

Development of Tablet Device App for Parkinson's Disease Patients' Continuous Self-Monitoring and Management

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Abstract: Clinical data collection in Parkinson's disease (PD) patients is typically limited to twice or thrice yearly visits with the neurologist. This creates potential for recollection bias and difficulty assessing disease severity and response to medication. We sought to develop a patient-driven mobile app that optimizes PD patient-reported outcome collection. We observed what health topics dominated discussion during appointments between patients and their neurologists. We assessed how often specific health events were included in the neurological history form filled out before the patients' appointments, how PD patients described symptom changes, and if PD patients kept a detailed account of their health events. We created an interactive prototype of an iPad app designed with specific patient physical and cognitive challenges in mind that would help PD patients keep detailed records of daily health status. PD patients, caregivers, and neurologists tested the prototype app, and iterative design changes were made based on their feedback. The app features a cognitively simple user interface that requires little instruction, an analog scale with graphical presentation for documenting slowness, tremor, walking/balance, dyskinesia, mood, speech and additional video/audio input that can provide neurologists with objective accounts of PD patients' health condition. We interviewed PD patients who participated in the initial pilot to evaluate usability of this app in a PD population. The pilot demonstrated that an iPad-based app was easy to use. PD patient testing of the iPad app is ongoing. Once the study is completed, several validity measures will be assessed by independent interviews with patients and providers.

Keywords: Mobile application, medical history taking, monitoring, Parkinson's disease, self-management, tablet device, patient adherence, telemedicine.

1. INTRODUCTION

Parkinson's disease (PD) is a chronic, slowly progressing disease of the nervous system that manifests primarily as movement deficits [1]. PD patients face both cognitive and physical challenges due to the disease and its treatment. Mild cognitive impairment in PD has a cumulative prevalence of about 80%, and this can impact their executive abilities [2]. PD patients exhibit motor symptoms including bradykinesia, which must be present for diagnosis, as well as rigidity and tremor in various proportions [3-5]. These symptoms often come about very slowly due to the chronic nature of the disease. Currently there is no cure for the disease. The goal for PD treatment is to help PD patients maintain a good quality of life despite their challenging mobility problems.

Despite active research investigating potential biomarkers, there are no established molecular tests or biomarkers that can be used to diagnose PD [6]. Physicians

diagnose PD based on the patient's medical history and an on-site physical examination [7]. Because medical history is one of two crucial sources of information used to diagnose and evaluate PD, reliable medical history tracking is essential. It is imperative to obtain an accurate health history for a PD patient but that can be difficult because many early symptoms of PD occur decades before mobility problems appear [8]. Furthermore, the disease progresses over the course of the patient's lifetime and keeping an accurate medical history for long time periods can be challenging.

An integrated summary of disease data is necessary for physicians to best treat new PD patients, predict patient prognosis, and evaluate disease status. More short-term and detailed data about symptom fluctuations are required for physicians to make changes to a patient's current prescriptions and treatment plan, while long-term tracking provides comprehensive information about disease progression. This type of information could also greatly enhance telemedicine management of PD. Telemedicine provides PD patients access to movement disorder specialists regardless of their geographical location [9]. It is our intention to create a tablet-based tracking system that is more accurate and useful to the physician by integrating short-term tracking of a patient's symptoms and medication.

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2. MATERIAL AND METHOD

We studied existing evaluation tools and general health recording systems for Parkinson's disease. In particular, we focused on the paper versions of the neuromedical history forms and the Hauser diary [10-12], which are filled out by the patient or their caregivers before their neurologist appointments to provide a summary of the patient's medical history. Twenty-two PD patients were observed during scheduled appointments with their doctors at the NIH Parkinson Clinic at the National Institute of Neurological Disorders and Stroke. Immediately following the appointments, patients and physicians were interviewed about the current neuromedical history forms. Specifically, we were interested in knowing about the reliability of the information from those records. We also asked what the doctors wanted to see in the medical histories from patients.

