestructureerd interview Uiteindelijk leverde deze studie een meetinstrument in de vorm van een vragenlijst met 11 relevante, discriminerende en betrouwbare kwaliteitsindicatoren op voor fysiotherapeutische zorg bij de ziekte van Parkinson.

De ontwikkeling en evaluatie van een patiënt specifieke vragenlijst als meetinstrument voor de gezondheidstoestand van patiënten met de ziekte van Parkinson.
Het meetinstrument dat beschreven wordt in hoofdstuk 4.2 richt zich op het kunnen meten van gezondheidswinst als gevolg van fysiotherapie bij patiënten met de ziekte van Parkinson. Hiervoor is een patiënt specifieke vragenlijst ontwikkeld. Deze vragenlijst biedt patiënten met de ziekte van Parkinson de kans om uit een vooraf gedefinieerde lijst van 26 activiteiten (verdeeld over de vijf domeinen uit de fysiotherapie richtlijn) de meest problematische activiteiten aan te vinken. Daarnaast hebben patiënten de mogelijkheid om een activiteit naar eigen keuze toe te voegen. Na het selecteren van problemen kiezen patiënten een top drie met de voor hen meest belangrijke activiteiten die ze graag met fysiotherapie verbeterd zouden willen zien. Tot slot geven patiënten voor de top 3 per activiteit aan in welke mate ze moeite ondervinden bij de uitvoering van deze activiteiten. Dit gebeurt door middel van een numerieke schaal (0-10). De vragenlijst is twee keer voorgelegd aan 81 patiënten met de ziekte van Parkinson. Patiënten bleken de meeste problemen te ervaren in de domeinen lopen, transfers en arm-handvaardigheid. De overeenkomst van de gegeven antwoorden tussen de eerste en tweede vragenlijst was redelijk tot goed en varieerde van 71 tot 94% voor de geselecteerde problemen en van 74 tot 82% voor de geprioriteerde domeinen. Een groep van 69 patiënten werd telefonisch gevraagd naar hun meest problematische activiteiten en de antwoorden kwamen goed overeen (96%) met die van de vragenlijst. Verder gaf 93% van de patiënten aan dat de vragenlijst relevante activiteiten bevatte. Uiteindelijk leverde deze studie een meetinstrument voor gezondheidswinst als gevolg van fysiotherapie bij de ziekte van Parkinson op in de vorm van een patiënt specifieke vragenlijst met 26 relevante en betrouwbare activiteiten. Aangezien patiënten wel problemen hadden met het juist formuleren van geprioriteerde problemen is het aan te bevelen de vragenlijst in de vorm van een interview af te nemen in plaats van zelfstandig te laten invullen door de patiënt.

Stap 5. Wetenschappelijke studie naar de doelmatigheid van het ParkinsonNet concept.
ParkinsonNet heeft de potentie om paramedische zorg voor de Ziekte van Parkinson te verbeteren (hoofdstuk 3) en met de beschikbaarheid over betrouwbare meetinstrumenten (hoofdstuk 4.1 en 4.2) wordt het mogelijk de meerwaarde van ParkinsonNet te evalueren binnen een gerandomiseerde en gecontroleerde studie. In hoofdstuk 5.1 wordt de opzet van deze studie besproken voor de fysiotherapie component van ParkinsonNet en in hoofdstuk 5.2 worden de resultaten weergegeven.

Stap 6. Implementatie en disseminatie van ParkinsonNet
De ParkinsonNet studie beschreven in hoofdstuk 5 laat zien dat ParkinsonNet tot een miljoenen besparing kan leiden indien de resultaten uit hoofdstuk 5 vertaald worden naar de totale populatie patiënten met de ziekte van Parkinson in Nederland. Daarom is besloten om snel over te gaan tot het uitbreiden van het aantal ParkinsonNet netwerken in Nederland. Momenteel zijn er 65 ParkinsonNet netwerken en is landelijke dekking bereikt (panel 2). Hierbij zijn naast fysiotherapeuten en neurologen ook ergotherapeuten, logopedisten en parkinsonverpleegkundigen aangesloten.

