

ANALYSIS

Revolutionising management of chronic disease: the ParkinsonNet approach

Patients with Parkinson's disease need long term support to manage their condition. **Bastiaan Bloem** and **Marten Munneke** describe the benefits of a model of integrated care provided by a network of specialists and suggest it has promise for other long term conditions

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Advances in medical knowledge and technology, escalating healthcare costs, and rising patient expectations and involvement in their care are changing the management of chronic disease. Here, we describe how ParkinsonNet, an innovative regional network introduced in the Netherlands in 2004, has improved the quality of care and reduced the healthcare costs of patients with Parkinson's disease. The scheme uses a select group of trained health professionals linked together through a shared online platform to which patients also have access.

Care of patients with Parkinson's disease

Parkinson's disease is a common and disabling neurodegenerative disorder.¹ A Dutch study of 6969 community residents aged ≥ 55 years showed a prevalence of 1.4%,² and an incidence ranging from 0.3/1000 in people aged 55-65 years to 4.4/1000 for those aged over 85.³ Most patients live with the disease for many years because the risk of death is increased only modestly in the absence of dementia⁴ but the burden of disease on patients and carers is considerable. A survey among US veterans showed that health related quality of life was substantially diminished among patients with Parkinson's disease and that the impact of the disease outweighed that of other chronic disorders such as coronary heart disease, arthritis, diabetes, or stroke.⁵

Before the introduction of ParkinsonNet in the Netherlands in 2004, feedback from focus groups and online patient forums suggested that Dutch patients with Parkinson's disease were dissatisfied with their care.^{6,7} They complained that treatment tended to be exclusively focused on suppression of symptoms with drugs (and sometimes stereotactic neurosurgery) and that referral to other disciplines for other forms of management and support—for example, physiotherapy, occupational therapy, and speech therapy—was arbitrary, and allied health professionals with expertise in Parkinson's disease were hard

to obtain. In addition, patients were concerned that they often received care from health professionals with no specific training or expertise in Parkinson's disease.^{8,9} In a European survey of over 2000 patients, nearly half of respondents indicated that they had not seen a neurologist with additional training in Parkinson's disease during the first two years after diagnosis.¹⁰ Their concern was backed by a questionnaire study showing that physiotherapists, occupational therapists, and speech therapists thought they lacked expertise in dealing with patients with Parkinson's disease.⁹

A further concern was that interdisciplinary collaboration and communication between medical specialists and allied healthcare professionals was inadequate,^{6,9} with evidence that it was better among health professionals who had higher case loads of patients with Parkinson's disease.¹¹ Finally, patients complained that they were not involved enough in decisions about their treatment and insufficient attention was paid to the quality of their lives.^{6,7,10,12,13,14}

The ParkinsonNet model

ParkinsonNet was developed to tackle these problems by standardising and integrating the delivery of care to patients with Parkinson's disease, ensuring that it was evidence based and provided by health professionals with specialist expertise (box). It also aimed to create the infrastructure for clinical trials to obtain further evidence on best management.

ParkinsonNet established regional networks of selected and highly motivated health professionals to whom patients are referred for long term care. Initially we focused on setting up dedicated training for physiotherapists because this is the commonest non-drug treatment recommended for Parkinson's disease,^{8,15} and national guidelines recommend physiotherapy as a mainstay of management. We were aware, however, that

Key components of the ParkinsonNet approach

Guidelines: evidence based recommendations and consensus based statements (www.parkinsonnet.nl/parkinson/behandelrichtlijnen)

- Monodisciplinary—for physiotherapy, speech therapy, occupational therapy, nutrition, and nursing home care
- Multidisciplinary—includes a consensus based model for regional and transmural organisation of multidisciplinary care and is also available in a patient friendly format

Selection

- Inclusion of a restricted number of motivated healthcare providers

Preferred referral

- Patients and physicians funnel referrals towards ParkinsonNet experts to increase their caseload through use of standardised referral forms with referral criteria

Education

- Baseline training of participants in treatment guidelines (4 days)
- Learning on the job: increase experience by treating many patients
- Continuous interaction and information exchange between participants through an annual national conference, regional interdisciplinary meetings (at least twice a year), and participation in web based national and regional communities

Commitment

- Members agree to work according to treatment guidelines

Transparency about quality of services and health outcomes

- Data published in the Parkinson Atlas (www.ParkinsonAtlas.nl)

