


Personal digital health in Parkinson's disease: Case histories and commentary

Digital Health
Volume 7: 1–12
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DOI: 10.1177/20552076211061925
journals.sagepub.com/home/dhj


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Abstract

The use of self-tracking of bio-behavioral states along with prescription dosing information is increasingly popular in the care and study of many human diseases. Parkinson's Disease is particularly amenable to such tracking, as patients live with the progressive disease for many years, increasing motivation to pursue quality of life changes through careful monitoring of symptoms and self-guided management of their medications and lifestyle choices. Through the use of digital self-tracking technologies, patients independently or in conjunction with professional medical advice are modulating their medications and behavioral regimens based on self-tracking data. Self-trackers engage in self-experimentation with their health, and more broadly, in personal digital health. This paper briefly depicts notable, recent patient accounts of self-tracking and the uses of digital health in Parkinson's disease: those of Sara Riggare and Kevin Krejci. It also highlights important facets of a previously unreported case: Velva Walden's care as managed jointly by her caregiver son. Key aspects of self-tracking inherent to these cases are examined and potential opportunities to advance personalized medicine through the use of digital health and self-experimentation are outlined.

Keywords

Self-tracking, Parkinson's disease, self-experimentation, symptom tracking, medication compliance, personal digital health

Submission date: 23 October 2021; Acceptance date: 2 November 2021

Personal digital health, or the use of various forms of technology for the purpose of understanding or improving one's own health, is often used by those afflicted with chronic, progressively deteriorating, neurological conditions, such as Parkinson's disease (PD).^{1,2} Self-tracking, the practice of monitoring one's own health with the intention of improving well-being, has become more popular worldwide, aided by advances in public participation in personal digital health technology use and associated community interests in quantitative aspects of well-being.^{3,4} Self-experimentation, the practice of people experimenting with their own care with scientific motivations and/or practices, has a long and varied history in health practice and research.^{5,6} The two practices along with a variety of other advances in personal digital health have enabled a new and viable approach to health inquiry.⁷ People with PD are using personal digital health tools to self-track and self-experiment on their conditions to aid in effectively self-managing and mitigating symptoms of PD. The cases covered herein highlight some of the potential applications, benefits and challenges of personal digital health in PD. Our

treatment of these cases may help to expose researchers, clinicians, those with PD, and caregivers on how specific aspects of personal digital health could be of use.

PD is a neurological disorder in which there is progressive death of dopaminergic neurons in the substantia nigra portion of the mid-brain, which is responsible for facilitating coordinated muscle movement and the dopaminergic system as a whole. Deficiency or impairment of dopamine synthesis and utilization due to cellular dysfunction or death leads to a progression of motor symptoms (i.e. bradykinesia, rigidity, and tremor and non-motor symptoms including postural

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hypotension, dysarthrophonia, and neuropsychiatric disorders.^{8,9} The incidence and prevalence of PD are well-established, with cases expected to exceed 1.2 million in the US by 2030, and many more cases expected thereafter with increased size of the aging population.¹⁰ In the United States, the total economic burden of PD is estimated to be 51.9 billion dollars annually as of 2017 and numerous challenges remain in all four stages of PD: Early, Maintenance, Complex/Advanced and Palliative.¹¹ Further, patients with PD may differ significantly in terms of their symptoms and severity, disease progression, and their response to treatment and risk of complications.¹² Therefore, a personalized medicine approach timed well against medical treatment requires a combined approach of self-monitoring and active management of the neurological disease. It is in this arena that personal digital health can aid those with PD the most.

