

Challenges of Parkinson's Disease: User Experiences with STOP

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ABSTRACT

Parkinson's disease (PD) is the second most common neurodegenerative disorder, impacting an estimated seven to ten million people worldwide. Measuring the symptoms and progress of the disease, and medication effectiveness is currently performed using subjective measures and visual estimation. We developed and evaluated a mobile application, STOP for tracking hand's motor symptoms, and a medication journal for recording medication intake. We followed 13 PD patients from two countries for a 1-month long real-world deployment. We found that PD patients are willing to use digital tools, such as STOP, to track their medication intake and symptoms, and are also willing to share such data with their caregivers and medical personnel to improve their own care.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in ubiquitous and mobile computing.**

KEYWORDS

Parkinson's disease; smartphone; logging; empirical evaluation

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1 INTRODUCTION

Parkinson's motor and non-motor symptoms have a major impact on patients' quality of life [9, 28]. From a patient's perspective, the three most prevalent symptoms are tremor, slowness and stiffness in early stages of PD, and medication "wearing-off" in later stages [32]. People with PD visit their clinician approximately one or two times a year, but their symptoms can fluctuate within hours or days [43]. Symptom evaluation is performed mainly based on trained visual observations.

As PD progresses, the doses and diversity of drugs patients need increase, while their effectiveness decreases. In addition, the medication effects on managing PD symptoms are not immediate. Oftentimes, there are other diseases burdening the patient, further confounding the symptoms reported. Medication management is seen as the most important aspect in managing multiple conditions [10]. It is burdensome for patients to keep a medication diary and to ask them to recall detailed medication intake information after a few months. Further, estimating changes in motor symptoms is challenging. Hence, current practice is prone to recall bias and there is a need for tools that aid with semi-autonomously logging of medication intake information, as well as on daily PD symptoms.

We present a mobile tool STOP that PD patients can use to log their medication intake and measure the effects of the medication to the motor status of a hand. STOP provides a ball-balancing game that logs the smartphone's accelerometer, gyroscope and rotation sensors' data; and facilitates medication intake logging. Medication logs act as an introspection mechanism for patients to check and reflect upon their medication adherence. We evaluated our tool with 13 Parkinson's Disease patients recruited from two different countries. We started by interviewing our participants to better understand the challenges of living with PD, namely regarding medication and restrictions PD poses. Secondly, we evaluated STOP

usefulness in understanding medication adherence and evaluating symptoms. In this paper, we report on our 1-month long deployment in the real-world and users' experience using STOP.

2 RELATED WORK

Coping with PD is difficult as its symptoms can impact one's ability to perform daily tasks. Modern smartphones have a wide variety of inbuilt sensors useful for observing PD symptoms. The systematic literature reviews by Rovini *et al.* [35] and Klimova [19] exemplify many studies' use of mobile applications for assessment and diagnostics of symptoms, and for body motion analysis. Arora *et al.*'s [1, 2] study with PD-diagnosed and healthy participants used an Android application to monitor voice changes, gait, posture, finger tapping, and response time, to infer symptoms that were later used in regular weekly video-conference meetings with a doctor. Based on the collected data, they estimated the symptom severity as UPDRS points (Unified Parkinson's Disease Rating Scale [11]). The UPDRS scale is used for general assessment of PD. However UPDRS **does not track the daily or hourly changes** in the symptoms. With STOP, we want to fill in this gap by providing **intermittent yet daily measurements indicative of hand tremor PD symptoms with reasonable accuracy and minimal user burden**. We do not target to estimate the UPDRS overall PD score, but to provide data that could be helpful to doctors to better assess the effectiveness of the prescribed medication. On the other hand, having such on-demand check of PD symptoms at hand allows PD patients to quickly revisit their medication log and whether the hand tremor symptoms are getting significantly worse.

LeMoyné *et al.* [21] attached an iPhone to a glove and leveraged the accelerometer to evaluate the severity of patients' tremors. Such approach is not practical: using a glove in daily measurements is burdensome, and attaching the phone alone might be challenging for PD patients and does not scale for a real-world deployment. On the other hand, Barrantes *et al.* [4] and Woods *et al.* [46] show that the smartphone accelerometer is capable to classifying essential tremors and PD tremors, which inspired our work.

Nunes and Fitzpatrick [25] investigated self-care with PD by analyzing online community posts and interviews describing the daily efforts of PD patients, and divided self-care into four categories: taking medication, exercising, adapting lifestyle and accepting the consequences of the disease. We revisit their findings in the Qualitative Findings and Discussion section.

Not exclusive to only PD, medication non-adherence is a common problem that considerably lowers the effectiveness of a medication-based treatment [13]. Medication logging is effective to measure [12, 17, 29] and even improve [8, 41] medication adherence for PD patients, a functionality we deemed as essential for STOP. There are a variety of technical solutions focusing on improving medication adherence and managing medication, offering medication reminders and different overviews of medication compliance, such as Ubimeds [39] and MediFrame [7], as well as electronic pill boxes, such as MedTracker [15]. Not requiring specialised hardware, the high availability of smartphones today can provide a convenient medium to manage and maximize medication adherence [6, 8, 37] by software application functionalities (e.g., notifications, logs, feedback).

In PD care, in addition to the medication diaries, patient self-reports are used to track motor fluctuations [14, 23, 27, 31, 34]. For example, tracking medication "wearing off" and "in effect" time slots is prone to diary fatigue [31] as it requires repeated measurements (e.g., every 30 minutes). On the other hand, fall diaries [3] are widely used for recording the time and circumstances surrounding a fall event. Being less often, they are less laborious to maintain updated.