Patient centred approach

- For example, through use of guidelines for patients, web based communities for patients, personal digital community, and a patient centred questionnaire (PCQ-PD)

Information technology platform:

- Informative website (www.ParkinsonNet.nl)
- Healthcare search engine (www.ParkinsonZorgzoeker.nl)
- Web based communities for patients and professionals (www.MijnParkinsonzorg.nl)
- Electronic health record with decision support
- Telehealth solutions, including video consultations in a safe environment

the evidence base for physiotherapy in Parkinson's disease was incomplete, and more trials were needed to assess its efficacy and cost effectiveness.¹⁶

Networks were later expanded to include neurologists, nursing home physicians, rehabilitation specialists, psychiatrists, psychologists, pharmacists, specialised Parkinson nurses, occupational therapists, speech-language therapists, dieticians, social workers, and sex therapists, all of whom are trained to treat patients with Parkinson's disease and base their management on current guidelines. Through ongoing treatment of large numbers of patients the knowledge and expertise of the dedicated specialised networks grows exponentially.

A second important feature of ParkinsonNet has been the establishment of an information technology platform. This includes a dedicated website (www.ParkinsonNet.nl) with a search engine (www.ParkinsonZorgzoeker.nl) and web based communities for both patients and health professionals where they can talk to each other (www.MijnParkinsonzorg.nl).⁷ In an ongoing feasibility study, we offered 210 patients the opportunity to open a private community that acts as their personal e-health record, and where the patient can enter relevant information. Of these, 179 joined the private community and now give their doctors and other professionals access to it so they can also share and enter information. ParkinsonNet also offers a site with a decision support tool, where patients find important background information, including evidence about effectiveness and complications for the various treatment options in advanced Parkinson's disease, allowing them to participate in making an informed decision. In addition patients are given

the option of having consultations in their own homes through secured video links.

Development and implementation of guidelines

Treatment guidelines for physiotherapists were developed by a national panel of physiotherapists and neurologists with expertise in treating Parkinson patients, and supported by the Dutch Parkinson Patient Foundation and the Royal Dutch Society of Physiotherapy. The guidelines are based on scientific evidence, supplemented with practice based evidence generated by consensus meetings among experts.¹⁷ Other guidelines were then drawn up by similar national expert panels (again supported by the patient foundation and relevant professional organisations) for speech therapists and occupational therapists and to define best care in nursing homes and by nurse specialists (box).

Implementation of regional networks

The first regional network was established in 2004 in the catchment area of the cities of Nijmegen and Arnhem, and initially included 19 physiotherapists, nine occupational therapists, and nine speech-language therapists (selected on the basis of personal motivation, previous expertise, and location out of a total of 5297 allied health professionals working in this area).¹⁷ The experience with this network was positive, showing an increase in Parkinson specific knowledge among participating therapists, a better adherence to the treatment guidelines, and a more than sevenfold increase in annual patient volume for ParkinsonNet therapists compared with control therapists

between 2003 and 2006.¹⁸ ParkinsonNet coverage was gradually extended, achieving nationwide coverage in 2010. There are now 66 regional networks with 2970 trained professionals from a wide range of disciplines for around 50 000 patients (figure 1). The largest groups include physiotherapists (n=1022), occupational therapists (n=392), speech-language therapists (n=379), dieticians (n=156), nursing home physicians (n=129), and specialised Parkinson nurses (n=76). The only professionals not yet part of ParkinsonNet are neurosurgeons and geriatricians; these disciplines are scheduled to be trained later. General practitioners are not planned to be part of ParkinsonNet because they have little direct involvement in Parkinson specific management decisions and therefore do not need to receive specialised training. Nevertheless, they have an important generic role in overseeing comorbidity and polypharmacy, and in referring patients to specialised members of the network. We therefore ensure that GPs know about the existence of ParkinsonNet and the healthcare finder, to structure the referral process.

Making the most of information technology

One of the key aims of ParkinsonNet has been to promote transparency about the quality of care provided to patients and for this to be made publicly available. An example is the Parkinson Atlas, which displays information about a limited set of variables at the level of ParkinsonNet regions such as healthcare costs, numbers of hip fractures, admission rates to hospital or rehabilitation centres, and quality of interdisciplinary collaboration (www.ParkinsonAtlas.nl). A particularly useful tool is the “Parkinson healthcare finder,” a web based search engine that allows both patients and referring physicians to identify ParkinsonNet specialists (www.ParkinsonZorgzoeker.nl).

