
Designing Free-Living Reports for Parkinson's Disease

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ABSTRACT

Parkinson's disease is a progressive neurodegenerative disorder that is also characterized by its motor fluctuations throughout the day. This makes clinical assessment to be hard to accomplish in an appointment as the patient status at the time may be largely different from his condition two hours before. Clinicians can only evaluate patients from time to time, making symptom fluctuations difficult to discern. The emergence of wearable sensors enabled the continuous monitoring of patients out of the clinic, in a free-living environment. Although these sensors exist and they are being explored in a research setting, there have been limited efforts in understanding which information and how it should be presented to non-technical people, clinicians (and patients). To fill this gap, we started by performing a focus group with clinicians to capture the information they would like to see devised

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from free-living sensors, and the different levels of detail they envision. Building on the insights collected, we developed a data-driven platform, DataPark, that presents usable visualizations of data collected from a wearable tri-axial accelerometer. It enables report parameterization and includes a battery of state-of-the-art algorithms to quantify physical activity, sleep, and clinical evaluations. A two-month preliminary deployment in a rehabilitation clinic showed that patients feel rewarded and included by receiving a report, and that the change in paradigm is not burdensome and adds information for clinicians to support their decisions.

KEYWORDS

Parkinson's disease; Free-living; wearable technology; Data-driven; Accelerometer

INTRODUCTION

Parkinson's disease (PD) is a frequent progressive neurodegenerative disorder, affecting about 1% of the world population. The ageing of the population will increase the number of people living with that disease in the following years. PD manifests itself by the reduction of dopamine levels, due to the death of the brain cells that produce it. This phenomenon occurs only if more than seventy or eighty percent of cells die [3] [7]. This disease is characterized by tremors, rigidity of the trunk and limbs and low movements. With the progression of the disease, the postural instability can be very disabling, creating difficulties in the tasks of standing, sitting, and walking.

One of the characteristics of PD is that the disease progression is highly variable and the symptoms, alongside the degree of disability, are likely to fluctuate over the duration of a day [7]. Clinicians can only evaluate patients from time to time, making symptom fluctuations difficult to discern. Challenges for clinical practice include understanding the progression of the disease, the response to pharmacological and non-pharmacological interventions, and the fluctuations the patient goes through alongside their explanations [5].

One way for clinicians to understand what happened with the patients in a free-living environment is by asking them questions, but this can be less precise than needed because recall is unreliable [4]. Recurring to diaries to help patients resume their day and provide useful information to the clinicians is an alternative. However, there is a compliance issue when using diaries as well as a subjectivity one.

The democratization of sensing wearable technologies opened several possibilities in the continuous monitoring of people, and particularly in what relates to their health and wellbeing [5]. The amount of data these devices can produce, and the rich insights that can be derived from it, ask for a shift to a data-driven consultation paradigm, that needs to be carefully designed [6].

We developed DataPark, a web platform with the purpose of helping clinicians obtain more information about patients. Objective data is obtained with the usage of a tri-axial accelerometer sensor

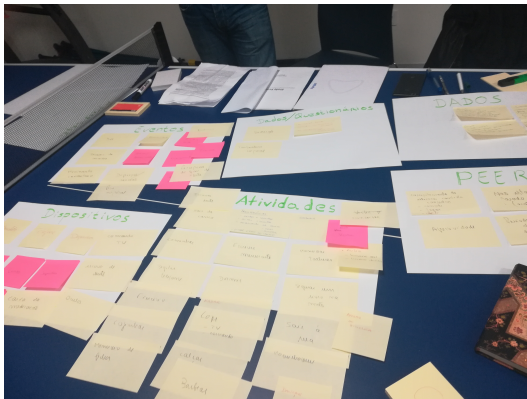


Figure 1: The setup in the focus group meeting

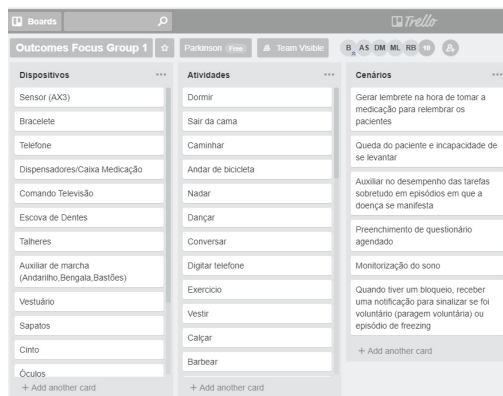


Figure 2: An example of some of the digital boards created with Trello (trello.com; last visited on 07/01/2019)

(AX3). Clinicians can generate a personalized report according to the needs of each patient or the analysis they want to perform.