After these interviews, a mock-up of an electronic version of several Unified Parkinson's Disease Rating Scale (UPDRS) scale-based questions was created as an iPad app. Prototype testing in patients, performed in 18 of the 22 patients interviewed, focused on validating a minimum button size [13] and the level of difficulty patients experienced with typical hand gestures on a tablet device. After collecting both patients' and physicians' requirements and accounting for patients' physical limitations using tablet devices, we created the *Movement Disorders Journal (MD Journal)* app for the iPad.

3. RESULTS AND DISCUSSIONS

We built an iPad app called the *MD Journal* that allows both a detailed, short-term look at a PD patient's disease as

well as a longitudinal view of disease progression. (Fig. 1) shows the home screen of the app. This app has three main components: a medication tracker, a "Parkinson's Disease Diary (PD Diary)" [10], and daily tracking modules for long-term symptom and side effect tracking. In order to easily communicate the data, we have created a graphical viewer for visual summaries of these data.

3.1. Medication Tracker

The medication tracker is designed for PD patients, caregivers, and medical staff. It provides a platform to store a medication's name, dosage, and dose frequency along with the name of the prescribing doctor. The app provides two ways of viewing the medication schedule; the medication schedule can be organized chronologically (Fig. 2a) or by medication name (Fig. 2b).

The medication tracker also allows the PD patient to indicate when a medication dosage was taken and if that occurred at its scheduled time. An audible alarm to guide medication administration can be turned "on" or "off" as desired. The medication tracker not only aids in medication compliance, it also provides doctors with more detailed information for analyzing treatment effectiveness.

3.2. PD Diary

For short-term data collection, we created the "PD Diary" section of the app, which serves the same purpose as paper-based diaries that track in 30-min intervals in that patients record their motor status, specifically the absence or presence of dyskinesia, and the timing and dosage of their medication administration. If dyskinesia is present, PD patients indicate the degree of troublesomeness of the dyskinesia.

