A seat at the table for people with Parkinson’s disease

Participatory and collaborative health care are fast becoming buzzwords. Jules Morgan looks at how researchers, professionals, and patients are collaborating in networked models of health care.

Progress towards effective treatments, for Parkinson’s disease (PD) has been slow. A major setback is recruiting participants to trials, so how can researchers find more people willing to take part? A culture of partnership between those conducting the trial and the patient community could be the key. Could patient participation in trial design expedite the discovery of better treatments? Motor and non-motor symptoms of the disease drastically affect quality of life, so a network that enables knowledge sharing across clinical and therapeutic disciplines is surely a win-win for professionals and patients alike. With added cost-saving benefits, networked health care could be the next big thing.

A radical model of health care founded in the Netherlands in 2004, ParkinsonNet, and recently, the evolving Parkinson’s Excellence Network in the UK, have embraced participatory health-care as well as participatory research. In other parts of Europe, and in the USA, similar networks are emerging, with patients taking a more active role in research and disease management.

Steven DeWitte, both a person with PD and patient advocate in Connecticut, USA, tells The Lancet Neurology about a phonecall he received from a researcher looking for a patient perspective on a protocol he was developing. “I gave it a very critical eye...waiting for him to say no, that’s not relevant. But he said, Steve everything you say applies”. DeWitte explains how inclusivity exemplifies what he believes is crucial in the field of research, “People with Parkinson’s are not only to be engaged in the process, but are central to it”. A patient-centred collaborative health care approach is a perfect fit in a PD landscape, as DeWitte terms it, because patient participation equates to empowerment and people with PD are then better informed and more motivated to take part in trials.

Parkinson’s Movement, part of The Cure Parkinson’s Trust, a US-UK alliance, is a patient-based think tank that DeWitte calls an epicentre of collaborative health care. “Here, like-minded people get together to make a difference...a lot of good work is being done in what I call silos, Parkinson’s Movement builds crossovers, and this is how research is pushed forward and we, as patients, get treatment sooner”. What might prevent people from partaking in a trial? Obvious concerns include unknown adverse effects, disruption in drug regimens, and the possibility of receiving the placebo. “We have to involve them at the start of the process”, DeWitte says. He understandably expresses frustration for the lengthy process of trials, but knows that science takes time. “When you sit at home and your left-hand is shaking uncontrollably it can’t be soon enough”. He speaks highly of the innovative leaders in PD research, but time is a commodity people with PD cannot afford.

Networked health care aims to increase recruitment of study participants, but symptom management using drug and alternative therapies also benefits from this health-care model, claims Bas Bloem, cofounder of the Dutch ParkinsonNet. This premise was the cornerstone of ParkinsonNet— with an emphasis on multidisciplinary training, the quality of treatment is monitored across primary, secondary, and community care facilities. Bloem, a semi-professional volleyball player, aptly uses a sporting metaphor; “Each player has their own role in the game, but it can only work if you play as a team.” Aspiring to quality-assured standard of care, ParkinsonNet allows the patients to partake in delivering basic related outcome measures and a quality of care index, a validated instrument that is patient-centred.

Bloem told The Lancet Neurology how the roots were planted when he and roommate Marten Munneke met while studying at Leiden University, Netherlands, and designed a trial project for PD using a non-drug treatment, physiotherapy. From this project he found that “led by physiotherapists with no PD training, the trial would have reached a dead end before it even started”. Thus began the building of ParkinsonNet. “We started with a small multidisciplinary network of about 20 physiotherapists in Nijmegen and Arnhem, gradually expanding to a pool of now over 3000 trained members in 12 disciplines with national coverage. Some people mistake ParkinsonNet for an IT network. ParkinsonNet is a network of people of flesh and blood”, says Bloem.

The benefits of such a network might be applicable to generic health-care provision. The charity Parkinson’s UK reports how a lack of joined-up care and knowledge sharing is “costing the National Health Service (NHS) in England millions in extra treatment and unplanned hospital admissions”. They estimate that NHS spending on care for patients with PD was £212 million in 2012-13. More than £177 million was spent on unplanned visits to hospital and £20 million. Comparatively, patients with PD older than 65 years of age are three times more likely to have unplanned admissions than are people without PD of the same age. With best practice guidelines and evidence-based recommendations, the overall cost of care is reduced, claims Bloem. In a cluster-randomised trial to test the efficacy of community-based physiotherapy
For the ParkinsonNet approach see BMJ 2014, 348: g183B
For the observational study see KPMG-Plexus, Vektis; 2011: 1–42
For more on Kaiser Permanente see https://healthy.kaiserpermanente.org/
For the Van Andel Research Institute see http://www.vai.org/
For the Parkinson’s UK 2011 audit see http://www.parkinsons.org.uk/professional/uk-parkinsons-audit/post-uk-parkinsons-audits
For the National Institute for Health and Care Excellence Parkinson’s Guidelines 2006 see https://www.nice.org.uk/guidance/cg35

networks for patients with Parkinson’s disease, Bloem’s findings showed that ParkinsonNet networks did not change health outcomes for patients in ParkinsonNet clusters. There was no difference in the patient-specific index for PD at 16 weeks, covering gait, balance, transfers, reaching and grasping, and physical capacity (primary outcome), and secondary outcomes were also disappointing, with no change in the modified Parkinson activity scale. However, health-care costs were reduced in ParkinsonNet clusters compared with usual-care clusters. Bloem adds, “our research has demonstrated that ParkinsonNet reduces health-care costs by around £20 million each year, and this equals around 5 to 6% of our annual expenditure on chronic Parkinson care”.