We chose an iterative co-design approach where clinicians and HCI researchers crafted all elements and aesthetics of the platform and its reports. In addition, we performed a preliminary study with a stable version of the platform that showed the benefits and limitations of DataPark and offered new perspectives for its future.

Our findings suggest that a data-driven approach for getting a summarized analysis of objective data from different environments can help clinicians to better understand patients' fluctuations during their daily life. It also showed patients more engaged with therapy when they knew they were going to receive a report. Conversely, albeit valuing the benefits of sharing reports with patients, the clinicians also showed some concerns with providing patients with clear evidence of their motor decline.

PRELIMINARY STUDIES

Our first goal was to understand what were the needs of clinicians, which events or measures they would like to see collected, and how they would envision it to be presented. First, we conducted informal interviews with clinicians and observations of clinical assessments with patients. This enabled us to understand the complexity of assessing a person with PD, even when in close proximity. Our main study was then a focus group to capture a broader perspective of what were their needs.

Five participants took part in the session. It was composed of one neurologist, two physiotherapists, and two nurses. The focus group was prepared around a set of different boards (Devices, Activities, Data) that were iteratively filled with information (e.g., post-its) by the participants or the researchers as they emerged. For each one of the different boards we asked participants to write down examples. For Devices, we asked participants to write down devices (or objects) they would like to sense, i.e. where they know that understanding usage patterns of that object could be relevant to monitor as a proxy for disease progression; examples of such devices were *mobile phone*, *TV remote*, *clothes*, *glass*, *toothbrush*. As for Activities, we were looking for daily Activities that they found relevant to be reported in a free-living assessment context; examples were *sleep*, *walk*, *swim*, *get dressed*, *ride a bike*, among others. In the Data board, they were asked to think about data they could see derived from the aforementioned devices and activities, and write down / discuss the most relevant they could think of; Sleep and Gait measures were the most discussed, which is aligned with the focus of the literature in the area of sensing technologies for PD [1] [2]. Gait measures include step length, step time, number of steps, for example (Figure 1).

In the end, we challenged each of the participants to list or draw a possible report and enumerate some important points that should be part of it. Sleep, gait, and physical activity were referenced by all the clinicians.

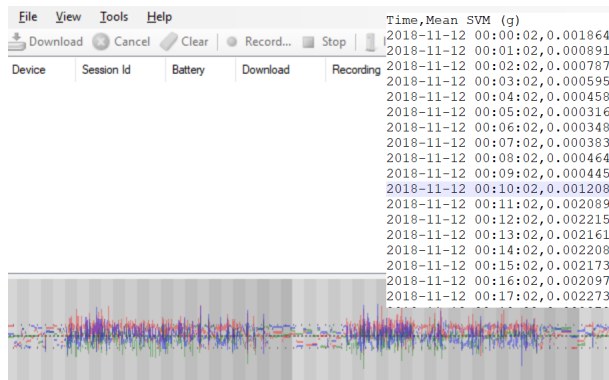


Figure 3: Omgui tool and the output: a chart of vector magnitude distribution and a CSV file about the same vector magnitude spent



Figure 4: An example template of a DataPark report, containing energy, charts, a physical activity chart and measures

To allow for participants to continue the discussions after the session and consolidate the information, we created a digital version of the paper boards as they were at the end of the meeting in Trello (Figure 2). We asked participants to complete all the information they could and asked them questions to elicit action (e.g., "you mention a couple of objects (e.g., a book). What type of useful data you see being collected from those objects that can inform on the status of a person with PD?").

A new board called Scenarios was created with the purpose of capturing real-world scenarios that could be relevant for PD, so we could retrieve more data from those examples. One example was the usage of sensors to detect *freezing of gait* that could then issue a request for the patient to confirm the episode.

We grouped all the information from the boards and the example reports and informedly designed a first prototype with digital reports derived from wearable accelerometer data. Our purpose, in this initial phase, was to gather as many data as possible so we could have a picture of the clinicians' ideas.