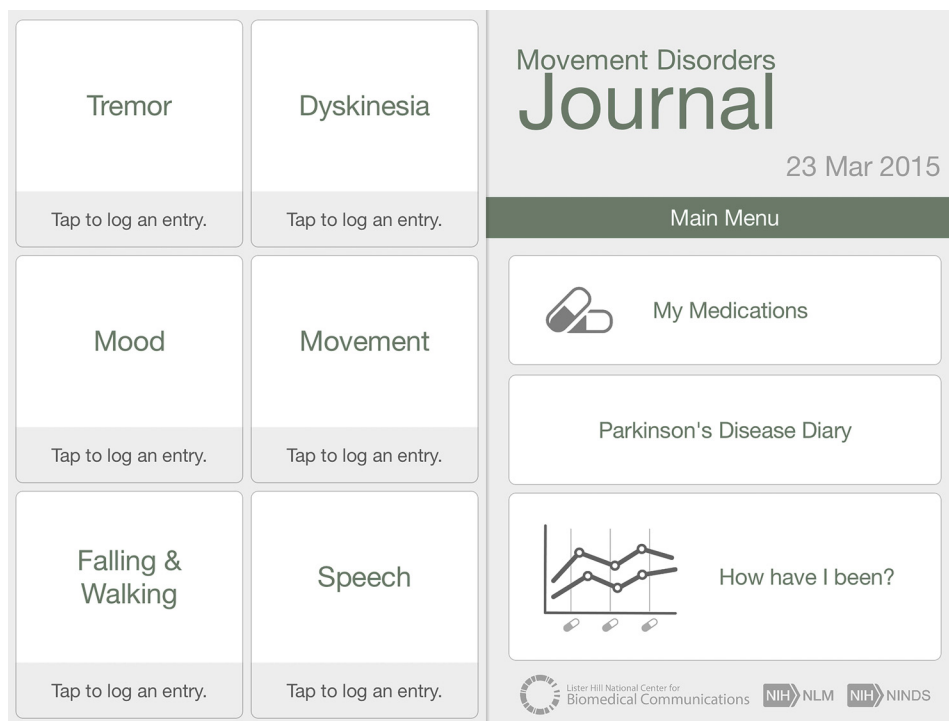
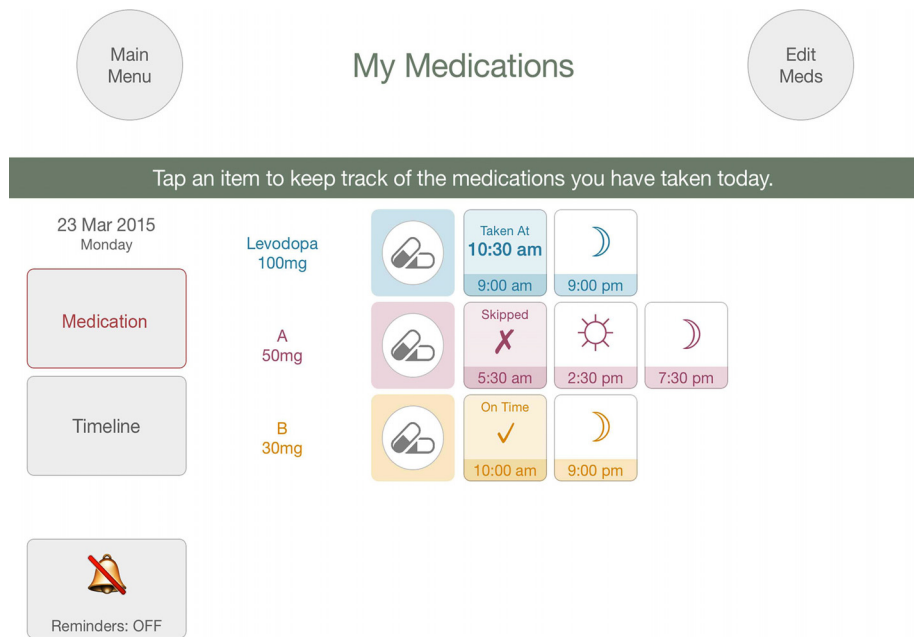
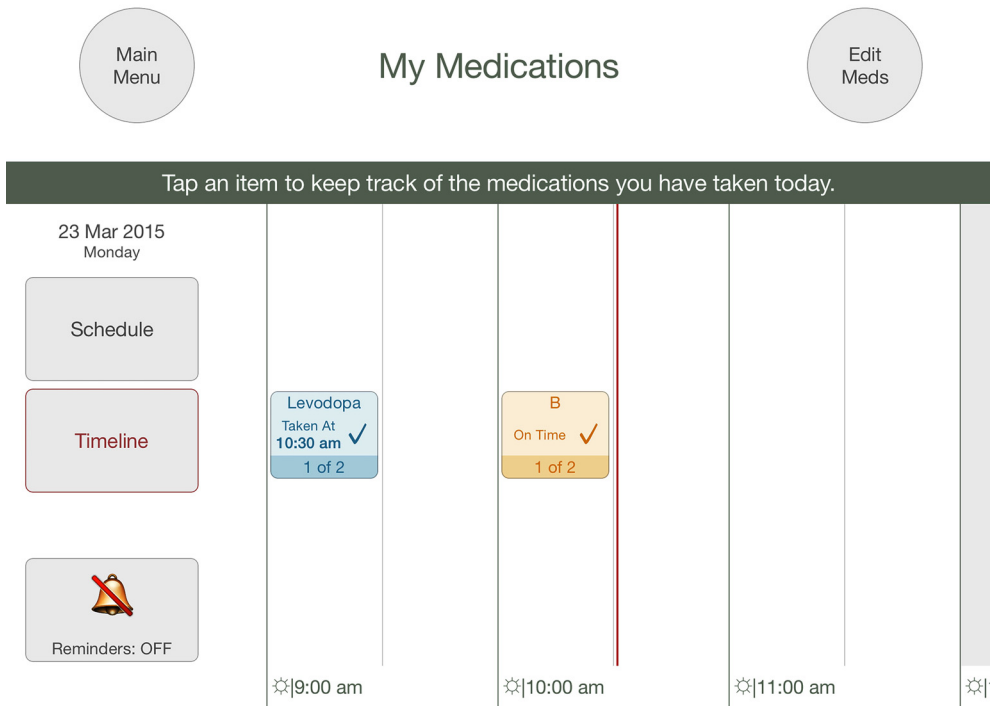