Patients self-modulating PD

Studies by researchers such as Sara Riggare and Kevin Krejci, as well as research conducted by many other patients with PD employing their own self-tracked methods, suggest strong potential for self-experimentation to aid in managing PD symptoms. Patients may monitor their symptoms for numerous reasons, yet are likely to have similar goals in mind: first, to better understand and manage their PD to improve their own quality of life, and second, to improve quality of life for others with this debilitating disease and minimize the impact of PD on loved ones and caregivers.¹³ Although there are often challenges associated with tracking symptoms, the benefits can outweigh these inconveniences and the burden may be diminished with innovative technological advances and training.¹⁴ In particular, the increasing availability of self-monitoring digital health devices promises to enhance the usefulness of self-quantification in patients with PD.^{15–17}

This paper explores work by David Walden on behalf of his mother Velva Walden, Kevin Krejci, and Sara Riggare, three digital health self-trackers with PD, in order to consider their tracking methodologies and help to consolidate features of their tracking for others who may wish to employ various digital data collection techniques. These three cases were chosen as they are relatively well-documented, are openly available for review, and in the case of Walden, has never been reported on publicly. These cases of personal digital health occurred over a timeframe of over 15 years, allowing for some comparisons over time and across self-trackers to be made. The challenges and benefits associated with self-tracking in PD are examined and future directions in personal digital health are explored.

Velva Walden: Facilitated medication adjustment

Current methods of self-tracking within PD have improved over time with the continued development of accurate,

non-invasive personal tracking technology for quantifying and monitoring symptoms. However, this has not always been the case. Many people with PD and their family members have tracked symptoms and treatments, without the assistance of specific digital tracking technology. Additionally, challenges in managing prescribed PD medications are regularly tracked in medical offices and households alike. As pharmacologic therapies primarily target an increase in serum dopamine levels, numerous formulations of a commonly prescribed agent Sinement® (carbidopa/levodopa) and its timing of administration can lead to an “off effect”, further exacerbating PD symptoms. A case example of tracking without technological aids is from David Walden, a colleague of the third author. This case exemplifies how changes relating to medication adjustments in type, formulation, and dosage may improve symptoms and it is also a case of caregiver assisted care (vs. wholly self-care). Throughout the early 2000’s, David tracked the care regimen of his mother, Velva Walden, who in her late 70s was diagnosed with PD. In 2004, Velva moved into David’s home rather than a nursing home, as Velva’s neurologist suggested that she might live longer if she were living in home care versus in an institutionalized setting. They chose this course and it was likely influential in extending Velva’s life expectancy. David was able to observe her frequently (often hourly and certainly many times daily) and make controlled adjustments of her medications appropriately. This likely increased speed of response to symptoms by reducing the delay in communication that would be present between nursing home caregivers and the neurologist. When no medication changes were required in response to symptoms, the original prescription was adhered to.

Because few systematic records of Velva’s actual symptoms are available, the rationale for medication adjustments was not fully available for review. However, we know that adjustments were deployed based on Velva’s momentary symptoms as observed by David and other caregivers. Goals of tracking included immediate symptom relief and ways to achieve greater stability by balancing levels and timing of the whole regimen when possible. The medication alterations that David made, with physician guidance, typically involved the route and timing of administration, the dosage and formulation (i.e. immediate or extended release), and the addition or subtraction of other pharmacologic agents.

An example of personalized caregiver medication adjustment that David actively participated in was the modification of carbamazepine administration, which was changed to be taken at midnight instead of 7:00 pm to help alleviate Velva’s neuropathy, or burning sensations in her feet, throughout the night. This adjustment was maintained for weeks, suggesting that it improved Velva’s symptoms. Among other changes, David recorded alterations in the dose and formulation of her carbidopa/levodopa over the

course of a month. Some of the changes were made over a few weeks and others day-to-day. The timing of each dose was also altered during a particular month that we considered. Although symptoms were not systematically recorded, the records reflect a clear example of adaptive caretaker-led case management with professional supervision.