Begin 2011 zullen ook alle ParkinsonNet netwerken voorzien zijn van psychosociale zorgverleners en diëtisten. De meerwaarde van de multidisciplinaire component van ParkinsonNet wordt momenteel onderzocht binnen een wetenschappelijke studie. Patiënten hebben zelf nog geen actieve rol binnen ParkinsonNet. Dit is wel gewenst en de mogelijkheden hiertoe worden momenteel in kaart gebracht. De vertaling van het ParkinsonNet concept naar andere landen of aandoeningen dient goed overwogen te worden. Het valt hierbij aan te bevelen het stappenplan uit panel 1 te doorlopen. Hierdoor ontstaat er een concept op maat wat de kans op slagen zal verhogen.

Panel 2 Overzicht van de ParkinsonNet netwerken in Nederland.

Momenteel zijn er 65 ParkinsonNet netwerken waaraan 748 fysiotherapeuten, 289 logopedisten, 265 ergotherapeuten, 82 diëtisten en 54 psychosociale zorgverleners deelnemen.

1. Steenwijk
2. Friesland
3. Groningen
4. Drenthe
5. Noord-Oostpolder
6. Zwolle
7. Hardenberg - Ommen
8. Twente
9. Deventer
10. Harderwijk
11. Lelystad
12. Noord-Holland Noord
13. Alkmaar
14. Hoorn
15. Purmerend
16. Zaanstad
17. Beverwijk
18. Haarlem
19. Amsterdam West
20. Haarlemmermeer
21. Amsterdam Centrum-Oost-Zuid Oost
22. Amsterdam Zuid
23. 't Gooi
24. Almere
25. Utrecht Stad
26. Utrecht Zuid-Oost
27. Bemland
28. Ede-Wageningen-Veenendaal
29. Apeldoorn
30. Arnhem
31. Zutphen
32. Doetinchem
33. Arnhem
34. Nijmegen-Boxmeer
35. Tiel
36. Utrecht Zuid-West
37. Woerden
38. Leiden
39. Den Haag
40. Zoetermeer
41. Delft
42. Schiedam
43. Rotterdam Noord
44. Rotterdam Zuid
45. Drechtsteden
46. Gorinchem
47. Waalwijk
48. Oss-Uden-Veghel
49. Helmond-Geldrop
50. Venlo
51. Weert
52. Roermond
53. Sittard-Geleen
54. Heerlen-Kerkrade
55. Maastricht
56. Eindhoven
57. Tilburg
58. Breda
59. Roosendaal
60. Bergen op Zoom
61. Zeeland-Noord
62. Zuid-Hollandse Eilanden
63. Zeeuws Vlaanderen
64. Gouda
65. Amsterdam-Noord

De ' Parkinson Zorgzoeker' is een zoekmachine op de website www.parkinsonnet.nl waarmee de dichtstbijzijnde ParkinsonNet zorgverleners opgezocht kan worden.

List of publications:

Nijkrake MJ, Keus SH, Kalf JG, Sturkenboom IH, Munneke M, Kappelle AC, Bloem BR: Allied health care interventions and complementary therapies in Parkinson's disease. Parkinsonism Relat Disord 2007;13 Suppl 3:S488-S494.

Snijders AH, Nijkrake MJ, Bakker M, Munneke M, Wind C, Bloem BR: Clinimetrics of freezing of gait. Mov Disord 2008;23 Suppl 2:S468-S474.

Keus SH, Munneke M, Nijkrake MJ, Kwakkel G, Bloem BR: Physical therapy in Parkinson's disease: evolution and future challenges. Mov Disord 2009;24:1-14.

Nijkrake MJ, Keus SH, Oostendorp RA, Overeem S, Mulleners W, Bloem BR, Munneke M: Allied health care in Parkinson's disease: referral, consultation, and professional expertise. Mov Disord 2009;24:282-286.