DATAPARK

We created a data-driven platform, DataPark, to collect objective data from uncontrolled environments. The output is a report that includes measures about physical activity and sleep.

AX3 and Data

We used an inertial sensor, Axivity AX3, for getting the objective movement data from the patients day-to-day. This device already makes available with an analysis open-source platform. However, the data is not easy to understand for non-technical people. The output provided consists in a chart with the raw data and a set of CSV files with the analyzed data (see Figure 3). They make available algorithms about vector magnitude, wear time and sleep analysis. The output needs to be prepared and exhaustive analyzed for extracting relevant information from it. This is not easy to do by clinicians, mostly because they do not have the time needed but also, in some cases, the skill set to get meaningful information from the raw or the processed but text-based data.

Personalized Reports

Our approach focused on offering clinicians the data in an easy understandable way. For that purpose, we gathered all the data we found relevant and focus our platform in the design process. For each data measure we presented, we had to decide what was the best way for presenting it. We did this together with our clinical partners as we learned that their experience and habits with visualizing medical data had a strong influence in the acceptance and understanding of different visualizations.

Each report is composed by a set of charts, tables and measures that gives a processed analysis over the raw data (Figure 4). In this proof-of-concept, our analysis focused on physical activity, energy

and sleep. The first one give us the different positions patients were during each day. Energy shows how much *kcal* were spent by the patients. Sleep consists in understanding the fluctuations patients may undergo during the night period. It measures changes in sleep positions and wake-ups.

All the different modules produce a variety of charts. We use different types of views for data, for example by day, or week, or period of the day. If needed, clinicians can adjust each report according to the patients or the type of analysis they want to see or discuss. Also, we give the change for clinicians to build their own reports, by choosing what information should appear and how it should be presented. In the platform, we save the previous evaluations of each patient. We allow comparisons between different evaluations. Reports can be printed or saved as PDF for further analysis.

PRELIMINARY RESULTS

We deployed DataPark in a rehabilitation clinic and residential unit for neurodegenerative diseases, for a period of two months. We wanted to understand the qualities and limitations of the output data and understand how the platform influences the clinical practice. Twenty-two patients with PD agreed to participate in our IRB-approved study; one neurologist and three therapists used DataPark during the study. Patients were asked to wear an inertial sensor for a period of three or seven days, depending on the rehabilitation program they were associated with. At the end, clinicians had access to a report about the period in evaluation. We conducted semi-structured interviews to understand how the platform influenced the normal workflow of dealing with the patient.

We received the feedback from the clinicians' perspective and their perception on the patients' perspective. Patients enjoyed to have an overview of how their week was. Examples of what they like the most are energy expenditure (expressed in *kcal*) and sleep analysis, as they can provide meaning to it. Some of the patients had previously participated in another evaluation and get excited for being able to participate again. The participants have been anxious for receiving a summary report that somehow can give them a perspective of how their week was.

This study was performed in a free-living context (not controlled task), however patients stayed at the clinic, so they were outside their home environment. Patients knew they were being evaluated, and their behavior could be different if they were at their homes.

Clinicians reported no changes in taking care of patients by using sensors. This shows that inertial sensors do not influence the normal procedure. The use of the web application did not show to have an influence in the time to perform the tasks. In the same way, there were no major difficulties on using the web application neither the learning time was large.

The functional reports were of easy comprehension. All the data presented in the reports was important for clinicians and they considered that having this type of monitoring gives the opportunity for better understanding patients in a free-living context. Clinicians pointed negative aspects of using sensors:

"The comparison of the data in different periods, if there was a regression in the results, it could lead to patients' demotivation."

"If getting the data and understand it is a very complex process, it would not work and could harm the evaluation."

They also pointed positive aspects:

"Allow to have a more objective perception of the results of each stage of the evaluation."

"Possibility to have a more real perspective on the functional state of the patient in their environment."

CONCLUSIONS AND FUTURE WORK

There is a variety of objective sensor data that can be useful for monitoring and assessment of PD. However, there is the need to design interfaces that allow for clinicians to interpret and benefit from this data. If we are able to achieve this early, then clinicians will be better equipped to collaborate with researchers and designers in developing the next generation of data-driven consultation platforms and sensors.

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