David's records provide an example of the utility of modulating PD dosing in conjunction with medical oversight that supports new insights about self-care. His tracking was recorded on his computer and used by the neurologist to further illustrate his mother's symptoms and responses. (Note that David did not plot the values, but instead kept a log; we have plotted a prototypical example of his records in order to compare the format to work in other cases). Figure 1 depicts the use of three drugs commonly used to treat and manage the symptoms of PD: Quetiapine Seroquel®, carbidopa/levodopa Sinemet®, and amantadine Symmetrel®, Sinemet is routinely prescribed to replete diminished stores of dopamine to reduce tremors and rigidity, but may alter cognition and lead to other psychiatric illnesses. Symmetrel® is a weak, non-competitive antagonist of the NMDA receptor, which increases dopamine release and prevents dopamine reuptake. Seroquel®, an antipsychotic, is commonly prescribed to treat psychosis associated with PD.

Therefore, it is plausible to anticipate increased use of Sinemet® and Symmetrel® which may result in increased psychosis necessitating an increased need for Seroquel administration®. By making minor medication adjustments and tracking the outcome, David strove to make modifications in concert with lifestyle changes and in light of short-term outcomes. Based on David's records and caregiver facilitated self-tracking in consultation with medical professional advice, Velva's medications could be effectively tailored to her PD to support momentary symptom management and quality of life.

The Waldens' case is an early example of self-tracking in the PD community and highlights that this concept is not entirely new. This case is also an example of how variable dosing in conjunction with physician oversight can help improve a patient's quality of life and potentially their outcomes, as suggested by Velva's neurologist. We also see it as an early example of how a data-literate and quantified society have proliferated into home-based caregiver/patient medical experience. Contemporary methods of self-tracking have the same goal of improving quality of life, but differ from David's tracking in how the data is being collected. Much of the data that David collected regarded the medication alterations made, however, the