Similar to STOP, researchers have used smartphone applications and platforms to combine self-evaluation and sensing. For example, ParkNosis [36] assists in PD diagnosis via a spiral drawing test, tremor measurement using smartwatch, tapping tasks and an assessment questionnaire, aiming to an early diagnosis of PD. Lakshminarayana *et al.* [20] show that tracking PD with a mobile app can improve medication adherence, and the collected data can improve the quality of clinical consultation. They designed a Parkinson's tracker app with self-monitoring features, medication reminder and log, and games for monitoring finger tapping responsiveness and cognition. We extend this work beyond reaction time by adding hand tremor sensor data. Our work utilizes the smartphones' sensor to assess tremor and leverages gamification as a methodology to increase the users' engagement to the routine assessment, a limiting factor for systematic symptom tracking [33]. With the purpose to understand the lasting effects of medication, patients are prompted to regularly play a brief 10-seconds long ball-balancing game. Playing a game is unobtrusive, it doesn't draw attention in public places.

3 STOP

This study is an in-the-wild pilot of the first implementation of STOP. Our overarching goal is to leverage mobile sensing and to design a set of digital tools for supporting PD patients and their medical clinicians. STOP is designed together with a medical expert specialized in Deep Brain Stimulation (DBS), and took into account several design guidelines [26, 38, 42, 44] (details in following sub-chapters). Taking inspiration from earlier literature of using accelerometer to assess PD tremor [1, 4, 26, 34, 46], STOP extends this work to leverage smartphone's sensors for regular symptom and medication taking for PD in a gamified approach. Here, we report the real-life user experiences and design implications for the next iteration of STOP.

Elderly is a very diverse, challenging to reach out to group of participants, depending greatly of how familiar are they with mobile devices. More crucially, for PD patients, every person has a unique mix of symptoms. We must acknowledge it is difficult to estimate the longitudinal burden of logging, especially due to how PD uniquely affects each end-user. Hence, we built STOP and collect the corresponding end-user feedback in a naturalistic setting to better understand how to best fit their personal life.

STOP is available for both Android and iOS platforms. The application core functionalities are: an accelerometer-based game that quantifies patients' hand motor performance, a medication journal where users log their medication intake time, and a daily survey for reporting the overall severity of PD symptoms.

3.1 Accelerometer-based Ball Game

Politis *et al.* [32] asked PD patients to rank their symptoms and gained insights on what symptoms restrict the patients' quality

of life the most. Tremors were the second-most mentioned motor symptom in the early stage of PD, and the most mentioned motor symptom in the later stages of PD. According to Weiss *et al.* [45] and LeMoyné *et al.* [21], a smartphone’s accelerometer sensor can quantify Parkinson’s tremor and the performance of the Timed Up and Go (TUG) test. Our application uses a gamified component that is designed as a brief ball-balancing game: the user holds the smartphone horizontally on the palm of the hand (see Fig. 1) for a set amount of time, keeping a ball at the center of the screen, inside the inner circle (Fig. 2). Once the time expires, a score is given. During the game session, STOP logs the accelerometer, linear accelerometer (acceleration without gravity’s force), gyroscope and rotation sensors, the position of the ball in relationship to the inner circle’s center, and screen pixel density.



Figure 1: Hand and device position while playing the game.

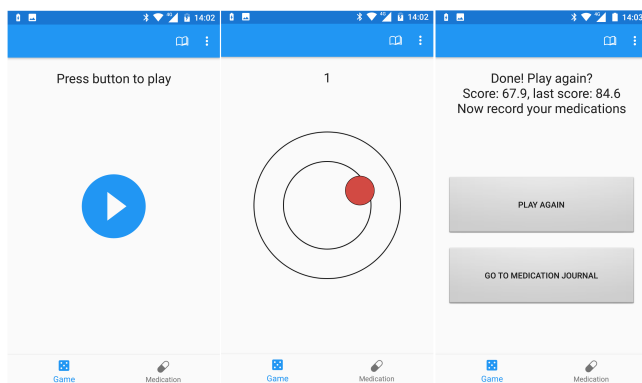


Figure 2: The ball-balancing game. The purpose of the game is to keep the red ball still in the center of the circles.

The game’s score is calculated as $(1 - MD/MSD) * 100$, where MD is the Mean Distance in pixels between the center of the screen (x and y coordinates) and the ball’s current coordinates; MSD is the Maximum Screen Distance possible (maximum x and y, accounting for the screen resolution). The score ranges between 0-100; a score of 100 is given if the ball stays perfectly still in the middle of the circle, and is lower if the ball moves from the center. In practice, it is extremely challenging to obtain a perfect score (i.e., 100). In [18], a baseline was empirically determined with 10 healthy individuals. A value in the range of 96 or above is considered for no symptoms, which we adopted in our analysis.

For reusability and flexibility, the game is customizable: the inner circle size, the ball sensitivity (i.e., how much motion is needed to move the ball in the screen) and the game time limit. Based on our baseline measurements, we kept the circle size (150 pixels) and game time fixed (10 seconds) in the trial. Then, to gamify and challenge our participants, we randomly change device’s accelerometer sampling frequency, defined as the game ball sensitivity, four times per day between 1 (slow) and 5 (fast) for the Android version.

