Early View

MOVING ALONG

International Parkinson and Movement Disorder Society

Adapting Technologies for Parkinson's Disease – Not The Other Way Around

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With the miniaturization of technology, the last couple of decades has brought an increasing panoply of devices that capture a range behaviors of interest, many of interest in the field of Movement Disorders. The developmental sequence, however, has been as follows: Company A develops Product X and offers it as a means to "learn" more about [tremor, bradykinesia, mobility, dyskinesia, etc.] in patients with Parkinson's disease. Meanwhile, Companies B through F develop Products Q through U, ostensibly also focused on quantifying the granularity of the same behaviors, and ask that we help with validating each of these products to find a way into our patients.

Enter the MDS Task Force on Technology. On its second incarnation, the group has been mandated by our President, Dr. Christopher Goetz, to enact the vision of maximizing the diagnostic and therapeutic potential of mobile health technologies. The driving force has been to move our role from passive recipients of technology, guiding clinicians and patients make decisions on available technologies, to active stakeholders, informing how technology should be adapted to meet the clinical and research needs to enhance the monitoring and care of patients. Indeed, the Task Force was born with the mission "to facilitate the rational development and integration of technologies in order to enhance relevant behavioral measurements and delivery of treatments to patients with movement disorders."

The MDS Task Force on Technology recently suggested a roadmap for reorganizing the developmental flow of mobile health technologies into patient-centered digital outcome measures.[1] Key components includes the creation of an open-source platform to integrate mobile health technology output and standard operating procedures in the assessment of clinical suitability of the data yielded by these technologies to assist with the regulatory approval of devices and algorithms.

The low-hanging fruit to aim for in the near future, and an early proof of concept of the proposed framework, is the reconfiguration of a Parkinson's diary for the digital age. While the available diaries, mostly paper-based, have been helpful in providing hard endpoints for clinical trials, forcing patients into their "off" and "on" dualism is not adequate for clinical care or to measure the nuanced behaviors associated with fluctuations in motor and non-motor symptoms. The Task Force has issued a proposal for an e-Diary/Tracker that would harness the complementary information provided by diaries and wearable sensors.[2] The latter stands to provide continuous, objective measures, independent from patient feedback; the former, digested through machine learning algorithms, relevant context. Combined, such e-Diary/Tracker would individualize the range and severity of patients' fluctuations, anticipate the likelihood of "good" and "bad" times, and empower patients themselves with actionable information, which could accomplish what no other mobile health technology has: long-term adherence.

Pending further deliberations with Dr. Goetz and the MDS Officers, the MDS Task Force on Technology will plan to enact the work proposed through collaborations with method experts on the generation of a central, ideally MDS-sanctioned technology-integrating platform. Such common-language portal will read and integrate data from diverse proprietary technologies, allowing users to select the most suitable "channels" of information. The synchronized and integrated data could be accessed from familiar interfaces such as, smartphones, tablets, computers, and electronical health records, yielding potential benefits to all stakeholders.

References

1. Espay AJ, Hausdorff JM, Sanchez-Ferro A, et al. A roadmap for implementation of patient-centered digital outcome measures in Parkinson's disease obtained using mobile health technologies. Mov Disord. 2019;34(5):657-663.
2. Vizcarra JA, Sanchez-Ferro A, Maetzler W, et al. The Parkinson's disease e-diary: Developing a clinical and research tool for the digital age. Mov Disord. 2019;34(5):676-681.

Members of the MDS Task Force on Technology, meeting in Hong Kong. Left to right, front row: Jeff Hausdorff, Alice Nieuwboer, Serene Paul, Lynn Rochester, Fay Horak, Alberto Espay, Paolo Bonato; back row: Tiago Mestre, Álvaro Sanchez Ferro, Walter Maetzler, Ralf Reilmann, Bas Bloem, Björn Eskofier (guest), and Jochen Klucken. Absent: Ray Dorsey and Aristide Merola.