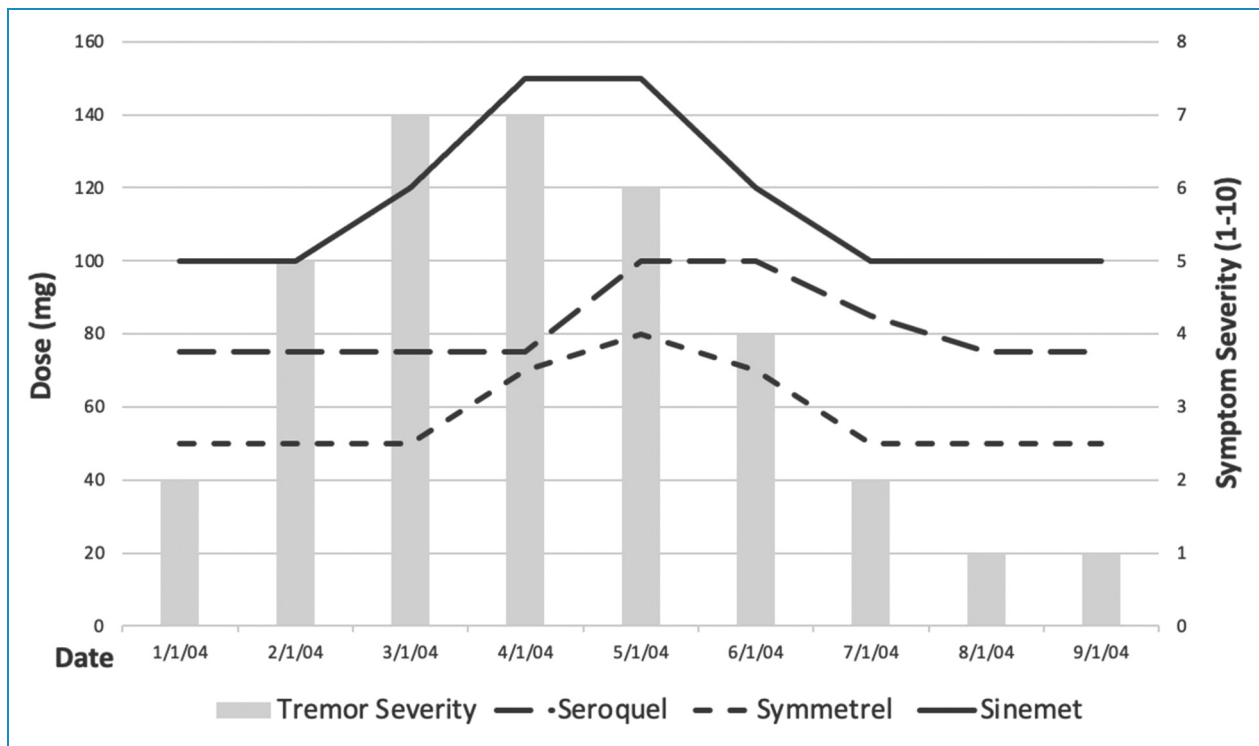


Figure 1. Variable dosing reflecting rigidity changes using three drugs prescribed to manage PD symptoms.

Note. David Walden recorded his mother's medication intake over time and made alterations in conjunction with her physicians based on her symptoms. The graphic depicts a sample of Walden's variable dosing in response to changes in his mother's rigidity, which would indicate a greater need for Sinemet® and Symmetrel®. This prototypical graph is extrapolated from some records received from Walden. Plotted is a rough line of the trend; data were too sparse to allow calculation of error terms.

symptoms themselves were not formally tracked to the degree they are being tracked in other contemporary cases which benefit from mobile technology. Advances in technology and methods since the early 2000s have also improved our capabilities in self-tracking at lower time-scales and with less burden. As described in subsequent cases below, some patients with PD have been using wearable sensors and other forms of monitoring technology to track symptoms of their condition and better understand how controlled adjustments affect them.

Kevin Krejci: Tracking and technology

In contrast to the Walden case, the case of self-quantifier with PD, Kevin Krejci, highlights the growing accessibility and development of personal bio-tracking technology, which has revolutionized symptom tracking and management.^{18,19} Krejci was diagnosed with PD in 2013 and has been using forms of digital health technology to self-quantify since then.²⁰ Examples of technology that Krejci has used include wearable sensors; mobile phone applications to track sleep, diet, rigidity, medications, and stool tests; and personal narrative documentation which enabled him to monitor and experiment with his condition.^{18–20} This case exemplifies a focus on technology and need for self-care (on good days and challenging days), as well as initiatives targeting non-pharmacological therapies and other key indicators of health (i.e. sleep, activity levels, diet), all supported by sound medical science. Krejci has used self-tracking technologies to identify correlations between his disease and his overall health, subsequently making adjustments to improve his quality of life or mitigate symptoms.¹⁸

A good example of a self-tracking technology Krejci used to further understand his condition was with the use of stool tests. Krejci tracked his stool microbiome and determined he had a deficiency in long chain fatty acids. In response to this, Krejci ingested nutritional supplements.²¹ There is supporting evidence that fatty acids and PD are linked and his tracking was designed to further his understanding of this interaction.²² Krejci has not however reported on his findings since. Krejci further utilized self-tracking technology to investigate his sleep quality and his PD symptom severity. He used various sleep tracking applications and found the more quality sleep he received, the better his PD symptoms were.²¹ Krejci also examined lifestyle factors affecting his sleep and made beneficial adjustments such as more exercise and less alcohol intake.²¹ Among other types of tracking technology, Krejci used smartphone applications to track his ability to type using a typing test, and an Ambulatory PD Monitoring (APDM) Wearable Technologies motion monitoring system to quantify his sway and gait.²⁰ Krejci has presented his research at various conferences and has posted his results online for public use. He has completed

mostly correlational analyses focused on lifestyle changes with the aim of improving his quality of life.²¹ The self-tracking done by Krejci is innovative in that he used a variety of technologies combined with scientific and personal judgment to combat his symptoms.

Krejci's tracking is also unique when compared to other cases of self-tracking and highlights how self-quantification has evolved since the time at which the Waldens engaged in self-tracking. His focus and ability to track specific symptoms with various new forms of wearable technology further improved his symptom management. For instance, Krejci used wearable sensors to track his body movement to further understand and quantify his symptoms, such as rigidity or tremors. The data collected provided him, and others, quantitative insights into how these symptoms present.²⁰ Krejci's work demonstrates how self-quantifiers are using personal digital health technology in creative ways to improve their quality of life. Compared to the Walden case, it clearly demonstrates how advances in self-tracking technology have expanded options for self-care for patients with PD.