Fig. (1). The home screen of the *MD Journal* app shows the three main components of the app and the "How have I been?" graphical viewer. The medication tracker is found under the "My Medications" module and the six daily tracking modules are listed separately on the left side of the home screen.



(2a)



(2b)

Fig. (2). **2a.** The “My Medication” screen shows medications arranged by medication name. The different medications are arranged vertically. Detailed information about each drug is arranged horizontally from left to right; the name of the medication and dose are shown followed by an optional photo of the medication, and then each dosage is listed. If the box has not been pressed, the dosage box lists the scheduled medication time. Should a patient take a dose of medication at a time different than originally scheduled, the patient can note that on the dosage box. As shown in the first dose after the photo of levodopa, the box indicates that the dose was taken at 10:30 a.m. and not at the scheduled 9 a.m. time. If a dosage was skipped, it is indicated with an “X” and “Skipped” label. When the medication is taken on time, this is indicated with an “On Time” label. Both views for “My Medication” allow the user to easily turn the alarm on or off with the alarm button in the bottom left corner (also see Fig. **2b**). **2b.** The “My Medication” screen showing medications listed chronologically. Each medication box lists the name of medication, the time it was taken, and how many doses of that particular medication. The first box indicates that levodopa was taken at 10:30 a.m. and that is the first of two doses for that day. The second box shows that medication “B” was taken on time and is the first of two doses.

The options for status are as follows: “asleep”, “off”, “on with no dyskinesia”, “on with non-troublesome dyskinesia”, and “on with troublesome dyskinesia” [10] (Fig. 3a). During “off” periods, patients experience underlying symptoms of PD because levodopa has worn off [14]. When PD patients are responding well to levodopa during “on” periods, they move with less difficulty, but can experience dyskinesia.

We have improved 30-min interval tracking diaries by displaying the results as a graph so the user can have a better understanding of the PD patient’s motor status during a day. This graphical viewer allows the patient to see a graph of motor status over the 24-hour tracking period (Fig. 3b). In interviews with PD patients during prototype testing, the patients valued having the ability to see the logs of their motor status represented as a graph. In regards to function, we added a comparison with specific medication timing that allows direct evaluation of the medication administration and its correlation with symptoms. An alarm feature has also been added to remind the PD patients to log their motor status. The alarm notifies PD patients every 30 minutes for 24 hours and can be turned “off”, which is especially useful for periods of sleep. If a “PD Diary” log is missed, the log defaults to “asleep” because we operated on the assumption that if an entry is missed, the PD patient may be sleeping. However, the entries can be easily changed if that is not the case.

Typically, doctors manually compare the paper-based 30-min interval tracking diaries with the PD patient’s levodopa schedule. The *MD Journal* app tracks the patient’s symptoms with actual timing of medication intake allowing physicians to calculate the drug dynamics more quickly and with better accuracy.

The “PD Diary” section of the app ports over the medication list from the medication tracker section. All the PD patient has to do is select one of the medications to track at the beginning of the “PD Diary” set-up. The user is asked to record the exact timing of the medication intake during the 24 hours of tracking. Once the user records the timing of the medication, the timing is overlapped on the graph as seen in (Fig. 3b).

3.3. Daily Modules for Long-term Tracking

One tool that is missing from PD management is a long-term symptom and side effect tracker. We designed the daily tracking modules to address this unmet need. For longitudinal data collection, six symptoms considered most relevant and representative, as well as most appropriate for reliable long term tracking, were picked from the UPDRS [15]; these symptoms are: tremor, dyskinesia, walking & balance, speech, mood, and movement. This is intended for PD patients to report the average of each symptom on a daily basis. The scales from UPDRS were modified to a daily scale and each has five choices (Fig. 4a, b).

