DataPark: A Data-Driven Platform for Parkinson's Disease Monitoring

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ABSTRACT

Monitoring of people with Parkinson is performed in appointments and through questionnaires. Traditional methods are still limited and imprecise in capturing motor fluctuations, which, for example, jeopardizes accurate medication adjustments. There have been several efforts to develop sensors and digitize these assessments, in the clinic and at home. Conversely, there have been limited efforts to understand how clinicians deal with this gamut of information, and the opportunities and challenges of data-driven consultation. We present DataPark, a platform that enables subjective and objective data collection for Parkinson's disease. Clinicians are able to schedule subjective assessments which are then presented to patients through an interactive voice response system. On the objective component, patients may wear an inertial sensor during physical assessments and/or during free-living periods (i.e. wearing a bracelet for a set of days), generating usable reports on those activities. We report a preliminary two-month deployment in a rehabilitation clinic of the objective assessment components, and a follow-up focus group on the future integration of the subjective component.

INTRODUCTION

Parkinson's disease (PD) 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 [11]. 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 [3]. The democratization of sensing wearable technologies opened several possibilities in the continuous monitoring of people, and particularly in what relates to their

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health and wellbeing [5]. The amount of data these devices can produce, and the rich insights that can be derived from them, ask for a shift to a data-driven consultation paradigm, that needs to be carefully designed [8].

Based on a set of preliminary studies [1], we developed DataPark, a web platform that helps clinicians obtaining more information about the evolution of a patient's condition. Objective data is collected through tri-axial accelerometers (AX3 [6]). Clinicians can also author subjective data collection workflows, which trigger automatic calls using interactive voice response (IVR) technology, at the scheduled periods. All the collected information is then presented to clinicians in personalized reports. We resorted to 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. We also performed a focus group with clinicians on the authoring and collection of subjective data.

Our findings suggest that a data-driven approach for getting a summarized analysis of data from different environments can help clinicians to better understand patients' fluctuations during their daily life. It also showed patients are more engaged with therapy when they are faced with reports for their awareness and discussion. There was a concern with the limited available time for personalization of subjective assessments, mitigated by the existence of reusable templates.

DATAPARK

The main goal of this platform is to provide clinicians with better tools for understanding patients' fluctuations and health state. For that purpose, we used an inertial sensor to get objective data. We also collect subjective data using an IVR system that allows automatic calls to be performed at scheduled times or upon specific events. DataPark aims to allow clinicians to have access to the range of sophisticated assessment tools available in the literature in a way that augments their capability.

Use Case Scenario

Pedro is a 70 years old man with PD that lives with his wife, Maria, in Lisbon. In the last appointment, his neurologist (Dr. Manuel) asked him to wear a bracelet in the week before the next appointment and warned he would receive a call every night for him to score his function during the day. This ended up being a rough week for Pedro. He did not sleep well for two or three days and this had an effect on his mobility during the week. Dr. Manuel had also set open reporting for Maria, and asked her to register, through a call, specific events in Pedro's day. In the day of the appointment, Pedro goes to the clinic and starts the traditional test battery. The physiotherapists help Pedro in the tasks while they manage the test steps in a mobile application. At the end, Pedro goes to see Dr. Manuel: when he gets into the room, the Dr. is already looking at Pedro's week, and quickly notices large

Figure 1: An example template of a DataPark report, containing energy, charts, a physical activity chart and measures

Figure 2: An example template of a DataPark report, containing the several physical tests performed

fluctuations and identifies the rough nights. He jumps to the clinical assessment reports and sees that Pedro is actually performing better than in the last assessments and that the worse days were likely due to sleep deprivation. With Pedro and Maria, they discuss the fluctuations in the printed reports and try to understand how can Pedro improve his sleep patterns.

Objective Assessment

Sensors. Using AX3 allows us to collect data from the evaluation sessions, and also the daily fluctuations patients go through. A desktop platform, OMGUI, provides data extracted from the sensor. However, for clinicians it is not easy to understand and analyze this information. One of the reasons is the time and skill needed for processing the data. The output provided is composed of text files with tables of numbers, suitable for research but hardly for practice.

Free-Living. The main goal of the objective free-living assessment is to provide the resources for clinicians to better understand the patients' daily fluctuations.

To address that purpose, our analysis includes a battery of state-of-the-art algorithms to quantify physical activity, energy expenditure, sleep [2] [7] [9] [10]. Our main concern was how to present all the data collected/analyzed in such a way that would be an improvement for clinician's awareness of a patient's condition.

Our output consists in a report that is divided in different sections based on the algorithms in use. The visualization resorts to charts and numeric/textual measures. For each one of the type of the data available, we had to decide the best suited visualization. It was an iterative process involving prototyping and direct collaboration with clinicians. Figure 1 shows an example of the final report prototype.