3.2 Medication Journal

Medication logging is effective for improving medication adherence for PD patients [8]. We designed the journal interface given the range of interaction limitations of PD patients [26, 42, 44]. The actionable buttons are large and change color on touch (see Fig. 3). The timekeeping was planned to be conducted with as short interactions as possible, as suggested by [38]. Users can choose manual input (‘Now’ and ‘Specify time’ buttons) or the voice input, powered by the natural language processor provided by Wit.ai [22]. The journal recognizes human speech-style inputs like “three hours ago” or “yesterday 1 p.m.” minimizing the burden of touch input for PD patients. Ultimately, the medication journal provides a list of past intakes as a medication adherence retrospective tool on how participants follow their prescribed medication schedule.

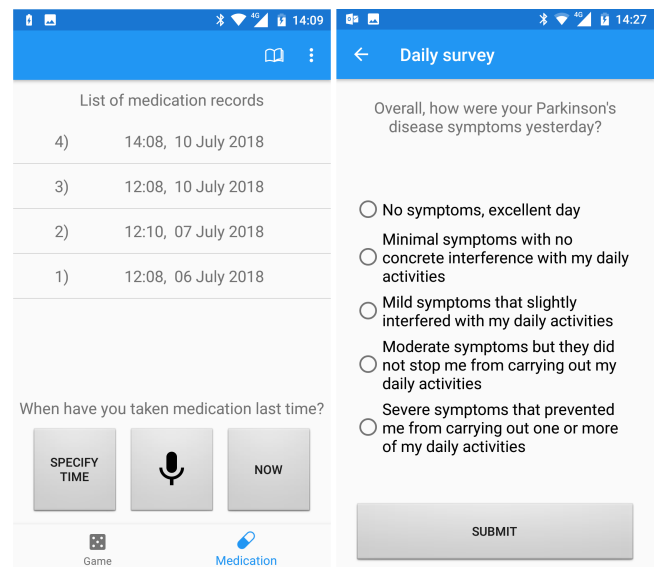


Figure 3: The medication journal with different input options (left) and daily PD symptoms’ survey (right).

3.3 Daily Symptoms Survey

Every morning at a random time between 10:00 and 11:00, we prompt participants to perform a retrospective overall rating of their PD symptoms. The response options are shown in Fig. 3; they are loosely derived from the symptom evaluation used in the UPDRS section II (Unified Parkinson’s Disease Rating Scale, part II) [11]. The UPDRS-II scores assess some PD motor symptoms severity and their effect on daily activities. The higher the score, the more severe the symptoms. The daily survey gives insight into the daily variation of PD and its effects on the users’ quality of life. The survey is a more traditional and generic PD symptom tracking approach than the gamified option, that focuses hand’s motor symptoms.

3.4 Notifications as Engagement Triggers

In STOP, notifications are used as reminders to regularly play the game, record medication intake times, and to deliver the daily symptoms' survey. Notifications are shown randomly during five notification periods, one per period. The game and medication reminders are shown in the morning (8:00-11:59), at noon (12:00-14:59), in the afternoon (15:00-18:59) and in the evening (19:00-21:59). The retrospective daily PD symptoms' survey is delivered between 10:00 and 11:00.

3.5 Data Collection with STOP

We collected the following data using STOP:

- **Patient characteristics:** when the application is opened for the first time, we ask for the participant's age, how long ago PD was diagnosed (e.g., months, years ago), which medications are being taken, and a self-evaluation of PD symptoms using the UPDRS part II scale (see Fig. 4).
- **Mobile device sensor data:** collected during the game session time from four smartphone's sensors – accelerometer, linear accelerometer, gyroscope and rotation.
- **Medication time data:** the medication intake time from the journal.
- **Notification data:** when the notifications are shown and when they are opened.
- **Feedback:** feedback on-demand about the app typed by users.

Figure 4: Participant profile query and medication input screen.

4 EXPERIMENTAL SETUP AND DEPLOYMENT

4.1 Recruitment

We recruited people with Parkinson's from two countries, Finland and the UK. In these locations, we were able to conduct the interviews in the native languages of the countries. In Finland, we reached participants through a discussion and knowledge sharing forum for Parkinson's patients and their relatives, and through its Parkinson's association's official communication channel. In the UK we used our Parkinson's patient network. In both places, we encouraged current participants to invite other people with Parkinson's they might be in touch with. We considered the participants as one sample, comparing populations in these countries is not our research goal.

The study required the use of the STOP for one month and participation in three interviews (at the start, half-way, and end of the study). For eligibility, the participants were required to have a clinical diagnosis of PD and to own a smartphone (Android 4.4+, or iOS 10.0+), with an internet connection. If participants completed the study protocol, they were rewarded with a store gift card, 100€ in Finland and 50£ in the UK. The amounts were different due to budget availability.

We recruited 14 participants over a 3-month period, eight from Finland and six from the UK, nine females and five males. One left the study after the initial interview due to family issues. Five users had an iOS device, while eight used Android. The age range of the participants was 52-73, with PD diagnosed 2-17 years ago. The number of different PD medicines in use varied from 1 to 5, and daily medication intakes from 1 to 7 times per day. Three participants had a deep brain stimulator (DBS). Using the UPDRS scale II score, participants self-evaluated their symptoms, with scores ranging from 3 to 31 (a higher score means higher symptom level). See Table 1 for a detailed participant overview.

4.2 Installation and Guide

The application was delivered via Google's Play Store for Android devices and Apple's App Store for iOS devices. As participants were geographically distributed in Finland, we conducted the initial interview over the phone. The installation link was sent over SMS, and the study guide, including screen captures and an overview of the app functionality, was sent by e-mail. In the UK, we had an initial face-to-face interview where we installed the application and walked through the study guide.