The online communities allow ParkinsonNet professionals to communicate easily with each other so that they can exchange experiences and update each other about new scientific information. The communities for patients allow them to contribute to the quality of care of fellow patients. For example, patients used a “wiki” (a web application which allows people to add, modify, or delete content in collaboration with others) to create an encyclopaedia of useful information on living with Parkinson’s disease, such as how to handle legal issues related to driving, discussions about how patients perceived their quality of care, and experiences with complementary medicine.

Scientific underpinning

ParkinsonNet has been evaluated in several studies (table 1). As most of these trials were not randomised, their results should be interpreted with caution. However, introduction of a ParkinsonNet network seems to increase referral of patients to members and result in better adherence to treatment guidelines.^{18 19} Although the introduction of ParkinsonNet has not been associated with improved clinical outcomes on assessment scales, the costs of care fell in most studies.^{19 20} Furthermore a large observational study of health insurance claims showed that patients with Parkinson’s disease in ParkinsonNet areas sustained fewer fractures than those in other areas, including a 55% decrease in hip fractures.²⁰ The proportion of day care treatments in rehabilitation centres was also lower in ParkinsonNet regions, which we suspect is an indirect reflection of the improved care delivered within the community, closer to patients’ homes and at a lower price.

The absence of clinical benefit in the cluster controlled trial,²¹ which was designed as an implementation study, may have been

because at the time ParkinsonNet included only physiotherapists whereas networks were multidisciplinary in the observational study of healthcare claims.²⁰ Optimal care may require an integrated multidisciplinary approach,²¹ hence the greater effects in the observational study. Moreover, the ParkinsonNet networks in the observational study had been operational for over three years, whereas professionals in the first trial had just completed baseline training. Experienced ParkinsonNet physiotherapists, who are trained to treat freezing of gait and improve the safety of transfers (such as from bed to chair),^{17 22} are likely to have helped reduce the number of injurious falls and prevent fractures.

We recently published the results of a non-randomised trial comparing one Dutch region that had both a specialised Parkinson centre and a regional ParkinsonNet with two geographically separated control regions that had neither (table 2).²³ The minor benefits in the primary outcomes of daily living and quality of life disappeared after we controlled for baseline differences. Subsequent analyses identified the referral process as the weakest link in this model because the advice of the specialised Parkinson centre was not consistently handed over to community based ParkinsonNet physiotherapists. This shows that optimal care requires not only a skilled community network but also effective coupling to hospital based care.

What do patients think?

We have received substantial feedback on ParkinsonNet from patients, through focus group interviews,⁶ our patient experience questionnaire,¹³ and the lively web based communities.⁷ These online forum discussions are informal, diffuse, and driven by patients, so formal quantitative analyses are difficult. A recurrent theme is the fact that patients value the ability to be seen by trained experts who understand the complexity of their condition.⁶ Most patients appreciate the ability to identify these experts themselves using the web based search engine, because it allows them to select experts who fit their needs, irrespective of whether they were being referred by their physician or following self referral (which is allowed in the Netherlands).

ParkinsonNet has also, however, received some criticism from patients. The main complaint is that the ParkinsonNet “label” does not guarantee high quality care. The perception is that some professionals have followed the baseline training but have not maintained or increased their expertise over time. Other patients, already satisfied with their existing treatment, have refused referral to ParkinsonNet experts. To address these issues we are creating a quality of care registry to provide information about the level of expertise and quality of care delivered by all ParkinsonNet participants. This quality registry will not only contain data from national healthcare claims (such as hip fractures and costs) but also information from neurologists (detailing which management items were discussed during each consultation) and from patients—obtained from our patient centred questionnaire.¹³ This validated instrument enables direct comparisons of quality of care across institutions and regions, as seen “through the eyes of patients” and will help patients to make an informed choice.

Effect on health professionals

Our annual survey of members suggests that ParkinsonNet participants take pride in being recognised as experts in the disease and value being part of a professional network with similarly interested colleagues with whom they can communicate easily. The main criticisms have come from professionals with an interest in Parkinson’s disease who were not selected to participate in ParkinsonNet, who now see fewer

patients. We are therefore considering lowering the barriers to entry of new members into ParkinsonNet while simultaneously offering transparency about the level of expertise and quality of care members provide (using the quality registry mentioned above). This will allow us to offer feedback and extra training for poorly performing professionals and to find replacements if necessary.