We give the option for clinicians to create their own report according to the needs of each patient or the desired analysis. We allow filters to be applied (e.g. by day) and it is also possible to choose the charts to be presented. Finally, we provide the option to save the report as PDF file, with the main goal of handing it to patients.

Clinical. The goal of this component is to enable clinicians to objectively measure functional outcomes in clinical appointments, resorting to inertial sensors, and thus allow a more thorough awareness of patient evolution.

We developed an Android mobile application, DataPark Mobile, companion to the main platform. The main purpose is for supporting and guiding the clinician during the physical tests and questionnaires. Given that, per our preliminary observations, therapists already use their mobile phone stopwatches to time exercises, using the mobile phone to allow them to control the workflow of a session was seen as adequate. Still, we designed the application to work similarly to a stopwatch, with limited and large interactive elements.

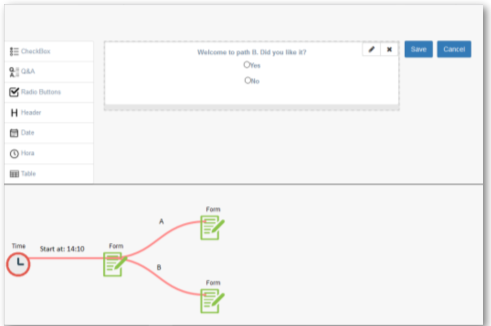

Figure 3: An example of the authoring tool for creating scheduled questionnaires by clinicians for the patients to fill at home

We cover physical tests like Time up and Go (TUG), Sit-To-Stand, ten meters walk, two minutes step, among others. The specific analysis of these exercises is made easier by the usage of the companion application: as the therapists indicate the exercise that the person is doing, our analysis can be specific to it.

Similarly to the free-living reporting, we provide usable visualization of the tests and responses. Each type of data has a set of measures to be presented (Figure 3. We compare the values obtained with reference values, in the literature. It is also possible to apply filters and to generate reports for printing.

Subjective Assessment

The goal of the subjetive assessment is to capture more information about patients outside a controlled environment. For that purpose we used an automatic call system (IVR) that supports the patients in filling questionnaires (this can also be done through a mobile application but we hypothesize the IVR system to be more inclusive). We developed a tool that enables clinicians to create questionnaires and schedule when they will be administered to patients. These questionnaires can be saved as templates and reused later. Patients receive an automatic call [4] that will guide them through a questionnaire. The patient can use the phone keyboard or the speaker for answering questions. Clinicians can visualize the responses and also have access to charts with summary data. In future iterations, this data will be possible to be visually integrated with the objective one.

PRELIMINARY RESULTS

For the objective assessment, we deployed DataPark in a rehabilitation clinic and residential unit for a period of two months. Subjective assessment consisted in a focus group with clinicians.

Free-Living

Twenty two patients wore the inertial sensor for a period of three or seven days, depending on the rehabilitation program. In the last day clinicians had access to a report with the analyzed data. To understand clinicians perspective we conducted semi-structured interviews. Although we did not receive direct feedback from patients, clinicians reported they enjoyed to have access to a report of how their week was. It was a free-living study, however, patients stayed at the clinic, so they were outside their controlled environment. This could influence their behavior because they knew they being evaluated. Regarding the readability of the reports clinicians said that they were easy to understand. They pointed concerns about the evolution of the platform (*"If getting the data and understand it is a very complex process, it won't work and could harm the evaluation."*), as well as positive aspects (*"Possibility to have a more real perspective on the functional state of the patient in their environment"*).

Clinical

Seventeen patients used the inertial sensors during clinical evaluations. Depending on the rehabilitation program it consisted in two (begin and end) or one evaluation sessions.

Several requests to improve and enrich the mobile application were made, when the therapists noticed that it could drastically improve their assessment completeness. Comparing the initial evaluation with the re-evaluation, ease of use was clearly improved, which shows that the application was easy to learn. As to the data, the therapists were impressed with the accuracy of the analysis and became confident in allowing the system to perform the analysis while they could focus more on the patient.

Subjective

We performed a focus group with three clinicians. The aim was to perform a preliminary discussion of using automatic scheduled calls for collecting subjetive data. The feedback was positive as clinicians clearly understand the possible benefits of using the system. They suggested possible applications for it and were excited with collecting information in different situations, e.g., getting information from the peers. Another example was going beyond monitoring allowing for interventions when something is detected or to get more information when a specific event happens (e.g., a call could be performed for a peer when a fall is detected, or the patient after a fluctuation to collect *in situ* feedback).

CONCLUSIONS AND FUTURE WORK

Research in sensing technologies for Parkinson is highly promising. However, after several years of advances it is still a mirage for clinicians. We report the design and deployment of a platform that seeks to holistically approximate objective and subjective assessment state of the art technologies to clinical practice. Besides providing this capability to clinicians, this endeavor also aims to receive their informed feedback creating a feedback loop that can converge technological advances with the needs of clinical practice.

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