4.3 Consent Protocol

The study consent was embedded into STOP. In addition, the participants in the UK signed a paper version. Our team is certified on HIPAA, GDPR and ethical research guidelines. The application data is securely sent to our hosted server every 30 minutes over Wi-Fi or cellular data connection. Participant identification is done via a randomly generated 128-bit Universal Unique ID (UUID), assigned when installing the application for the first time. The application allowed participants to quit the study at any time, which deleted the collected data from their smartphone and our server.

Table 1: Participant self-reporting details

	P01	P02	P03	P04	P05	P06	P07	P08	P09	P10	P11	P12	P13
Age	69	52	57	60	67	65	58	71	72	66	65	73	54
Years PD diagnosed	6	3	2	11	2	17	6	5	10	5	3	13	8
DBS	No	No	No	Yes	No	Yes	No	No	No	No	No	No	Yes
Num. of PD medicines	2	4	2	5	1	5	4	1	4	3	2	4	3
Num. of daily medication	1	5	1	4	2	7	5	4	5	4	4	5	5
UPDRS II score	13	5	5	20	13	31	11	9	16	10	3	8	11

4.4 Interview Protocol

Each participant was interviewed three times, over the phone or in person. The interviews took approximately two hours in total for each participant. The first interview was conducted before installing STOP, second at half-way through the study, and the last at the end:

- **Initial interview:** to understand the daily life challenges of PD, and mobile device usage. Concretely, we asked 1) what they use the phone for, 2) how they respond to notifications, and 3) how they would describe their phone usage. We also inquired about the 4) challenges PD has on their daily lives and 5) on mobile device usage. We asked the participants to 6) describe their medication regimen, if they have solid schedule for medication, or if they have some medication taken when needed.
- **Half-way:** focused on STOP usage feedback. We asked 1) how they play the game, 2) if they use one or two hands, 3) how often they played, and 4) if they noticed the notifications. We asked about the game scores, 5) if they noticed differences in the game scores before and after taking medication. We asked about 6) technical and 7) usability challenges, and 8) conducted a System Usability Scale (SUS) survey [5].
- **Debriefing:** focused on STOP’s impact on medication adherence. We probed on 1) how often they logged their medication, 2) the preferred timekeeping method and 3) whether the medication intake log was immediate. We inquired about the gamification experience, 4) how often they played, 5) which hand they used, 6) how they perceived STOP, i.e., as a game or as a tool, 7) did they replay for higher score, and 8) did they notice the change in game sensitivity (ball speed). We asked 9) whether the scores reflected the self-perceived PD symptoms, 10) did they delay or skip playing due to worsen symptoms and 11) did they manage to manipulate the score by i.e. changing position. We asked about 12) perceived benefits of using the app, and 13) whether they believed that their medication adherence had improved and 14) how they feel about sharing the results for medical personnel. We concluded with 15) asking if they had any technical or usability problems during the study, and 16) probing for suggestions for future development. Finally, we 17) repeated the SUS survey.

5 QUANTITATIVE RESULTS

In this paper we focus on the qualitative (interview) data. This section provides an overview of the collected quantitative data that presents the use of the application.

In our 1-month long deployment, our 13 participants recorded a total of 1856 medication logs and 2213 game sessions. The data set for P5 is incomplete as they removed the application before proper synchronization of data. P7 had issues installing the application so we missed the first week of data (collecting 3 weeks).

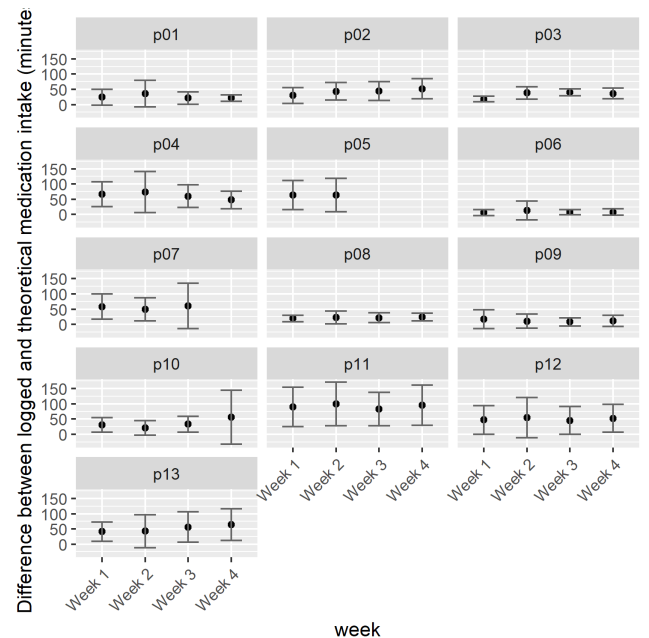


Figure 5: The weekly time adherence of the participants in minutes.

To assess the impact of STOP on medication adherence per participant over time, we measured the average difference between the reported medication intake time and the theoretical scheduled time on a weekly basis (Fig. 5). Further, we computed a Mann-Kendall test to detect monotonic trends on each participant’s medication adherence time series data, adjusting p-values using False Discovery Rate. We found a significant negative trend for P4, which suggests he improved his adherence. On the contrary we found a significant positive trend for P10 which suggest his adherence worsened during the 4 weeks of the study. For the majority of our participants however, medication adherence remained stable throughout the study.

Table 2: The p-values of medication adherence trends in a Mann-Kendall test.