Nijkrake MJ, Keus SH, Ewalds H, Overeem S, Braspenning JC, Oostendorp RA, Hendriks EJ, Bloem BR, Munneke M: Quality indicators for physiotherapy in Parkinson's disease. Eur J Phys Rehabil Med 2009;45:239-245.

Nijkrake MJ, Keus SH, Quist-Anholts GW, Overeem S, De Roode MH, Lindeboom R, Mulleners W, Bloem BR, Munneke M: Evaluation of a Patient-Specific Index as an outcome measure for physiotherapy in Parkinson's disease. Eur J Phys Rehabil Med 2009;45:507-512.

van der Marck MA, Kalf JG, Sturkenboom IH, Nijkrake MJ, Munneke M, Bloem BR: Multidisciplinary care for patients with Parkinson's disease. Parkinsonism Relat Disord 2009;15 Suppl 3:S219-S223.

Nijkrake MJ, Keus SH, Overeem S, Oostendorp RA, Vlieland TP, Mulleners W, Hoogerwaard EM, Bloem BR, Munneke M: The ParkinsonNet concept: development, implementation and initial experience. Mov Disord 2010;25:823-829.

Keus SH, Nijkrake MJ, Borm GF, Kwakkel G, Roos RA, Berendse HW, Adang EM, Overeem S, Bloem BR, Munneke M: The ParkinsonNet trial: design and baseline characteristics. Mov Disord 2010;25:830-837.

Munneke M, Nijkrake MJ, Keus SH, Kwakkel G, Berendse HW, Roos RA, Borm GF, Adang EM, Overeem S, Bloem BR: Efficacy of community-based physiotherapy networks for patients with Parkinson's disease: a cluster-randomised trial. Lancet Neurol 2010;9:46-54.

Curriculum Vitae

Maarten J. Nijkrake was born in Hengelo (O), the Netherlands, on the 7th of February 1978. He finished secondary education at the Twickel College in Hengelo in 1995. That same year he started studying physiotherapy at the Hogeschool Enschede, the Netherlands. After graduation in 1999, he started working as a physiotherapist in a primary care practice in Rees, Germany. During 2000, he decided to start studying Biomedical Sciences (major in Human Movement Sciences) at the Radboud University Nijmegen in the Netherlands. After graduation in 2003, he first started to work as a physiotherapist at the Department of Physiotherapy at Radboud University Nijmegen Medical Centre (RUNMC). One year later, he gained a research position for physiotherapy in Parkinson's disease at the Department of Neurology (RUNMC) and there he carried out most of the work described in the thesis. Currently, he is the national coordinator for the physiotherapy component of ParkinsonNet and still works as a physiotherapist for the Department of Rehabilitation and Parkinson Centre Nijmegen (ParC). Maarten Nijkrake lives together with Liza Hubers in Nijmegen.

Dankwoord

Dit proefschrift kenmerkt zich door relatief lange dankwoorden (acknowledgements) bij de verschillende hoofdstukken. Het laat zien dat veel mensen een bijdrage hebben geleverd aan de totstandkoming van dit proefschrift. Naast alle deelnemende patiënten en zorgverleners ben ik deze mensen dan ook ontzettend dankbaar voor hun inspanningen. Graag wil ik hieronder nog een aantal personen in het bijzonder bedanken.

Bas Bloem en Marten Munneke, respectievelijk promotor en copromotor. Bij jullie is 1+1 > 2, al noemen jullie dat tegenwoordig zelf heel bescheiden '2.0'. Zorg kan bij jullie altijd beter, ideeën zijn meer dan welkom, en "laten we het vooral samen met een enthousiast team doen!" Jullie hebben mij gevormd als zorgverlener, onderzoeker maar ook als mens. Dank daarvoor!

Sebastiaan Overeem, mijn andere copromotor. Super onderzoeker: gedreven, kritisch, scherp en een virtuoos als het gaat om het schrijven van artikelen. Bedankt voor je constructieve en snelle feedback waardoor bijna alle publicaties in één jaar de deur uit gingen.