Self-tracking technologies like those that Krejci employed allowed him to focus on monitoring and recording particular symptoms and manipulating lifestyle factors in order to understand their influence. PD symptoms do not manifest in the same way for everyone, symptoms and their severity often vary within and between days, especially as the disease progresses.¹² Krejci's case also highlights how accessible self-tracking can aid an individual in coping with the many different ways in which PD presents itself over the course of the disease. Krejci's case, in comparison to the Walden's, also highlights the variability of self-tracking tied to diverse symptoms, treatments, and the precision of tracking methods employed. More generally, the opportunity for tailoring within digital health and self-experimentation allows for diverse types of research to be conducted within self-tracking communities. The breadth and depth of symptom differences in PD is highly compatible with this varied approach.

Sara Riggare: Self-tracking through a self-designed protocol

The forms of digital health and self-tracking that Walden and Krejci employed continue to be developed by Swedish researcher Sara Riggare, who was diagnosed with PD at age 32 years in 2003.²³ Like Krejci's tracking, Riggare has used technology to help quantify her symptoms, and like Walden's tracking, she has conducted research into medication effects on specific symptoms.²⁴ Riggare engages in both the medication adjustment of Walden and the symptom tracking and lifestyle adjustments of Krejci, demonstrating how these efforts can be combined to possibly provide insights into the interplay between lifestyle, medication and symptoms.

Most notable is Riggare's experiment in which she used a mobile phone to track her rigidity and also used this information to better understand how her medications affect this symptom.²⁴ This reflects a change in how self-quantifiers are moving towards not just digitally tracking symptoms, but digitally tracking medication dosages and resulting symptoms in conjunction. By generating precise and accurate symptom data, the effect of medication on disease treatment can be understood in greater detail. A graph reflecting Riggare's medication intake and symptom severity over two days from her study can be seen in Figure 2.²⁴ Riggare reports that she brought this information to her neurologist so that they could consider when to alter the timing and dosage of her medications according to how her symptoms presented at the time.²⁴ Riggare further notes that such tracking could be useful in other clinical encounters and could likely help clinicians make better informed decisions about a patient's condition.²⁴

Riggare has also studied the effects of nicotine on her levodopa induced dyskinesia (LID) through the application of self-tracking and experimentation.²⁵ LID is the rapid uncontrollable movements that patients with PD may experience and is considered a burden to many.

Former studies suggested that nicotine could have an effect on LID, and thus Riggare chose to investigate.^{25,26} In collaboration with a research team, Riggare designed a within-person study to determine the effects of nicotine on her LID by comparing the effect of nicotine delivered through e-cigarettes compared to placebo periods in which she served as her own control, and reported any changes in her PD symptoms. Riggare was blinded to condition during the study, but data analyses revealed that she was able to clearly determine when she had taken nicotine rather than the placebo, based on her symptom relief.²⁵ Although this study did not confirm nicotine's effectiveness in treating LID, it did demonstrate how self-tracking and N-of-1 experiments can be employed by those with PD to understand their condition. Formal operationalization of variables was not pursued by Krejci or Walden and is not typically pursued by self-trackers. By working with other researchers and employing an experimental design, Riggare has added a core feature to how PD self-tracking is pursued. Although not every individual with PD may have the ability to conduct such experiments, Riggare's work demonstrates how self-tracking and experimentation could be utilized to help people alleviate