	Med logs	tau-b	p value	Adjusted p value
p01	34	-0,148	0,224	0,454
p02	160	0,118	<=0.05	0,099
p03	37	0,159	0,17	0,441
p04	163	-0,238	<=0.05	<=0.05
p05	18	0,163	0,363	0,525
p06	178	0,109	<=0.05	0,099
p07	79	-0,043	0,576	0,681
p08	282	-0,047	0,244	0,454
p09	118	-0,058	0,356	0,525
p10	215	0,134	<=0.05	<=0.05
p11	141	-0,04	0,481	0,626
p12	86	0,024	0,746	0,8
p13	345	-0,009	0,8	0,8

Table 3: The medication input style.

	Med logs	% of Now	% of retrospective
p01	34	97	3
p02	160	77	23
p03	37	41	59
p04	163	23	77
p05	18	83	17
p06	178	43	57
p07	79	10	90
p08	282	24	76
p09	118	8	92
p10	215	60	40
p11	141	58	42
p12	86	42	58
p13	345	64	36

We calculated the amount of medication recorded by pressing 'Now', and medication recorded by specifying the time retrospectively manually or by voice. The input choice varied greatly across participants, see table 3, with the 'Now'-button accounting for 46% of the overall medication log input.

The notifications served as reminders to play the game, report medication intake and perform the daily symptom assessment, our goal was to nudge participants to use the app regularly. Table 4 shows the notification opening rate for each participant. Due to design limitation in iOS, notification logs did not work in tablets (P6 and P12). The ratio between opened/triggered notifications varied between 1.2% (P1) and 69.2% (P4), the average was 30.6%.

Part of the users (P1, P5, P7 and P11) told in the interviews they used the app when it suited to their schedule, not according to the notifications, describing the low rates in Table 4. P4 has the best notification response, he takes the medication 4 times per day (see Table 1), roughly matching the notification times. The good

Table 4: The opening rate of notifications per participant.

Participant	%	Participant	%
p01	1.2	p08	32.4
p02	11.1	p09	38.7
p03	45.0	p10	65.0
p04	69.2	p11	63.4
p05	2.4	p12	-
p06	-	p13	5.4
p07	2.3		

notification response might explain also the improvement in his adherence during the study.

From the UPDRS II survey [40] results we can assess a general tremor level of the patient (item 16. Tremor). The location of the tremor is specified in the interview discussions. In Fig. 6, the tremor level is indicated with a star after participants' answers. No star indicates no tremor, one star slight and infrequently present tremor, two stars moderate and bothersome tremor, three stars severe tremor interfering many activities, and four stars means marked tremor, interfering with most activities.

P2, P9 and P11 did not report having tremor, and we can see from the Fig. 6 that the standard deviation of their game scores is also narrow, i.e., higher and consistent scores. P2 has rigidity in his hands, he told it helps keeping the ball still. P9 has poor rotation in his wrists. P11 suffers from stiffness and slowness. From those, who suffer tremors, P1, P3, P4, P5, P10 and P13 suffer have it in hands. From them, P3, P4, P10 and P13 play with the affected hand. P3, P4 and P13 has a big variation in their scores (see Fig. 6). P10 was an iOS user, and the sensitivity did not change. It looks like the tremor did not affect to the variation of his scores. He mentioned in the interviews he expected to see more variation in the scores due to shaking. P1 and P5 played with non affected hand, P5 has a narrow deviation in his scores. P1 is right handed, but uses left for playing, explaining the variation in his scores.

To investigate the relationship between game scores and the sensitivity setting of the game, we computed Kendall tau-b correlation tests on a individual basis adjusting p-values using False Discovery Rate (Table 5). iOS users, P06, P09, P10, P12, and P13, played all their games with a fixed sensitivity, thus they were excluded. We found significant negative correlations for P01, P03, P08, and P11 suggesting that as the sensitivity of the ball increases, people got lower scores. This has been also confirmed during the test trial with healthy volunteers in [18]. This effect was bigger for P03 (tau-b = -8.13), and we can corroborate visually the sharp decrease in their game score in Fig. 6.

All our participants used STOP regularly, suggesting no significant difficulties to use its functionalities. Our participants medication adherence remained constant or improved in our study, with one exception. This suggests that STOP was useful to our participants to adhere to their medication schedule. As expected, our results on the game scoring suggest that the score is inversely affected by the ball speed, i.e., the faster the ball movement, the worse the score. Depending on the patient's PD progression, such

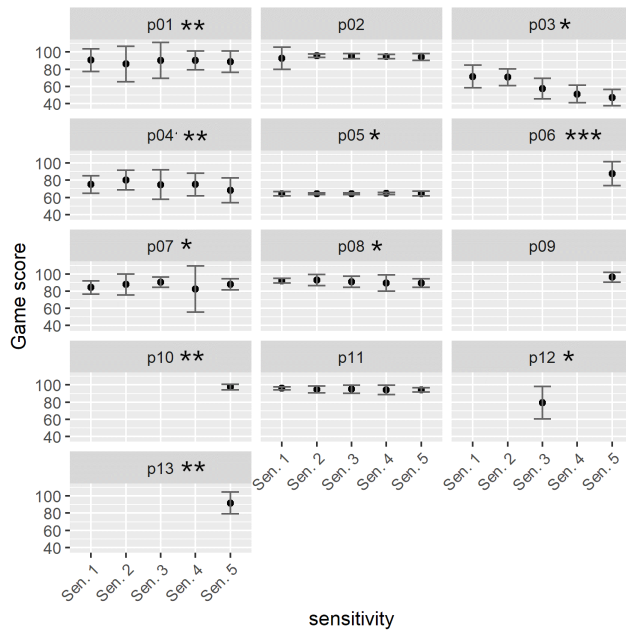


Figure 6: The game scores (0-100) in different sensitivity levels. Stars denote no tremor (no star), slight and infrequently present tremor (one star), moderate and bothersome tremor (two stars), severe tremor interfering many activities (three stars), marked tremor interfering with most activities (four stars), according to the UPDRS survey.