Ria Nijhuis-van der Sanden, Berry Kremer en Sander Geurts wil ik bedanken voor de tijd die ze hebben gestoken in het lezen en beoordelen van dit manuscript.

Collega's van de afdeling fysiotherapie. Deskundig, geïnteresseerd in mijn onderzoek, mijn leven, maar vooral ook in smakelijke verhalen over van alles en nog wat. Kortom, ik vind het een fijn en gezellig team om deel van uit te mogen maken. Allan Pieterse, afdelingshoofd, altijd meegedacht in het belang van mijn onderzoek, hopelijk ben jij snel de volgende! Jasper den Boer, fijn dat ik bij jou de kunst heb kunnen afkijken én dat je mijn paranimf wil zijn. Verder is de afdeling tijdens mijn promotietraject 'samengesmolten' met de afdeling revalidatie. Collegae, ook jullie wil ik bedanken voor de prettige samenwerking.

ParkinsonNet trial. Samyra Keus, een enorme klus die we samen tot een goed einde hebben gebracht door prettige samenwerking en een goede taakverdeling. Daarnaast was je een uitstekende reisleider tijdens onze congresbezoeken! De 'zussen' Marloes en Esther van Rossum (UMC St Radboud), Inge Lim en Esther Westerveld (VUmc) en Mireille de Jong (LUMC) van het onderzoeksteam. Jullie hebben duizend huisbezoeken afgelegd en ruim 3000 meetboekjes verzameld, dank daarvoor! Inge Boers, bedankt voor de invoer van data die je uiterst nauwkeurig controleerde. Rianne Esselink, dank voor je snelle en enthousiaste hulp bij het berekenen van de LED´s. Hanna Likumahwa, naast je secretariële ondersteuning was je ook wel de 'moeder' van ons jonge onderzoeksteam en bleek je bovendien een uitstekende chefkok te zijn. Ontzettend veel dank voor je inspanningen.

George Borm, Eddy Adang en Wim Lemmens, dank voor jullie deskundigheid en snelle hulp bij de analyse van de data.

Stagiaires. Alied Fijen, Simone Lanson, Hanneke Ewalds en Leanne Houweling. Allemaal bedankt voor jullie 'significante' bijdrage aan dit proefschrift. Hanneke, erg jammer dat je nét naast de KNGF scriptie prijs greep! Je had hem in mijn ogen (en die van de redacteur van het NTvF) eigenlijk wel verdiend.

ParkinsonNet projectteam. Allereerst dank ik Lars Oude Nijhuis (algemeen coördinator). Door je komst kwam er voor mij tijd vrij om dit manuscript te schrijven. Ik heb volgens mij wel een beetje gelogen over de hoeveelheid tijd die het coördinatorschap met zich meebracht, maar gelukkig heeft onze vriendschap hier niet onder geleden. De afronding van je boekje misschien wel, maar samen promoveren op één dag is ook veel waard! Gelukkig installeerde je snel een secretariaat in de persoon van Seher Ocal en samen met projectmedewerkers Cynthia Hofman, Paulien Verhoef en Robin Smit hebben jullie ParkinsonNet opgeschaald en verder ontwikkeld. Enorm bedankt! Hanneke Kalf en Ingrid Sturkenboom, samen hebben we een multidisciplinaire scholing opgezet en deze ook als zodanig uitgedragen. Ik vond het erg gezellig en een grote eer om met jullie op 'tournee' door heel Nederland te mogen. Fysiotherapie docenten, Yvo Kamsma, Alice Nieuwboer, Erwin van Wegen, Cees de Goede, Inge Lim en Ingrid Burgers. Ik dank jullie voor jullie deskundigheid, collegialiteit en vooral ook improvisatievermogen met betrekking tot de patiëntdemonstraties.