Implementation difficulties

The implementation of ParkinsonNet has inevitably thrown up problems. Table 2¹ lists the main ones and how we resolved them. One ongoing challenge is the funding of the administrative costs. The project cost around €5m to start up and annual running costs are about €1.5m. We estimate that the savings from implementation would more than cover these. Health insurers have embraced the ParkinsonNet approach as a way to promote transparency, improve the quality of care, and contain healthcare costs, and have formally agreed to fund ParkinsonNet. However, we have not been able to secure a permanent funding model where the cost savings generated within the healthcare process are used directly to finance the administrative costs. One major insurer has started to contract only ParkinsonNet professionals. Although this helps to enlarge the caseload for ParkinsonNet participants, it limits the freedom of choice for patients.

Wider application

ParkinsonNet has generated interest among policy makers, for several reasons. Firstly, it has succeeded in shifting care away from institutions (hospitals and rehabilitation centres) towards community based care, mainly in the patients' homes.²⁰ The reduction in costs in the cluster controlled trial was mainly attributable to ParkinsonNet care reducing the requirements for inpatient rehabilitation care, informal care, and paid home care.¹⁹ Recent unpublished work, again based on analyses of Dutch healthcare claims, showed that more intensive treatment delivery within the community is associated with less frequent admissions to hospitals and rehabilitation centres.

Secondly, ParkinsonNet has been associated with substantial cost savings (table 1¹). Thirdly, it has increased transparency about healthcare delivery and health outcomes and helped policy makers identify where good cost effective care is being delivered.

ParkinsonNet arose as a bottom-up initiative driven by professionals who wished to improve the quality of their services. In considering the case for setting up similar networks for patients with other long term conditions, focus should be on promoting collaboration within networks rather than stimulating competition between institutions. It is also vital to provide financial support for the structural process such as selection of members, standardising procedures, training programmes, and a quality registry.

Conclusion

ParkinsonNet has introduced a new "collaborative culture of care" where specialised professionals and engaged patients work together to try to achieve optimal outcomes. Patient participation, empowerment, and self management are key components. Recent exploratory work suggests that this network model has the potential to enhance care not only in the community but also for patients living in residential care and nursing homes.²⁴ The model may also be beneficial for patients with other forms of chronic disease, where management is

similarly impaired by lack of expertise among professionals, poor interprofessional collaboration, and a lack of tools to empower patients.^{25 26}

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Key messages

ParkinsonNet is a model where care is delivered by a restricted number of trained professionals who collaborate within regional networks

Collaboration is supported by a dedicated IT platform that provides information and enables communication between professionals and patients

Over 10 years ParkinsonNet has expanded to 66 regional networks and almost 3000 trained experts from 15 different disciplines covering the whole of the Netherlands

Evidence suggests that it empowers patients, promotes self management, improves the quality of care, decreases institutionalised care, and lowers healthcare costs

ParkinsonNet offers interesting perspectives to improve the quality of care for patients with other chronic conditions

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Tables

Table 1 | Summary of studies evaluating the outcomes and cost effectiveness of ParkinsonNet

Study	Design	Participants	Outcomes	Cost effectiveness
Nijkraake 2010 ¹⁸	Open label, controlled observation of first regional ParkinsonNet network	19 ParkinsonNet physiotherapists and 8 general physiotherapists who treated patients with Parkinson's disease	Caseload for ParkinsonNet therapists rose from a mean of 8.1 per therapist in 2003 to 17.6 in 2006 and they had better disease knowledge and better adherence to guideline recommendations than general physiotherapists	Not addressed
Munneke 2010 ¹⁹	Cluster controlled trial, comparing eight regions with a ParkinsonNet network to eight (geographically separated) regions with usual care	699 patients living independently in the community without comorbidity that interfered with daily functioning. (Exclusion criteria: MMSE <24); presence of major psychiatric disorders)	No difference in primary (PSI-PD at 16 weeks*) or secondary outcome (modified PAS; mobility domain PDQL-39) Better adherence to guidelines Tripling of caseload for ParkinsonNet therapists Lower costs associated with day care rehabilitation	Reduced healthcare costs (€727 reduction per patient during 24 weeks)
Beersen 2011 ²⁰	Observational study comparing the 2008-09 health insurance claims for patients living in the two oldest ParkinsonNet regions with those in 27 control regions	1485 patients with Parkinson's disease living in ParkinsonNet regions and 10 524 living in control regions	28% increase in patients receiving physiotherapy 12% fewer patients receiving day care rehabilitation (not significant) 55% reduction in hip fractures	Reduced healthcare costs (€640 reduction per patient per year in 2008; €381 reduction in 2009).
van der Marck 2013 ²³	Non-randomised trial comparing integrated care (specialised Parkinson centre plus regional ParkinsonNet) with usual care (IMPACT)	150 patients receiving integrated care and 151 usual care	Minor benefits for primary outcomes (ALDS and PDQL at 4, 6, and 8 months) in favour of integrated care model, which disappeared after baseline differences were controlled for	No difference in healthcare costs
Wensing 2011 ¹¹	Social networks methods to calculate strengths of interdisciplinary connections	104 health professionals who had joined a newly established ParkinsonNet network	Great variations in quality and density of connections between professionals Higher caseload and hospital affiliation associated with stronger connectedness to other health professionals	Not addressed