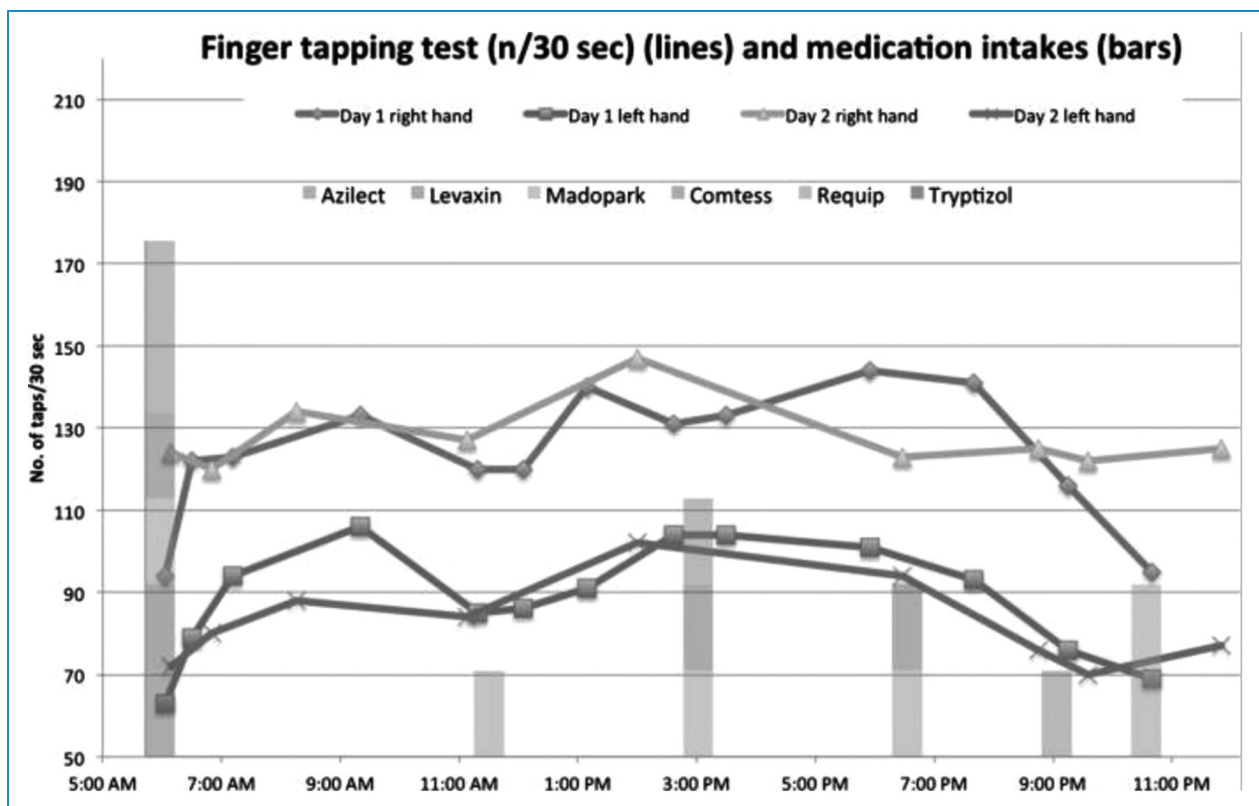


Figure 2. Riggare's finger tapping test ($n/30$ s) (lines) and medication intakes (bars).

Note. This figure was created by Riggare to record her ability to tap her fingers against her medication intake over two days to determine times of the day when her rigidity was more noticeable. The lines represent the trend in figure tapping ability in both her right and left hand, while the bars represent different medication intake times.²⁴

their symptoms and simultaneously advance scientific knowledge.²⁵

Beyond improving her quality of life with self-tracking and experimentation, Riggare is also investigating the methodology and applications of self-tracking and is the author of recently published studies exploring the nature of self-tracking in PD and its future.^{13,27} These studies are some of the first to explain the motives, burdens, and successes of PD self-trackers and suggest where the field appears to be headed.^{13,27} Additionally, Riggare has been an advocate for people with PD who self-track to be more involved in their health care and has called for clinicians and researchers to work together to aide those with PD who self-track.^{27,28} Riggare's research reflects how broad and developed PD self-tracking has become, as well as the how self-tracking is advancing as a both a therapeutic tool and as a scientific framework.

