Testing Feasibility and Utility of Remote Data Capture Technology to assess Parkinson's Disease

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1 Introduction

The requirement for face-to-face evaluation of patients when administering the Unified Parkinson's Disease Rating Scale (UPDRS) limits the availability of patient data due to logistical issues including mobility, transportation, and time. What is needed is a simple, reliable, and secure means of collecting clinical and clinical research data remotely. Use of remote technology, including telemedicine, has emerged in early studies as a promising tool for managing chronic illnesses such as PD with potential benefits including expanded access to care and reduced treatment cost. However, few investigations have examined the application of such technologies to improve clinical trials data collection. Here we evaluate the use of a recently developed HIPAA-compliant mobile device app, "CaptureProof," for photo and video capture in remote administration of a modified short video UPDRS (svUPDRS). Our 16 participant pilot study suggests mobile health app use is feasible in PD patients and is capable of providing high-value clinical information complementary to in-office assessments.

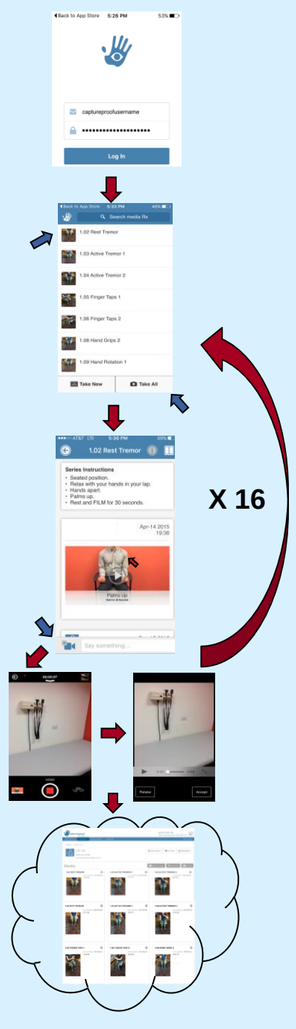
2 Design

Study Design
Sixteen participants with PD were trained to record a home video-based 11 item short version UPDRS (svUPDRS) using an iPod touch™ device, offered to them for the duration of the study. For patients experiencing motor fluctuations, recordings were made in the "on" state. In-office recordings were made at baseline and week 4 for comparison with in-person UPDRS Part III rating, and patients uploaded 3 interim weekly home recordings of the svUPDRS to a HIPAA-compliant cloud-based platform using CaptureProof™ technology. Two clinicians rated each of the in-person and video evaluations.

short version UPDRS (svUPDRS)
The Unified Parkinson's Disease Rating Scale (UPDRS) Part III was modified to construct a short version scale composed only of elements ratable by visual inspection. UPDRS part III motor scores for rigidity and postural stability were excluded in the svUPDRS (items 22 & 30).

As an added privacy precaution requested by the Weill Cornell Architecture for Research Computing in Health (ARCH), participants were instructed to film from the neck down. Facial expression and rest tremor in the face, lips and chin (items 19 and 20-face/lips/chin) were therefore not rated.

Home Video Training
At baseline all subjects received approximately 1 hour of hands-on training with a study coordinator. Subjects were encouraged to bring their videographers to this session. Study folders with an app instructions manual, CaptureProof username, and password were provided. An overview of iPod and CaptureProof app use was presented after which subjects recorded a full svUPDRS with coordinator assistance. Coordinators were available by phone during all home video recording sessions.



3 Demographics and Participant Information

1. Patient Characteristics (n=16)

Age	67 (51-77)
Gender	9M/ 7F
Hoehn & Yahr	2 (1-3)
Disease Duration (Months)	76.8 (35.3)
Levodopa Equivalent Dose	515 (300-2707)
Education (years)	17.7 (2.5)
Married or Living with Partner	75%
Completely Independent	14/16
Visitng Caregiver	1/16
Live-in Caregiver	1/16

2. Use of technology and transportation

Technology	
Owns smartphone or tablet	81%
Estimated daily use (hours)	4.3
Comfortable learning new technology	81%
Transportation	
Significant difficulty traveling to doctor	38%
Total time budgeted for doctor's office visit (minutes)	131
Transportation options	
Personal vehicle	4/16
Personal vehicle;caregiver must drive	1/16
Public transportation	11/16

4 Feasibility/Usability

- 15 completed all in-office visits, 1 completed baseline only
- 14 completed all home uploads, 1 completed 1 only and 1 completed 2 only
- 96.4% of all scheduled videos were uploaded
- 9 completed 100% of all videos
- The vast majority (99.7%) of videos were completed according to protocol and of ratable quality (13/16 provided videos deemed ratable in 100% of uploads)
- 91% of recording sessions were completed on the scheduled day (9/16 were 100% on time)
- Only 6/16 made 100% uploads to the correct module
- No correlation was observed between age, baseline tech exposure, or PD duration and success at video recording.
- A small number of subjects required several hours each of phone support to complete their 3 virtual visits
- Recording partners – often spouses or children – helped address challenges using technology

Barriers to Use / Lessons

Recording Partner
- Arranging time with recording partner is challenging (n=4)
- Demonstrating PD symptoms for recording partner may be embarrassing (n=1)

Technology
- iPod touch may be too small (n=4)
- Log-in / typing on device is frustrating (n=5)
- Train partners at baseline visit
- Fear of or frustration with technology may discourage participation

Reasons for Withdrawal
- Concomitant illness (n=1)
- Stress / difficulty coordinating recording time with spouse (n=2)
- Difficulty using app & fear of fraud / ID theft (n=1)

5 Utility

Table 3. svUPDRS scores correlate with UPDRS EQ

	r*	p-value	n	
Visit 0	0.61824	**0.0107**	16	*moderate-strong correlation*

*Spearman's rank correlation coefficient

Table 3 tests for correlation between scores on the gold-standard UPDRS and svUPDRS. Videos were recorded in-office within 1 hour of UPDRS assessment.

Table 5. Low variation in home svUPDRS scores

Pairing	difference	p-value*	n
1&2	-0.13 (3.7)	0.8899	15
2&3	0 (2.7)	1	14
1&3	0.21 (4.1)	0.8465	14

*Paired tests (t-test /signed-rank)

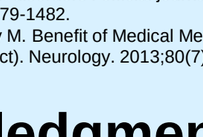
Table 5 shows paired tests for significant differences in total svUPDRS scores obtained for individual subjects across weeks 1, 2 and 3. No differences were detected.

Table 4. Video ratings of svUPDRS demonstrate strong inter-rater reliability

	ICC*	p-value
svUPDRS 0 (in-office video recording by investigator)	0.827 (0.565-0.938)	<.0001
svUPDRS 1 (at-home video recording by care partner)	0.919 (0.783-0.972)	<.0001

*Intraclass Correlation Coefficient

Home Video Examinations



Please ask to view videos

- We did not observe significant differences between in-office UPDRS tests at baseline and final visit
- Similarly, no differences detected comparing svUPDRS ratings for videos recorded in-office versus at home

6 Conclusions

- High quality of home video recordings for asynchronous video-recordings are feasible in early to mid-stage PD using a HIPAA-compliant app and cloud-based platform
- Ratings from the modified "svUPDRS" are in good agreement with scores on equivalent items from the in-person UPDRS
- Two independent raters did not differ significantly in ratings on the video-based visits
- 1 hour in-office training is adequate for most patients
- Asynchronous virtual visits are a novel tool for creating an archive of rich patient data beyond the scope & scale of what can be captured in a clinical setting

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captureproof.com