Werkplekken. Monique Schmidt, met jou heb ik de meeste werkplekken gedeeld. Samen werken aan multidisciplinaire zorg, jij was daarbij ParC en ik ParkinsonNet. Je bent een fantastisch mens en hebt altijd aandacht gehad voor alles en iedereen die ook maar een voet zette binnen het ParC. Marjolein van der Marck, jij kwam iets later om feitelijk 'ons' (combinatie ParC en ParkinsonNet) te evalueren. Jij bezit de gave om tegelijkertijd te kletsen en te werken. Je hebt altijd het netste bureau en alles binnen handbereik (nietapparaat, pennen, snoep etc.). Je data is nu bijna binnen en ik kijk al uit naar jouw boekje! Verder dank ik alle andere collega's van de ParC onderzoekerskamer, inclusief Maaike van Sonsbeek en Noortje Bergevoet, voor hun collegialiteit en bereidheid tot medewerking bij drukte rondom de organisatie van scholingen of het jaarsymposium. Ook dank ik de collega's van de onderzoekerskamer neurologie voor het bieden van een rustige schrijfplek en het vergroten van mijn neurologische kennis. Mocht ik ooit nog eens besluiten om arts te worden dan heb ik mijn co-schap neurologie alvast gehad!

ParC Dagcentrum. Alle medewerkers van het ParC Dagcentrum wil ik danken voor de samenwerking en het verrijken van mijn klinische horizon. Het was en is nog steeds een eer om deel te mogen uitmaken van zo'n deskundig team.

Johan Korteland, bedankt voor de fraaie opmaak van dit proefschrift, je snelle handelen en bereidwilligheid.

Mijn vrienden dank ik voor de gezellige in- en ontspanning, vaak in de vorm van fiets- en kroegtochten. Harald, Lars, Robert, Walter, Gerjon, Martijn en Rafael, bedankt voor jullie vriendschap! Harald, fijn dat je ook bij mij paranimf wil zijn.

Hans en Ineke, mijn ouders. Bedankt dat jullie mij altijd gesteund en gestimuleerd hebben in de dingen die ik erg leuk vond. Sander (broer), ik ben blij dat je mij ooit Nijmegen hebt laten zien! Schoonzus Bregje, fijn dat je destijds een goed woordje voor me hebt gedaan op de kijkavond in de van den Brugghenstraat. Het was een leuke tijd daar op de gang! Mijn zus Wieteke, we hebben dezelfde humor en interesse voor voetbal(lers). In de persoon van Sander Blokhuis heb je een prima rechtspoot en tevens reisleider voor de wintersportvakanties binnen gehaald. Hopelijk houden we deze gezellige traditie nog lang in stand en staan ook Marit en Teun over enkele jaren op de ski's!

Annie en Arnold, Sandra en Eric, Luca, Daan, en Marieke en Tommy, jullie als schoonfamilie wil ik bedanken voor de betrokkenheid, interesse en gezelligheid tijdens de afgelopen jaren.

Lieve Liza, bedankt voor je liefde, gezelligheid, betrokkenheid en steun. Ik kijk uit naar de toekomst in ons nieuwe huis!

Dissertations of the Parkinson Centre Nijmegen (ParC)

1. Jasper E. Visser. The basal ganglia and postural control.
   Radboud University Nijmegen, 17 June 2008.

2. Maaike Bakker. Supraspinal control of walking: lessons from motor imagery.
   Radboud University Nijmegen, 27 May 2009.

3. W. Farid Abdo. Parkinsonism: possible solutions to a diagnostic challenge.
   Radboud University Nijmegen, 7 October 2009.

4. Corinne G.C. Horlings. A weak balance: balance and falls in patients with neuromuscular disorders.
   Radboud University Nijmegen, 1 April 2010.

5. Samyra H.J. Keus. Physiotherapy in Parkinson's disease: towards evidence-based practice.
   Leiden University, 29 April 2010.

6. Lars B. Oude Nijhuis. Modulation of human balance reactions.
   Radboud University Nijmegen, 29 November 2010.

7. Maarten J. Nijkrake. Improving the quality of allied health care in Parkinson's disease through community-based networks: the ParkinsonNet health care concept.
   Radboud University Nijmegen, 29 November 2010.