Table 5: Effect of game score vs sensitivity.

	Games	tau-b	Estimate	p value	Adjusted p value
p01	168	-3.44	-0.20	<=0.05	<=0.05
p02	123	-2.14	-0.14	<=0.05	0.051
p03	171	-8.13	-0.46	<=0.05	<=0.05
p04	115	-1.19	-0.08	0.233	0.267
p05	160	1.93	0.11	0.053	0.071
p07	53	0.67	0.07	0.503	0.503
p08	223	-4.14	-0.20	<=0.05	<=0.05
p11	265	-4.86	-0.22	<=0.05	<=0.05

parameter should directly reflect the medication effectiveness and hand tremor symptom.

6 QUALITATIVE FINDINGS AND DISCUSSION

We made an Affinity Diagram (a method from HCI to synthesize qualitative data into design themes [16]) from the interviews, highlighting the concerns, experiences and strategies followed by the participants. The Affinity Diagram design themes are the subheadings of this section.

In the first interview, we aimed to understand how experienced the participants were with their mobile device, and what usage limitations PD imposes. In the middle interview, we ensured all

participants were able to use the application without any problems, and asked about their initial experience with the application. In the final interview, we focused on the ways and benefits of using the app, and conception of the app.

We used the System Usability Score (SUS) scale to estimate the general usability of STOP [5] in the middle and final interview. The average SUS score for the middle interviews was 79.62, and it increased to 80.00 points at the end of the study. As the change was minimal, we only analyzed the differences between countries in the final SUS using a Mann-Whitney U test and found that the scores for Finland (P01-P07) were not significantly different from those for the UK ($U = 9$, $Z = -1.726$, $p = 0.092$, $r = 0.478$).

6.1 Participant Profiles

Based on the initial interviews, it is clear that mobile phones are an integral part of participants' daily lives. In addition to phone calls and SMS, all users used the mobile for taking photos and browsing the internet. Some participants played games, others used smartphones for navigation and medication reminders and most used some social media application.

Participants described that the most prominent challenge on mobile device usage is typing, ten of our 13 participants mentioned it. According to our participants PD symptoms (mostly tremor and rigidity) are the root cause of a lot of typing mistakes and touching errors. One participant had to use his left hand for typing even though he is right handed due to tremors. One participant used voice commands for taking photos, due to rigidity and slowness symptoms. One participant used a stylus for typing, because his tremors disappeared when holding something in his hand. Four participants mentioned difficulties holding their phone during a call due to PD symptoms, including the fear of dropping the mobile phone. One participant revealed that unfamiliar/newly installed applications are difficult to use.

In general, PD's motor symptoms affect most of our participants' daily life. They make daily tasks difficult, such as using utensils, writing or getting dressed. Half of the participants described problems in moving, walking being slow and laborious, muscles feeling stiff or weak, balance being bad, and having lopsided positions. Three participants had problems sleeping, and felt tired. Surprisingly, these are partly related to the side-effects of their medication and not directly from PD. Swallowing and pain disturbed some participants; losing hair, memory lapses and speech difficulties were among the other afflictions that were mentioned.

"I manage somewhat ok from all my tasks. I live alone, so I do everything by myself. Lately I have become slower and it is slower to start moving, I get winded more easily, there is pain and hair loss. Few years ago, I started to notice rigidity in some movements, I stopped and noted that I need to consciously send a message from my brain: 'move the leg' or 'lift the paper' or when skiing 'hit the stick to the ground'." (P1)

"I have to plan some activities well, since the symptoms bring restrictions. For example, you have to consider whether you stand or sit when peeling vegetables, you might run out of energy if you stand. You need to plan also tasks that need balance, such as jumping over a dike. You must think which leg you use for jump and which for landing." (P7)

Some of the participants have learned how to cope with PD better, while others experience the symptoms as more restricting. The younger patients with shorter PD history seemed to experience the symptoms as more disturbing in their daily lives. A reason for this could be that patients with a longer disease history are more used to the restrictions.

6.2 Medication Concerns

The participants with medication intake more than four times a day (10/13 participants) felt that their medical and associated dietary regimen dominated daily life. Half of our participants had a fixed medication schedule and dosage. Some medication allows for schedule and dosage flexibility, taken as needed and depending on the experienced PD symptoms, also known as “boosters.” Few participants brought up self-regulative actions: P10 skipped the doses of medication if a previous dose was delayed for some reason. Another participant, P1, independently changed her medication schedule to better suit her daily rhythm.

“I use only Eldepryl and Sifrol, they shall be taken in the morning to empty stomach. Triangle drugs cause sleepiness during daytime and are dangerous in traffic. That is why I slowly changed my medicine schedule so that I usually take the medicine at evening around 18-19, in that way I sleep better and fall asleep easily. On the other hand, I wake up early, but the mornings are beautiful.” (P1)

We measured the time between the schedule and actual reported medication intake and used that as a measure of participant’s medication adherence (see Fig. 5). However, the “boosters” are not taken regularly. Some do not have a strict medication schedule at all: P10 reported taking it with breakfast, lunch, and dinner and when going to bed. He thought it was beneficial to track the timing using the journal, even though measuring adherence in minutes was not meaningful. Furthermore, sometimes a participant chose to take medicine earlier or later, if they had demanding activities, such as going to physiotherapy. Nunes and Fitzpatrick [25] discuss in their paper whether this should be considered as nonadherence, since patients are aware of the consequences of deviating from the schedule, but they want to be at their best performance ability for some occasion.

