ParkinsonNet - The Scientific Evidence

Is there any scientific evidence that demonstrates the value of the Dutch ParkinsonNet approach? Since the launch of ParkinsonNet in 2004, various research evaluations have been performed. Here, we summarize these studies, highlight the results and address several frequently asked questions.

Which scientific studies have been performed to date?

The value of ParkinsonNet has been investigated in various scientific studies (summarized in Table 1). Together, these studies show that ParkinsonNet improves the quality of care, improves the health outcomes of people with Parkinson's disease and reduces healthcare costs.[1-14]

Table 1 Overview of the studies that evaluated (components of) the Dutch ParkinsonNet approach.

Study	Set up	Participants	Results – quality of care	Results – health outcomes	Results – costs
Nijkrake (2010)[4]	Open label, controlled observation of the first regional ParkinsonNet network	19 ParkinsonNet physiotherapists and 8 general physiotherapists	Increase in the number of Parkinson's patients per ParkinsonNet therapist from 8.1 to 17.6. Increased knowledge about the disease and compliance with guidelines recommendations was better	Not investigated	Not investigated
Munneke (2010)[5]	Clustered, controlled study comparing 8 regions with a ParkinsonNet network with 8 (geographically separated) regions with regular care	699 patients who lived independently without co-morbidity hindering their daily functioning	Improved guideline compliance and tripling of patient numbers among ParkinsonNet therapists.	No difference in primary or secondary outcome measures	Lower healthcare costs (€727 less per patient during 24 weeks)
Beersen (2010)[6]	Observation study comparing the care claims from 2008 and 2009 for patients in the two oldest ParkinsonNet regions with those in 27 control regions	1,485 Parkinson's patients living in ParkinsonNet regions and 10,524 living in control regions	28% more patients receiving physiotherapy and 12% fewer patients receiving rehabilitation on a daily basis (not significant)	55% fewer hip fractures	Lower healthcare costs (decrease of €640 per patient per year in 2008; Decrease of €381 in 2009)
Van der Marck (2013)[7]	Non-randomised study comparing integrated care (specialised Parkinson's centre plus regional	150 patients with integrated care, 151 patients with regular care	Process evaluation showed that the advice of experts in the specialised Parkinson's centre was insufficiently implemented and little referral was made to	Small advantages for primary outcomes (activities of daily living- quality of life) in favour of integrated care model, which	No difference in healthcare costs

	Parkinson's network) with regular care		ParkinsonNet professionals.	disappeared after correction for initial differences	
Wensing (2011)[8]	Method of social networks to calculate the strength of interdisciplinary connections	104 healthcare providers who had joined a new ParkinsonNet network	Large variations in quality and density of connections between care providers. Higher patient numbers and hospital admissions associated with stronger links with other healthcare providers	Not investigated	Not investigated
Canoy (2012)[9]	Theoretical analysis by means of a capability approach	Not applicable	Added value of ParkinsonNet for both patients (feel safer) and professionals (more work satisfaction)	Not investigated	Not investigated
Ketelaar (2013)[10]	Questionnaire among 500 Parkinson's patients	380 patients completed the questionnaire	Respondents were prepared to switch to an expert physiotherapist. This willingness increased with the recognition of the value of Parkinson's expertise.	Not investigated	Not investigated
Van der Eijk (2015)[11]	Analysis of social networks within one ParkinsonNet network	104 professionals joining a new regional network	Better connections between participants in a network: 43% more professional contacts; estimation of the 'team result' did not change		
Sturkenboom (2015, 2016)[12,13]	Randomized and controlled study comparing 10 weeks of ParkinsonNet occupational therapy with regular care	124 Parkinson's patients receiving ParkinsonNet occupational therapy, 67 patients receiving regular occupational therapy.	Not investigated	Improvement of the primary outcome (execution of daily activities) in the ParkinsonNet occupational therapy group	Not significant difference of €125 per patient. Significant difference with respect to nursing home care (€1458) and positive cost effectiveness for informal carers
Ypinga (2018)[14]	Observation study based on insurance data (2013-2015)	2,129 Parkinson's patients treated by a ParkinsonNet physiotherapist, 2,252 Parkinson's patients treated by a general physiotherapist	Fewer physiotherapy sessions per patient (33.7 versus 47.9), higher percentage of patients receiving therapy from the same physiotherapist and a higher caseload per therapist (3.89 versus 1.48)	Significantly fewer complications (fractures, orthopedic injuries, pneumonia) in the ParkinsonNet group: 17.3% versus 21.3%).	Lower healthcare costs for physiotherapy (€456 per patient per year) and lower total medical healthcare costs (€612 per patient per year)
Rompen (2019)[15]	Description of interventions that were performed to implement the ParkinsonNet approach at Kaiser Permanente and first evaluation of	57 physical therapists, 18 speech therapists, 20 occupational therapists, 13 medical centers.	Increase of 37% in number of Parkinon's patients who received specialized allied health treatment. Successful transfer of a healthcare innovation to another	Not investigated	Not investigated

	concentration of care after implementation		country and healthcare system.		