The daily tracking modules were designed to provide an easily shared method of communicating the long-term history of a PD patient’s disease progression. The daily modules entries can be viewed as a list or as a graph within the app (Fig. 5). We also integrated audio, video, and text memos into the daily tracking modules to enable patients to create

more detailed information entries (Fig. 6). These representations of the data aim to provide an at-a-glance view of important health data.

Data from this app can also be exported as a comma-separated value file to enable sharing with healthcare providers. Eventually, this app will be integrated into a secure sharing system to allow for automatic sharing with healthcare providers upon patient consent.

3.4. General Design Considerations

While many health apps are created to educate healthcare providers, this app was created with the patient in mind. The *MD Journal* app was designed to have a simple user interface to ensure that PD patients experiencing cognitive difficulties could still easily use the app. Every effort was made to decrease the number of interactions or clicks that one must perform in order to complete a log. The daily modules tracking mood, speech, tremor, dyskinesia, slowness of movement, and falling/walking difficulties have either one or two questions that the PD patient must answer (Fig. 4a, b). Each screen was designed to provide enough information to guide the completion of the required tasks while keeping text and images to a minimum so as not to overwhelm and confuse the user.

Special consideration of PD patients’ physical capabilities was taken into account when designing the modes of interaction with this app. User testing with an early prototype of the *MD Journal* app demonstrated that swiping and pinching movements on the iPad screen were difficult for many PD patients. Thus most interactions within the *MD Journal* app are focused on tapping and when swiping is required, a large screen area is activated to respond to this motion. Early prototype testing also allowed us to validate the previously published optimal minimum button size for people with movement disorders [13]. The buttons are designed to be large enough that PD patients could still interact with the app even when experiencing tremors.

The audio, video, and text inputs were integrated into the app in order to facilitate communication between patients and healthcare providers. If a patient’s tremor is too severe, he or she could opt to make an audio or video recording. Similarly, if a patient is experiencing speech difficulties, they have the option to type a memo. The audio, video, and text inputs could provide informative data about the severity of tremor for the movement disorders specialist.

Despite the fact that the *MD Journal* was designed for PD patients, it can still provide important information to physicians. Our motivation in creating the daily tracking modules is to provide physicians with essential information while removing the noise that an extremely detailed daily diary, like a 30 minute interval diary, would introduce if done daily for long periods of time. The aim of this component of the *MD Journal* app is to distill the PD patient symptom and side effect information provided to the physician to what is minimally essential.

We believe that the convenience, simple user interface, and consideration of cognitive and physical difficulties faced by PD patients in designing the *MD Journal* app will enhance patient adherence, foster patient-doctor communication, and improve patient care and disease management.

Record Your Dyskinesia Level

Select a symptom level.

Asleep

I was sleeping.

Tap to Select

Off

Original PD Symptoms

Stiffness, marked decrease in mobility, or immobility.