Cost reduction is a driving factor for Bloem; “informed patients are cheaper patients because they help to make the right decisions.” In a 2014 analysis, Bloem and Munneke summarised the studies undertaken by ParkinsonNet by evaluating the outcomes and cost-effectiveness. While primary and secondary outcomes of the 2010 trial were disappointing, economic benefits, and benefits for softer outcomes (such as improved job satisfaction for the enrolled professionals and greater trust from a patient perspective towards those professionals), together with “hard evidence” of benefits—fewer hip fractures and therefore reduced unplanned hospital admissions are evident in the summary paper. These results are in line with results of an observational study published in 2011 that showed a 50–55% reduction in hip fractures, with a 28% increase in patients receiving physiotherapy.

One question is how transferable is this model? In low-income countries factors such as lack of expertise, sparsely populated regions, and fewer facilities and resources, could make it unfeasible. “I’m convinced it could work”, Bloem says, “if the wishes of the patients and doctors are the same, the model can be imitated, rather than replicated.”

DeWitte also recognises that on a global scale such challenges exist. “We have to select the pieces that work in our system and continue from there”, he says. Currently, in California a leading health-care provider, Kaiser Permanente is testing the feasibility of ParkinsonNet in a US setting, based on the Dutch model. Bloem, accompanied by Dutch royalty, recently returned from a trade mission to the USA, where a partnership was forged between ParkinsonNet and the Van Andel Research Institute (Grand Rapids, MI, USA). Patrik Brundin, Associate Director of Research at Van Andel, told The Lancet Neurology that “our primary goal is to optimise patient care and allow them to have the best quality of life. Differences in the organisation of the Dutch and US health-care systems obviously pose some challenges, but learning from the ongoing experience that ParkinsonNet has in California will help us circumnavigate possible obstacles upfront”. Brundin strongly believes that the model helps “connect patients to appropriate trials”, to increase participation from “a small minority” towards a “majority that want to take part”.

Earlier this year the Parkinson’s Excellence Network launched in the UK under the clinical leadership of neurologist David Burn (Newcastle University, UK). Steve Ford, Chief Executive of the charity Parkinson’s UK, recognised the potential of the ParkinsonNet concept and set up the organisation-funded UK Network. Parkinson’s UK undertook an audit in 2011 to measure the practices of the charity funded UK Network. Parkinson’s UK undertook an audit in 2011 to measure the practices of the charity according to the 2006 Parkinson’s Guidelines, including occupational therapy, physiotherapy, and speech and language therapy. This “listening exercise” is an underlying principle in patient participatory health care—a follow-up is underway for 2015, with an October data submission deadline. Key focus areas have been identified: better treatment, improved services, and giving patients more control over their disorder. After a “bit of a splash” at the launch of the UK network in February, Burn is optimistic about the future of the network addressing the needs of patients arising from the audit exercise.

So, how similar is this network to the ParkinsonNet model? “There is no doubt that ParkinsonNet is a trailblazer, but in my role I was not overtly influenced by the Dutch model. It is useful to draw parallels, however, it is hard to know how well ParkinsonNet is working as it struggles to prove better outcomes with evidence” Burn says.

Start-up and running costs were, and still are, problematic in the Netherlands’ fragmented financial reimbursement system: who pays for a national, multidisciplinary network? In the UK the network is funded by Parkinson’s UK. “We are not looking to cost the taxpayers money”, Burn clarifies, but to “work smarter by identifying good practice and knowledge sharing.” By asking the patients to measure the success of the initiative Burn envisages that it will translate into better health outcomes, citing the adage, “better research equals better health”. He adds, “our model will look to disseminate good practice in a distributed way across all NHS Parkinson’s services. If you want to be involved, you can join”.

The Parkinson’s Excellence Network in the UK is in its infancy and one “blindspot”, concedes Burn, is the minimal visibility in primary care settings. It is difficult to criticise a model that has such aspirations—one that consults and responds to the people it treats, and connects clinical and therapeutic expertise to optimise efficiency, improve quality of care, and broaden its outreach. As DeWitte explains, “something like this needs “planting, watering, and growth”. Bloem’s understanding is similar, “My father always said when you buy a house you are constantly refurbishing it, it’s never ready”. It is apparent, however, that the foundations are laid for a new era of patient-driven research in health care.

Jules Morgan