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Parkinson's disease patients' opinions on use of technology for communication and education

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Objective: Parkinson's disease (PD) is the most common neurodegenerative movement disorder in the U.S. Patients' opinions of technology-based tools for education and communication as related to PD are unclear, with little documented research addressing the issue. The goal of this research was to investigate patient opinions about technology-based tools. Education and communication using technology may affect satisfaction and adherence to treatment regimens. Prior to developing technology tools for clinical use, establishing the relevance from the patients' perspective, specifically accounting for the needs of geriatric patients, is crucial.

Methods: A quality assessment survey was administered to PD patients at the Parkinson's Disease Treatment Center at the New York Institute of Technology. The survey assessed patient opinions on willingness to use electronic methods including electronic forms, video education, emailed home-care instructions and the ability to email with healthcare providers. Additionally, patients were asked whether they felt that using technology (online tools, etc.) to communicate with the healthcare provider would result in a better understanding of their care or the healthcare-provider better understanding their needs. Associations between patient opinions of technology, having unmet needs related to PD, and being age 65 or older were assessed.

Results: 109 PD patients completed the survey. 27.2% (n=28) of the subjects reported having unmet needs related to PD. The majority of the patients were age 65 and older (78.0% (n=85)). Those who were age 65 and above were less likely to believe that using technology would result in a better self-understanding of patient care (OR=0.30, 95% CI:0.12, 0.79, p=0.01) and less likely to want an email summary of care/home instructions (OR=0.39, 95% CI:0.15, 0.98, p=0.05) than those under age 65. The results of our study indicate that PD patients over age 65 appear to have a less favorable view regarding the role of technology in communicating with healthcare providers and self-understanding of their care.

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A smartphone-based Interactive Rhythmic Auditory Cueing Evaluation (iRACE) for gait impairments

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Objective: Rhythmic auditory cueing (RAC) continues to receive attention as a promising therapy for gait impairments in Parkinson's disease. By synchronizing their movements to an external cue, patients can reduce their motor timing variability (MTV); MTV has been retrospectively and prospectively linked with fall likelihood. Currently, however, there exist no easy-to-use diagnostic tools to evaluate whether a given patient might benefit from a longer-term therapy program with RAC, or to optimize RAC parameters.

Methods: iRACE has been developed for Apple (iOS-based) iPhone/iTouch. The touchscreen of the device is used to quantify upper-motor timing during bimanual alternate index finger tapping, and the device's built-in tri-axial accelerometer to quantify lower-motor timing while walking. Both self-paced and externally-cued

conditions may be evaluated. Based on each participant's self-paced cadence, a "yoked" playlist is created to determine the precise tempo at which MTV is minimized. Accuracy of the accelerometer-derived step time series was validated using a Biometrics wireless tri-axial accelerometer system (www.biometricsltd.com/datalog.htm). Time-domain estimates of MTV were quantified using a widely-used method (percent coefficient of variation) for both finger tapping (i.e., inter-tap intervals) and walking (i.e., inter-step intervals, with steps identified using peaks in anterior-posterior acceleration). Walking and tapping statistics are presented directly to the user (i.e., therapist/neurologist) on the device's screen, and automatically uploaded to a central server for data management.

Results: The flexibility, portability, and validity of iRACE offers both prognostic and analytic applications, including (1) evaluating whether a given patient may benefit from the longer-term therapeutic application of rhythmic auditory cueing; and (2) tracking the improvement of motor timing performance after behavioral, pharmacological, or neurostimulatory interventions. Further work from our group will provide a large library (~3 million items) of music that has been carefully analyzed for tempo, enabling further customization.

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SENSE-PARK: measuring Parkinson's disease in the home environment in an objective, continuous and minimally obtrusive fashion

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Objective: The future treatment of Parkinson's relies on the accurate assessment of how it affects people with Parkinson's (PwP's) as individuals. SENSE-PARK is a pioneering project which combines expertise from technology with the experiences of those who live with Parkinson's and the scientific know-how of those who treat it. The objective of SENSE-PARK (EU funded, INFOS-ICT-2011-288557) is to develop a patient-centered, minimally obtrusive and empowering information system for use in the home environment, which provides PwP's with practical and motivating tools to monitor their condition in a continuous and objective way. In more detail, the SENSE-PARK system will inform the users about motor and non-motor functioning in daily life activities ('being', data collection via a wrist-worn data logger), leisure activities ('belonging', data collection via gaming console and adapted interface) and scientific environment ('becoming', validation purposes).

Methods: (i) Participatory approach; (ii) needs and requirements analysis; (iii) adapt and develop a PwP's-friendly interface; (iv) define relevant parameters to monitor disease progression; (v) sensor system development and data interpretation; (vi) hardware and software integration, IT infrastructure and telemedicine; (vii) iterative testing; (viii) scenario-based multicentre study.

Results: Through conducting a needs and requirements analysis that was facilitated by Cure Parkinson's Trust, project partners were able to define usability criteria and to prioritize symptomatic domains and parameters for measurement of Parkinson's. The symptomatic