

My own PROMs

Sara Riggare

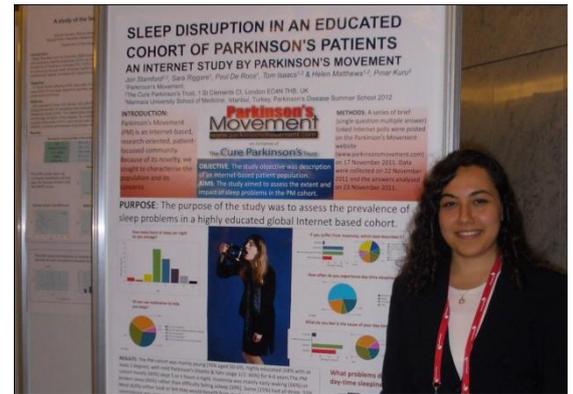
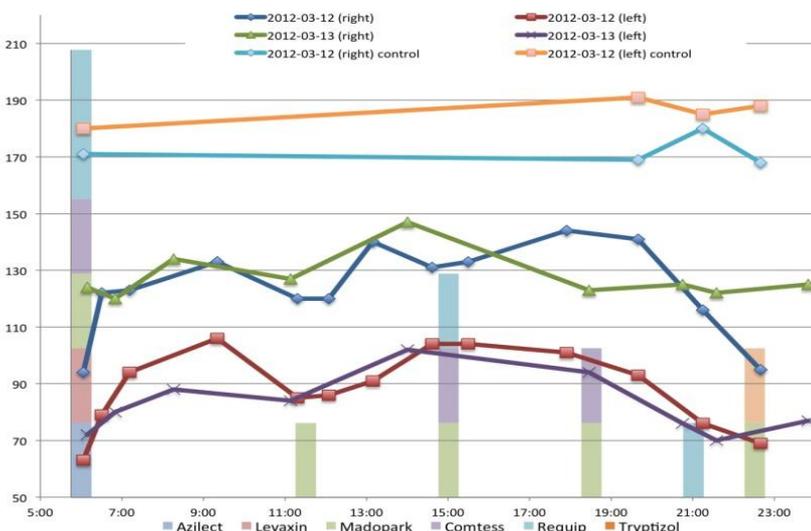
Being an engineer with an interest in technology can come in handy when trying to manage Parkinson's well. Personally, I have gained a lot from my curiosity and desire to understand causes and effects of what happens with me and around me.

Two years ago, I was accepted as a student in Health Informatics at the Karolinska Institute in Stockholm. Health informatics can be described as including every use of information technologies in any kind of healthcare context - for example, systems for managing hospital information, databases for clinical trials, electronic health records, different e-learning systems and websites for medical or health information both for healthcare professionals and for patients. The program gave me a very good base for what I am currently doing: I am now a doctoral candidate at the Karolinska, my research focused on ways for people with chronic diseases to use their own health data and observations to improve their health. For natural reasons, I am starting with Parkinson's and furthermore using my own experience and practices to see if there are things I do that also can be of benefit to others.

I call my first project "My Own PROMs". PROMs is an abbreviation of "Patient Reported Outcome Measures" and the term is mainly used in clinical trials for questionnaires where patients self-report their outcome of the treatment or intervention. In the project, I am planning to evaluate my symptoms and see where I can find patterns to help me understand my own "flavour" of Parkinson's.

In my first attempt, I use an iPhone app to do a tapping test: tapping for 30 seconds as fast as I can with the middle finger of each of my hands. I record the result and when plotting it against my medication times, I did find interesting patterns, see below.

Baseline tapping test (n/30 sec) (graph) and medication intakes (approx.)



PM poster on sleep at MDPD Berlin

SLEEP DISRUPTION IN AN EDUCATED COHORT OF PARKINSON'S PATIENTS: AN INTERNET STUDY BY PARKINSON'S MOVEMENT

Jon Stamford^{1,2}, Sara Riggare¹, Paul De Roos¹, Tom Isaacs^{1,2} & Helen Matthews^{1,2}

¹Parkinson's Movement, ²The Cure Parkinson's Trust

INTRODUCTION: Parkinson's Movement (PM) is an Internet-based, research-oriented, patient-focussed community. Because of its novelty, we sought to characterise the population and its concerns. **METHODS:** A series of brief (single question multiple answer) linked Internet polls were posted on the PM website on 17/11/2011. Data were collected on 22/11/2011 and the answers analysed on 23/11/2011. **RESULTS:** The PM cohort was mainly young (76% aged 50-69), highly educated (68% with at least 1 degree), with mild Parkinson's (Hoehn & Yahr stage 1/2: 66%) for 4-6 years. The PM cohort mostly (60%) slept 5 or 6 hours a night. Insomnia was mainly early waking (66%) or broken sleep (66%) rather than difficulty falling asleep (30%). Some (15%) had all three. Most (63%) either took or felt they would benefit from medication to help sleep. Daytime somnolence was common (81%) with 53% experiencing daily episodes. 36% attributed this to a combination of Parkinson's and medication. 50% felt daytime somnolence compromised driving safety, with social (45%) and work problems (42%) also highlighted. **CONCLUSION:** Sleep disruption has major QoL implications in PD.