Quality of care

With regards to the quality of care, research has shown that ParkinsonNet leads to better use of guidelines by care providers[4,5],[5]to a higher concentration of care among [4,5,8,14] and to greater awareness of what other care providers in the region have to offer.[11] Moreover, a theoretical application of the capabilities approach showed that ParkinsonNet professionals experience [4] and that patients feel safer when they are being treated by ParkinsonNet professionals.[9 9]

"The most recent study shows that people with Parkinson's, when they are being treated by a ParkinsonNet physiotherapist, experienced fewer disease complications."[14]

Health outcomes

With regards to health outcomes, three studies found positive results. The most recent observational study (based on medical claims data)[14] showed that Parkinson patients treated by a ParkinsonNet physiotherapist had fewer complications (fractures, other orthopedic lesions, pneumonia) than patients treated by a generically active physiotherapist (17.3% versus 21.3%). ParkinsonNet physiotherapists treated a higher volume of people with Parkinson's disease than regular physiotherapists and required fewer treatment sessions (33.7 per year versus 47.9 per year). These findings confirm the results of an earlier observational study (also based on an analysis of medical claims) in which a 55% reduction in hip fractures and a decrease in hospital admissions was found.[6] Finally, in a randomized controlled study, ParkinsonNet occupational therapy was compared with regular occupational therapy; the results showed that ParkinsonNet care leads to better daily functioning.[12]

Two other studies found no effect on health outcomes. The first study was a cluster randomized trial published in 2010, in which eight ParkinsonNet regions (with only specially trained physiotherapists) were compared with eight regions where regular care was provided.[5] The absent effect on health outcomes can possibly be explained by the fact that these networks had been newly installed, so the participating therapists were therefore still relatively inexperienced (the analysis was started immediately after the baseline training, while three studies that were performed later – and which did demonstrate positive effects on health outcomes – had been conducted in more mature networks in which ParkinsonNet care providers had been treating a large volume of patients for several years). This is relevant because the case load (number of patients) treated by specialized ParkinsonNet professionals increases steadily over time, so they progressively accumulate more experience and knowledge.[4] Such experienced therapists are more likely to achieve tangible clinical benefits. In addition, the duration of follow-up may have played a role, particularly when it comes to health outcomes or events that occur rather infrequently (such as hip fractures). The 2010 cluster randomized trial had a follow-up duration of only 6 months, which is likely too short to monitor effects of fractures of the hip or elsewhere. In contrast, the more recent observational study assessed health effects over a three-year period. Finally, the 2010 study evaluated a monodisciplinary network (only specifically trained physiotherapists), whereas the later positive studies evaluated multidisciplinary networks that are more likely to positively affect the patients' health.

The second study that demonstrated only a modest effect on health outcomes was a trial that studied the effect of integrated care.[7] This was a complex study, aimed at evaluating care that was delivered by a Parkinson's expert centre (where only multidisciplinary assessments were done), and where the recommendations of the expert centre were subsequently transferred to the referring neurologist and to ParkinsonNet professionals – in the hope that these would implement the treatment advice close

to the patients' own homes. However, a process analysis showed that for a majority of the patients, the advice given by the multidisciplinary team of the expert hospital was actually never followed up in the communiy. For example, the local neurologist often did not initiate a referral to the regional ParkinsonNet therapists. This lack of compliance may explain why only small (and clinically likely irrelevant) effects were seen in terms of effectiveness and costs. An important lesson of this study is that patients really deserve integrated care, where the expert centre is seamlessly coupled to the regional hospital and the regional ParkinsonNet team.

Costs of care

With regards to costs, three studies have shown that ParkinsonNet care is associated with a cost reduction, both in the short term and in the long term. The cost savings that were observed varied from €381 per patient per year in an observational study[14] to €727 per patient per six months in a two-year cluster randomized trial.[5] The aforementioned analysis of medical claims data[14] showed cost savings of €530 per patient per year. The clinical study that evaluated ParkinsonNet occupational therapy showed no cost savings, except for informal carers, but did demonstrate that the intervention was more effective.[12,13] A possible explanation for this latter finding is that it may take more time (than the 6 months of this study) before any positive health effects translate into a cost reduction.

Based on all studies, we cautiously conclude that, although the levels of the observed cost reduction differed slightly, the savings do appear to be substantial, with total cost reductions in the Netherlands amounting to 5% of the total annual budget for care for people with Parkinson's disease.[1]

Is more research needed to further substantiate the value of ParkinsonNet?

ParkinsonNet is an organization that is keen to learn and to continuously improve. While we are proud of the volume of well-conducted studies to date, we obviously realize that there is certainly room for further scientific evaluations. We also keep improving the ParkinsonNet concept itself, and this will also call for further formal evaluations. Examples of currently ongoing new trials include the NICE-PD study, where we evaluate the merits of specialised Parkinson nurses; the PERSPECTIVE study, where we investigate the cost-effectiveness of speech-language therapy delivered via telemedicine; and the PRIME study, where we evaluate a novel integrated care concept focused on proactive personal case management for people with Parkinson disease. We will regularly update this document as further studies are being added, or when new findings have been published. In addition, we listen carefully to any suggestions or questions from both patients, providers and other colleagues, to see how we can further improve.

Literature

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