Discussion

Based on our coverage of these three self-tracking and self-experimentation cases, we propose that four themes be considered around personal digital health initiatives in PD: (a) patient readiness to self-track, (b) the nature of anecdotal tracking data, and (c) broader potential benefits of self-tracking in PD. We also touch on some ethical challenges that need to be considered.

Patient readiness for self-tracking in PD

PD “on-off” states and symptom variability give the researcher many different aspects of PD to analyze, which in turn makes PD a prime model for self-experimentation.^{12,25} However, the future use of and the extent to which digital health and self-tracking can be used in PD largely depends on a few key factors, including a patient's educational training, personal motivation to track, and the effect of such tracking on health-related changes in their quality of life. Although Riggare's case corresponded well to these factors, they may not be present for every individual with PD, such as when their failing health heavily impairs or curtails their participation.

The ability to use, and education on how to use, quantitative information is potentially one of the largest hurdles to overcome when it comes to self-tracking.²⁹ Organizations and platforms do exist to help educate self-trackers. Quantified Self, founded by Gary Wolf and Kevin Kelly in 2007, is one such organization which connects and provides education for self-trackers from other self-trackers. To become better informed, participation in the Quantified Self-fora such as those at which Kevin Krejci has presented is recommended.¹⁸ Informal groups may also convene in care settings such as local hospitals or universities—caretakers and patients from diverse backgrounds and with varying symptoms have shared interventions anecdotally in support

groups such as the Rhode Island South County American PD Association Chapter.

One of the most challenging, yet potentially most easily overcome, aspects of self-experimentation with PD is the willingness to collect data on oneself. Again, Riggare exemplifies how a patient's willingness to learn about and conduct experiments on their condition can shape their health-related quality of life. The motivation to self-track may however not be of interest to every person with PD. Some members of the PD community may be inhibited by symptoms typical of various disease stages. One means of strengthening the appeal of self-tracking is through the use of wearable sensors to track data and minimize the burden associated with recording data for the tracker passively. Wearable sensors and other forms of “smart clothing” are currently being researched and used by patients with PD.^{30,31} Many of these sensors can be non-invasive and relay precise data to the self-tracker.³² Wearable sensors can be used to produce data that can be shared with neurologists to track symptoms and can also be used by patients to monitor their own activity and the progression of their disease, similar to methods employed by Kevin Krejci.³³ These forms of digital health technologies can make tracking easier and they can aid clinicians in making better informed treatment decisions.³³ This type of automated tracking technology can reduce the burden of tracking while providing accurate data from which to draw conclusions about a user's health.³⁰ Another form of technology which has sparked the interest of self-trackers is social media. Some patients utilize self-tracking websites or blogging platforms to share their experiences with PD.³⁴ Such platforms are thought to increase engagement of self-trackers and sharing of ideas which may lead to more people with PD aware of the potential utility of self-tracking and entice them to start recording their own data and testing their own theories.³⁵ Lastly, worth mentioning is the potential challenge of financial cost to patients associated with self-tracking, though there have been suggestions that personal digital health tracking in general could reduce the financial burden on the health-care system, and in time this could provide subsidy to self-trackers for devices and other tools and services.³

Anecdotal data versus systematic studies

The relative lack of publishable data on self-tracking to date creates a barrier to quantifying reasons why particular interventions work. By employing quantitative methods over self-tracked cases, one could delineate a systematic treatment approach rather than anecdotally sharing what seems to work from patient to patient. Along with tracking data, this direction will require a framework for interpreting the data and allowing “common users” (those unfamiliar with personal informatics) to be able to understand and gain insights from their tracking without necessarily