Some participants used reminders for medication (such as a phone alarm), yet others consider such reminders “annoying.” Palen and Aalokke [30] and MGee-Lennon *et al.* 2011 [24] have investigated the mechanisms the elderly use for remembering medication. [24] categorized them as paper-based, technological and specialized reminders (e.g., in mobile phones), temporal reminders (e.g., integration with daily routines), people-based (e.g., being reminded by other people), and physical reminders (e.g., using everyday objects). Our participants described also firm medication routines, some used also reminders or had people taking care of their medication. However, they told that the main reason for remembering the medication is their symptoms getting worse. It is not easy to forget to take the medicines in PD, as the symptoms get worse if medication intake is delayed and your body really needs the medication. Participants pointed out that when the effect of the medication is fading off, they eagerly awaited the time when they were allowed to take the medicine again, and the symptoms work as a reminder for medication intake. In other words, the effectiveness of notifications

to remind medication taking is highly dependent on the severity of PD and the users’ personal preference.

Only two participants mentioned they felt their medication adherence had improved during the study (P3, P5). This was not supported by data (see Fig. 5, Table 2). They might have been comparing their adherence to the time before the study, or simply paying attention to the medication might make the feeling of improved adherence. P11 commented in the half-way interview that recording the medication time made him notice how irregularly he takes his medication. However, based on the data, this did not impact to his adherence. He thought that the reason for irregularity was that his PD and symptoms were not that severe at the moment.

6.3 Experiences with Gamification

In the middle interview, all participants reported using the application regularly, using only one hand for playing the game, and usually the same hand. Most of the participants did not notice a significant difference in their game scores before and after medication, and the game score did not reflect the user perception of symptom level. From quantitative data (see Fig. 6) we noted that the affect of tremor to the score varied between participant. The tremor can be identified from the accelerometer data [4, 46], but our immediate score did not use it. Our score is determined by distance the ball deviates from the center (see section 3.1). Therefore, the analysis of the motion data is not conducted in this paper, we focus to understanding the practicality and usability of STOP in the hands of actual PD patients.

Three of the participants (P1, P5, P8) misunderstood the idea of the game at first, rolling the red ball along the black inner-circle, or rolling the red ball between both circles. We discarded these initial games’ data.

“First, I understood the idea of the game wrong, I rolled the red ball along the black line. After reading the instructions I understood the correct way for playing.” (P1)

One of them suggested having a bull’s eye to make the target clear or having a smaller circle or a dot in the middle of the circle pointing out the center. Also a simple note in the screen “Keep the ball in the middle!” could help.

Surprisingly, due to rigidity in the hand, P2 felt that the game was easy. Another example, P9, who has poor rotation in his wrists, said it was initially challenging to get the ball into the center of the inner circle. However, as STOP has a 5-second adjustment time before starting the game, keeping the ball stable was easy afterwards. Furthermore, this participant revealed he held his elbows against his body to stabilize the device. Three participants (P2, P5, P7) noticed some difference in their game scores according to the time of the day and symptom level. The rest of participants, however, felt the differences did not reflect their current state. Stress, tiredness and agitation were thought to decrease in the scores, and concentration to increase.

“I got usually quite similar scores, but sometimes I noticed I got a little lower score if I had, for example, stress.” (P2)

The findings of Nunes and Fitzpatrick [25] were similar; they discovered that emotions can affect their symptom severity. Negative feelings, such as being nervous or upset, made the symptoms

stronger, and feeling calm improved their ability to perform different activities.

Participants were required to play the game at least four times per day during the study. P10 said that the game session did not disrupt him much, and is integrated into his daily routine. P6 found the game boring:

“The game is expected to be played several times per day, it is hard to keep the device with you always. The application was boring. If I had to use this longer, there could be more games.” (P6)

Most participants played one game per session. Few had a routine of playing a few times in a row (P1, P3, P11), but only P11 mentioned he replayed for the good scores. P10 wanted the history of scores to be visible. Maybe showing the performance in the long run with the high score records would increase the attention to the score, and make beating own scores more appealing. On the other hand, people might focus on scores, and start changing the playing position or cheat by supporting the hand somehow for reaching high score.

We inquired our participants about their understanding of STOP as a game or as a tool. A third of users considered it as a game, and a third as a measurement tool. The remaining did not have a firm opinion. P7 clearly considered the ball game as a measurement tool for the symptoms, and he was testing the accuracy of the measurement. He described that he had tried playing two times in a row and expected the score to be same, but the score was different. This was expected, even though the ball speed remained the same in the same game session, it is extremely difficult to have **exactly** the same score unless the hand is completely still. Score variation is expected.

“Few times I played several times in a row, because I wanted to see do I get the same score, and in that way can the score be used for measuring condition. When playing in a row, the medication response is the same, it does not change so fast. Sometimes the scores were different, sometime I got similar scores.” (P7)

6.4 Experiencing the Medication Journal and Daily Survey

Three participants (P1, P2, P5) said in the interviews that it was difficult to reply to the daily survey, due to it being difficult to know which of their multiple diseases were causing the symptoms.

“Daily query is sometimes hard to answer, since I have osteoporosis and tumor in parathyroid (maybe caused by PD medication). You cannot always tell which disease causes the symptoms.” (P1)

P7 pointed out that the symptom query could be filled several times per day, since the condition varies during the day. Then it would be easier to track if some part of the day is continuously bad, and medication needs tuning. P2 and P3 said they need more response options to the query.