Tap to Select

On

No Dyskinesia

Good or practically normal mobility

Tap to Select

On

Non-troublesome dyskinesia

Not troubled by involuntary twisting or turning movements

Tap to Select

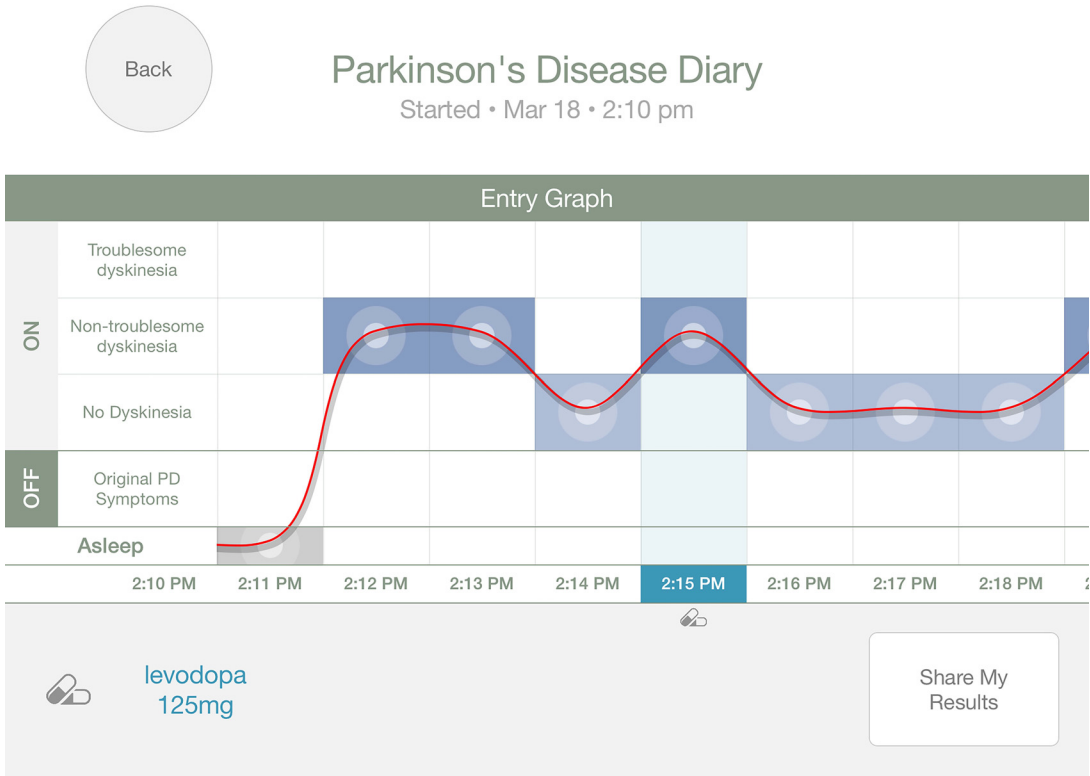
On

Troublesome dyskinesia

Troubled by involuntary twisting or turning movements.

Tap to Select

(3a)



(3b)

Fig. (3). **3a.** The “PD Diary” dyskinesia scale selection screen. This is the screen that appears when it is time to enter one of the 30-minute interval logs. **3b.** The graphical viewer of diary entries within the “PD Diary” component of the app shows the motor status overlaid with the time medication was taken (see pill icon below the 2:15 pm time period on the graph). Please note that the intervals were set at 1 minute intervals for user testing; the interval length will be changed to 30-minutes before the app is further tested by PD patients.

Back Tremor Continue

What proportion of the waking day are your tremors present?

None	1-25%	26-50%	51-75%	76-100%
Tap to Select	Tap to Select	Selected	Tap to Select	Tap to Select

(4a)

Back Tremor Continue

In general, how would you rate your tremor today?

Absent	Slight	Moderate	Marked	Severe
	Infrequently Present	Bothersome	Interferes with Many Activities	Interferes with Most Activities
Tap to Select	Tap to Select	Tap to Select	Selected	Tap to Select

(4b)

Fig. (4). **4a.** The “Tremor” module for daily tracking contains two questions. This question asks, “What proportion of the waking day are your tremors present?” The question and answer options are based on the UPDRS. **4b.** The second question within the “Tremor” module for daily tracking asks, “In general, how would you rate your tremor today?” The question and answer options are based on the UPDRS.

We hope that the *MD Journal* app will increase patient adherence in logging their entries into the “PD Diary” in real time and in taking medications on time. The alarm option could increase PD patient time adherence in making entries every 30 minutes. This feature is provided to help deter patient “hoarding”, in which a patient tries to recollect and log all their entries at a particular time period after the fact instead of logging their status at each 30-minute interval [16].