ALDS=Academic Medical Center linear disability score; MMSE=mini-mental state examination; PAS=Parkinson activity scale; PDQL=Parkinson's disease quality of life questionnaire; PSI-PD=Patient Specific Index for Parkinson's disease.

*PSI-PD covers the five main treatment areas of physiotherapy in Parkinson's disease: gait, balance, transfers, reaching and grasping, and physical capacity.

Table 2| Barriers encountered during the development of ParkinsonNet and tailored solutions

Barrier	Solution
Initial lack of commitment among national stakeholders	Involve key stakeholders as co-owners of ParkinsonNet
Non-participants see Parkinson caseload shrink/too many professionals wish to join*	Encourage non-participants to participate in specialised networks for other disorders
Greater travel distance for patients	Maximum acceptable travel distance negotiated with patients Telemedicine (eg, video consultations in secure environment)
Less freedom of choice/lack of competition	Patients can opt for non-ParkinsonNet therapists†
Insufficient insight into actual quality of care	Stimulate open debate about quality monitoring Established national Parkinson registry with transparent information on health services delivered, quality indicators, outcomes at patient level, and audits
Transparency seen as threat to professional autonomy	Transparency allows good professionals to display expertise
Electronic decision support seen as cumbersome by experienced professionals	Keep decision support optional instead of compulsory
Cost savings partially offset by "zero sum competition"†	Implement value based care (fee for outcome)

*Allowing too many professional to participate conflicts with our aim to increase the caseload among a restricted number of specialists.

†For example, orthopaedic surgeons who no longer treat hip fractures of Parkinson patients fill this gap by treating other patients.

Figure

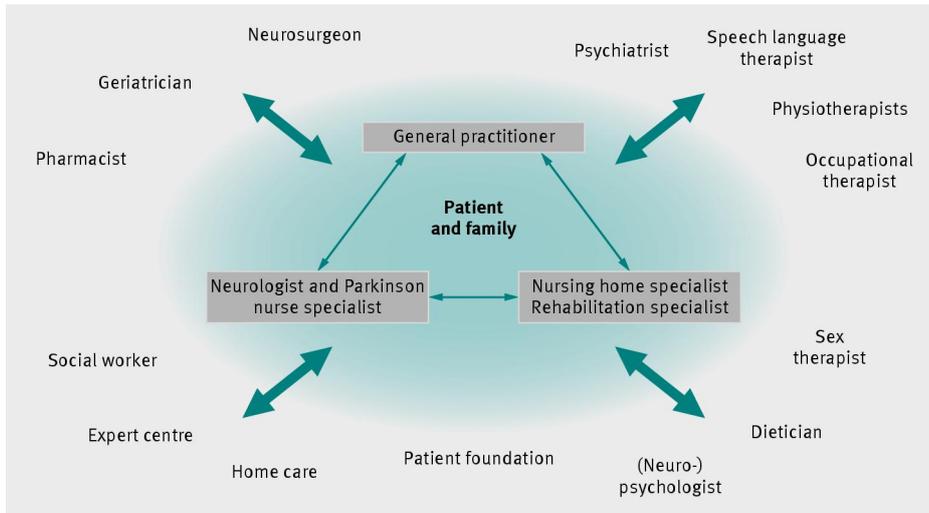


Fig 1 Disciplines involved in the care of patients with Parkinson's disease. Those in the central triangle are involved consistently; other disciplines can be engaged as needed.