The logo of the application, a stooping man with a tremor, was described to be depressing, reminding what the future with PD will be.

“The logo of the application is negative, depressing. Some positive picture would be better and encourage you through the day.” (P2)

The participants pointed out that inputting portions of tablets, liquid medicines or varying dose was missing from the STOP medication regimen input.

In the final interview, the majority of our participants did not feel that they benefited from using STOP. All participants had suffered from PD for years, and they had established routines for taking care of medication; some used alarm clocks, some had otherwise firm daily routines, so they did not feel a need for an app to assist with medical adherence. The game did not reflect the current symptom level, and they also described they know their body well enough to know when the booster medicines are needed. On the other hand, P1 said that main benefit of using the STOP application was joy of success in the game.

“Yes, there was a benefit, it was nice to be part of a study, and I was able to follow my performance. I thought that even though I have tremor and have continuous medication, I was able to succeed in this, and the good scores encouraged me. I didn't feel failure when I got lower score sometimes.” (P1)

All participants were comfortable with showing the data collected by the application for a doctor if it helped in the treatment.

“Of course, I could share the data for my doctor. I would not feel uncomfortable even though I had missing records. If you forget to take the medicine, you can feel it, you cannot miss a dose easily.” (P4)

The possibility to share the data was seen as motivation to use the app, measure their daily symptoms by playing the game and tracking medication.

The appearance of notifications was considered as irregular, since the timing was not exact, and the notifications were shown some time during the notification period. As seen from Fig. 6, P4 was the most engaged with the notifications. The notifications were considered as useful also by P9 too, as he would like to prioritize the notifications' order so that STOP notifications would always be at the top of the notification list. Medication reminders were also requested to be implemented into STOP, in addition to the existing notifications.

All participants stated they mainly updated the medication journal when taking their medication. They reported entering missed ones later in case they had forgotten to update the journal. According to the interview results, the 'Now'-button was the most used input modality, and was unanimously considered the easiest. This is supported by the data, as mentioned in chapter 5, 46% of medication records were recorded with 'Now'-button.

Voice input was an appreciated feature in the UK. It was not available in Finland due to lack of support for the spoken language. In spite of the availability of voice input, the 'Now'-button was used as much in both countries (a marginal 0.2 %-point difference).

The participants were willing to record more details in addition to the medication time into the journal, such as the name and dose of the medication. In case of “booster” intake, they wanted to record the reason for taking it. P11 mentioned that in general he prefers electronic diaries over the paper diaries, due to problems in handwriting.

7 CHALLENGES AND LIMITATIONS

The PD patients are mainly elderly and suffer from motor and cognitive complications, and many of them have just recently started to use a smartphone with a touchscreen instead of a mobile phone with buttons. Terminology related to smartphones and applications was not familiar for all. As we did not have a possibility

to meet all participants face-to-face in case of technical problem, it was challenging to give instructions via phone. On the other hand, participants obeyed the gaming schedule well, and wanted to contribute to the study. A participant with an old phone that had synchronization issues, apologized for causing more work, even though she had to do extra tasks to delivering the data manually to us.

It was sometimes time consuming to contact and reach the patients. PD itself might cause difficulties in coping with everyday life, and if any other issues in life happen, they would naturally impact patient responsiveness.

8 FUTURE WORK

We need to enrich the existing functionality. We need to implement new games into the application. As we know, PD symptoms are diverse. The user could choose the game that best captures his symptoms. Also, in the long run, the application will be more attractive to use if it has versatile functionalities. Additional games can be added over time via an application update, thus keeping the app from getting “boring.”

The main motivation for using the application was the possibility to share the collected data with a doctor. A web-based dashboard could be used for presenting the data from the application for the patient’s self-tracking and reflection. In turn, this dashboard could be used by the patients and caregivers, and the data can be shared with doctors. Further research is needed to assess which data to include and how to present it to be useful for a care professional.

9 CONCLUSIONS

We gained an improved understanding of the challenges PD patients face in their life, and the restrictions for smartphone use that PD creates. We identified design implications for the next revisions of the application, based on user feedback.

Tracking the medication by means of a mobile application is promising, especially when considering the different modalities of timekeeping and the medication journal log. As shown by Lakshminarayana *et al.* [20], data collected by a smartphone can improve the quality of clinical consultation. Our study shows that the participants are motivated to collect information about their condition and symptoms, and to track medication and details of how their daily life is affected by their PD symptoms. In future, we aim to communicate this information in a suitable form for the medical personnel.

All participants had suffered PD for more than two years, with the average being more than six years, and they had a clear routine for taking the medication. But this routine will likely break if (or rather when) medication is changed. Many of the PD medications have to be removed incrementally, while new medication is incrementally added. One must follow the medication regimen, tracking PD symptoms and side-effects more rigorously during the medication change, and STOP might be beneficial especially in such situations.

Our study highlights the non-trivial design of PD-oriented applications: despite our participants openness to use a smartphone app and the expected value for the medical clinicians, PD patients did not find STOP to be that useful for them in managing their PD. This

is mainly due to: 1) a perceived mismatch between the score and the users’ PD symptoms; 2) and their personal familiarity with the medication schedule over the years. However, the users appreciated the game element although it could be further diversified or challenging. Here, we carefully added gamified elements, to prevent potential interference with the medication adherence but will add additional tools to STOP in the future.

Due to the high availability of ubiquitous devices nowadays, self-assessment and self-reporting can become an integral part of PD treatment. The use of technologies is highly applicable for the PD observation, which is crucial to the treatment plan customization and medication effectiveness increase. Hence, we are aiming to design an assistive tool that will solve this problem.

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