The medication alarm feature of this app will help patients with medication adherence, taking their prescribed medications, and time adherence, taking their medications on time. The importance of medication adherence can’t be overstated, as non-adherence is associated with deterioration of motor function and insufficient symptom control, both of which lead to lower quality of life [17].

Evidence suggests that patients are more compliant when using electronic recording systems compared to paper-based systems [16]. We hypothesize that patients will demonstrate

increased adherence in making entries due to the alarm features and the convenience of having three useful tools in one app.

This app can provide a means of communication between the PD patient and their movement disorders specialist. PD patients often only see their specialists once or twice per year, however, it is possible that a PD patient’s condition has changed and needs to be monitored by the physician between visits. The *MD Journal* app is a tool for remote communication between the PD patient and their movement disorders specialist.

When visiting with a new physician or new facility, we observed that PD patients have to spend a substantial amount of time trying to explain their medication regimens during appointments. This was a source of frustration for some patients. Because this app can illustrate the medication schedule either in chronological order or by medication, we think that these features could significantly shorten the time spent discussing the medication schedule.

The “PD Diary” could also enhance patient care. While it was once thought that being “on” is better for the PD patient than being “off”, studies have shown that being “on with troublesome dyskinesia” is considered just as bad as being “off” by PD patients [25]. In order to maximize patient quality of life, physicians can use these data from the “PD Diary” to carefully tailor a PD patient’s levodopa dosage and frequency to maximize “on” times with no or non-troublesome dyskinesia.

Currently, telemedicine provides a means for remote interaction between patient and movement disorder specialist using video/audio conference technology for patients who have difficulties accessing PD movement disorder specialists. However, similar to in-office visits, telemedicine appointments still only occur once or twice per year. The *MD Journal* app would be a powerful augmentation of the telemedicine experience because it provides information about a PD patient’s status in the time between telemedicine visits. The proposed sharing functionalities of this app can allow PD patients and their caregivers to get feedback from their movement disorder specialist without being limited by appointment schedules.

The ability to attach a video clip to a journal entry in the *MD Journal* app can provide additional visual information about the patient’s symptoms during the periods between appointments. Furthermore, PD patients and their caregivers do not always understand the difference between tremors and dyskinesia [26]. Bringing a video recording to a movement disorders specialist can help the patient and caregiver to learn how to distinguish the two. This would improve the accuracy of symptom and side effect tracking, which, in turn, helps the movement disorder specialist to tailor treatment for the patient and improve overall patient care. Additionally, the video capture feature of the *MD Journal* app might be particularly useful for PD patients when describing their symptoms to their primary care physician, who typically has less experience with tremors, dyskinesia, etc. than a movement disorder specialist.

Finally because the *MD Journal* app daily modules use medical terminology from the UPDRS, PD patients and their caregivers can become familiar with these terms over long-term usage of the app. This familiarity with medical terminology can help to improve communications between PD patients and their doctors.

There are many potential future uses for this app. We hope that it will be widely used by the PD patient community, their caregivers and physicians. The long-term tracking ability of this app can give movement disorders specialists ample data to help make treatment decisions for their PD patients.

Patient-centered outcomes are a critical component of research and clinical practice for conditions like PD, where clinical reports and assessments are central to the care process. This app adds important tools in this context.

Our plans for testing the app include successive trials in subjects without and then with various levels of mild cognitive difficulties. Should this be successful, we will conduct an extended study in the home setting. In the future, we hope to use this app to help determine effectiveness of treatments

in addition to providing a tracking tool. We are interested in using the *MD Journal* app prior to, during, and after a particular treatment. These tracking data will provide quantitative information to help determine treatment effectiveness. Ultimately, we hope to seamlessly integrate the data from the *MD Journal* app into electronic health records.

LIST OF ABBREVIATIONS

MD Journal	=	Movement Disorders Journal
PD	=	Parkinson’s Disease
UPDRS	=	Unified Parkinson’s Disease Rating Scale

CONFLICT OF INTEREST

The author(s) confirm that this article content has no conflict of interest.

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