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Net results: A novel model of healthcare delivery in Parkinson's

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In 2004, feedback from focus groups and online patient forums suggested that Dutch patients with Parkinson's disease (PD) were dissatisfied with their care. Patients indicated that they often received care from health professionals without specific training or expertise in PD. A further concern was that interdisciplinary collaboration and communication between medical specialists and allied healthcare professionals was inadequate. Finally, patients complained that they were not involved enough in decisions about their treatment, and that insufficient attention was paid to the quality of their lives. As a result to this feedback and as answer to these challenges, ParkinsonNet was founded in the Netherlands. Today, this ParkinsonNet approach delivers high quality affordable patient-centered care to all patients with PD in The Netherlands.

The starting point for ParkinsonNet was the ambition to deliver the best possible care to all patients and families with PD in the Netherlands. To achieve this, ParkinsonNet has developed regional, multidisciplinary networks of healthcare professionals specialized in the often complex management of patients with PD. The participating professionals first receive a thorough three-day baseline training according to evidence-based treatment guidelines for PD. Most of these guidelines were developed by the ParkinsonNet team, as they were non-existent at the time the model was founded. The participants also received continuous follow-up training in the ensuing years. Furthermore, all participants are trained and supported to optimize their interdisciplinary communication and collaboration with other colleagues within the regional network. The model was started in 2004 with one small regional network (with around 20 specifically trained professionals) in the region of the cities of Nijmegen and Arnhem.

After six years, the model had reached full nationwide coverage, and it currently consists of 66 regional networks and close to 3,000 specifically trained professionals from 12 different disciplines (Figure 1).

Figure 1. The 66 regions of ParkinsonNet, with full nationwide coverage.

The trained professionals are deployed mainly within the community and this includes, in particular,, physiotherapists, occupational therapists, speech and language therapists, and dieticians. In its current state, ParkinsonNet is less prominently visible within the hospital setting, although specialized Parkinson nurses have been trained as part of the ParkinsonNet approach. When ParkinsonNet started, there was a clear lack of allied healthcare professionals with Parkinson-specific expertise and knowledge; moreover, guidelines were lacking, which led to unacceptable variations in the quality of care, with suboptimal health outcomes and high costs as a result. Now, 10 years later, every patient with PD can easily find an allied healthcare professional with Parkinson-specific expertise who works together with

other professionals, and who treats patients according to evidence-based guidelines (assisted by a custom-made online healthcare finder, see www.ParkinsonZorgzoeker.nl). A particular strength of ParkinsonNet is the ability to incorporate new scientific knowledge into updates of the evidence-based clinical practice guidelines. Moreover, via the continuous annual educational programs and via the web-based communities where the associated professionals are connected 24/7 (see www.ParkinsonConnect.nl), ParkinsonNet has the ability to rapidly disseminate and implement new knowledge within the actual healthcare system, allowing patients and their families to profit quickly.

The ParkinsonNet concept and the scientific underpinning of the concept are described in more detail in a recently published paper in the British Medical Journal.[1] A summary of the model and the components of ParkinsonNet described above is shown in Figure 2.

Net results

ParkinsonNet has been evaluated in a series of scientific studies. Taken together, the results point to greater cost-effectiveness within the full cycle of care. First, introduction of a ParkinsonNet network increases the selective referral of patients to its members (resulting in a much higher caseload per participant) and results in better adherence to treatment guidelines.[2;3] Second, a large observational study (based on analyses of health insurance claims of almost 30,000 patients) showed that patients with PD who are being treated within ParkinsonNet areas sustained fewer fractures than patients who (at the time) still lived in usual care areas, including a 55% decrease in hip fractures.[1;3] Third, the proportion of day care treatments in rehabilitation centers was also lower in ParkinsonNet regions, which is suspected to be an indirect reflection of the improved care delivered within the community, closer to patients' homes.[1;2] Finally, two studies

Figure 2. Model and components of ParkinsonNet. With quality of life as primary aim, the foundation of the model is based on expertise, collaboration, higher case loads, patients as partners and regional networks (green squares). The red squares show which elements are in place to support the foundation of the model. The blue squares indicate that continues innovation makes sure the model is always fed with the latest (scientific) information.

have demonstrated that introduction of ParkinsonNet is associated with substantially reduced costs of care, up to 20 million euros less annually, which equals around 4-5% of the total expenditure on direct Parkinson care.[1;2]

Feedback and transparency

An important component of ParkinsonNet is to offer all regional multidisciplinary teams feedback about their delivered (quality and costs of) care. For this purpose, the Parkinson Atlas was developed (see www.ParkinsonAtlas.nl) which offers detailed information about (outcomes and costs of) Parkinson's care, and which creates an ability to compare the results for different regions (benchmark). See Figure 3 as an example.

Proportions of hip fractures per region

> \> 3.0%
> 2.0 - 3.0%
> 1.0 -2.0%
> < 1.0%

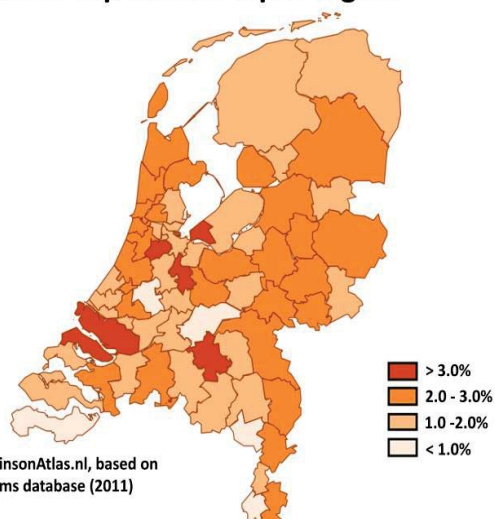Source: www.ParkinsonAtlas.nl, based on Vektis medical claims database (2011)

Figure 3. Exemplary screenshot of the ParkinsonAtlas, in this case demonstrating regional differences in the proportion of hip fractures across regions. This information is all publicly available via www.ParkinsonAtlas.nl and is used to create transparency about outcomes and costs, aiming to improve the overall quality of care and reduce unwanted variations in care.

Next steps in providing transparent feedback about the actual health outcomes of treated patients and about the healthcare costs for society have focused on creating a new national quality registry (termed ParkinsonInsight). This transparency is regarded as a crucial component of an optimal care delivery system, as it serves as a mirror for all healthcare providers to see which parts of their service repertoire are currently up to par, and which elements are possibly open to improvement. Transparency about outcomes and costs at a national level also allows professionals to learn from each other (identification of best practices), and to benefit from the experience of best practices. Furthermore, the quality registry offers vital intelligence for health insurers to tailor their actions, in particular to selectively reimburse the integrated networks that offer the greatest value to patients. In 2013 national consensus meetings were organized to define clinically relevant and measurable outcome measures to be included in the registry (this includes, among others, a set of PROMs (quality of life, CQ index) as well as outcome indicators such as hip fractures, and structure indicators such as the presence of a Parkinson nurse).

In 2014, ParkinsonNet began experimenting with this registry, and the registry is currently up and running, with already more than 5,000 Parkinson patients being registered. A unique feature of this quality registry is its multidisciplinary nature, allowing other health professionals (e.g. Physical therapist, Parkinson nurse) to also add information relevant to their discipline to the quality registry. Importantly, patients also add vital information to the registry, and they are asked to fill in several relevant questionnaires twice a year, e.g. about their quality of life (PDQ-39) and about their own experiences in healthcare (through the CQ Index that was developed by the ParkinsonNet team).[5]

Opportunities for spread

The ParkinsonNet model has been proven successful in the Netherlands. There are, however, many opportunities to learn from this model and to spread. Currently, this is done in two different ways. First, the model is imitated in an international setting. Both in Germany (Niederrhein region) and at Kaiser Permanente in the United States, the model has been implemented. Some generic components (as shown in figure 2) could be copied, while other elements that needed cultural and/or system-specific changes were tweaked and adjusted to match the specific local circumstances. Second, the ParkinsonNet model is now gradually being copied to improve the care for patients with other diseases. In The Netherlands, we have started with a similar model for COPD (with

Prof. Richard Dekhuijzen as the network leader), and we see great opportunities for other chronic diseases as well. The new model of healthcare delivery for patients with PD has been proven to be successful in the Netherlands, and now provides a great opportunity to reform chronic healthcare in the rest of the world.

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"RALLYING TO THE CHALLENGE"

PWP meeting, Sept 30 to Oct 1, 2015
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OUTCOME MEASURES IN CLINICAL TRIALS

Further details
http://grandchallengesinpd.org/rallying/

Take 2