having advanced knowledge of data visualization, quantitative data methods, and personal informatics tools.³⁶ Many people, such as in the early stage in Walden case, simply collect data on what is being administered and observed, looking for momentary benefits. True N-of-1 designs, such as multiple baseline studies, or alternating treatment designs over cases are likely to enhance collective opportunity for scientific advances.³⁷ When trying to decipher cause and effect, gaining an understanding of single-case methodology could allow common users to ensure that treatment outcomes are reliable, replicable, and generalizable.³⁸ If those with PD who self-track employed such methodology, it could improve the usefulness of their data and the insights gained from it. Riggare points out in her blog post “1 vs 8765 hours,” being able to scientifically self-track and understand data could prove beneficial for those with PD, as many with the disease are not cared for by a neurologist very often.^{13,39} The benefits of more rigorous tracking and interpretation of one’s own data could aid those trying to manage their disease when constant clinical support is not available. It is also challenging to provide education or otherwise convey understanding of empirical strategies to those who are not intrinsically involved with researching PD. This includes awareness of how to avoid increasing PD burden while concurrently improving quality of life. Riggare’s work provides an example of how relatively simple self-tracking methods can be used to create a positive effect on one’s quality of life, as she demonstrated in her experiment’s testing rigidity and medication intake and nicotine’s effectiveness in reducing LID.^{24,25} Incidentally, this approach is also likely to find support in recent movements to increase telehealth use.⁴⁰

Lastly, the effectiveness of self-tracking can be limited by the burden associated with patients having to put energy into yet another activity. In some instances, the addition of self-tracking to one’s care routine may cause moments of physical or mental distress.^{13,41} For example, if the tracking requires those with late stage PD to engage in a range of physical motions, the severity of their symptoms may not allow them to perform these motions and thereby prevent data collection. Patients with PD who are older, who have a longer disease duration, or who report more severe symptoms tend to experience fatigue more frequently, possibly impacting their willingness to engage in research or tracking activities.⁴² When self-quantifying, the regimen must have a favorable balance of positive to negative effects to feel worthwhile to patients and caregivers.¹³ Although tracking itself may yield positive effects, the burden it adds may not be worthwhile in some instances, especially if it causes otherwise unnecessary pain. However, in certain cases this burden can be at least partially ameliorated by utilizing personal digital health tracking technology in conjunction with manually recorded tracking, or simply reducing the frequency of tracking.⁴¹ If the burden is too great, then that specific regimen may not

be appropriate. Reactivity and intrusiveness are two additional potential factors that must be considered when crafting and evaluating a self-tracking regimen that is incorporated into the scientific record. Reactivity involves how the degree to which reports by a person who knows they are being tracked are biased, and intrusiveness involves the amount to which tracking interferes with or affects the trackers daily life.^{43,44} By carefully evaluating the self-tracking regimen’s potential reactivity and intrusiveness, the burden and fatigue caused by the tracking could be reduced and internal validity of studies could be increased.

One way in which those with PD may be able to address these types of challenges and gain support is by joining community support groups, either online, or in person. Most notably, the American PD Association runs support groups in every U.S. state.⁴⁵ There are also other digital health focused support groups, such as “PatientsLikeMe,” which focuses on quantifying and managing PD (and other diseases like ALS, HIV, etc.) through tracking user symptoms and drug doses.³⁴ Kevin Krejci is a member of PatientsLikeMe, and has presented on his data collection, methods, and his story at Quantified-Self Conferences, which are another venue where PD self-trackers have been sharing ideas.⁴⁶ As discussed previously, Krejci’s case is generally similar to Riggare’s with one exception: he has not formally published his findings. There are many more PD patients like Krejci who are actively tracking their own symptoms, but have not published their work because they have no reason to do so, or publication of such work is seen as an added complication and burden. To alleviate these issues and still allow data sharing, PatientsLikeMe provides an online platform for its users to share their findings without officially publishing their work through the peer-review processes.³⁴

Information collected on digital health platforms such as “PatientsLikeMe” allows those with various diseases, including PD, to record data that can be expressed through data visualization techniques and used to help gain insights into the effectiveness of treatment or disease progression. Data visualizations can be brought to physicians to help better treat conditions.^{47,48} Traditionally, physicians base diagnoses and treatment options on their judgments, and not formal, frequently collected data.³³ If physicians were able to access and evaluate patient health data across a wide range of the patient’s activities in daily life, physicians could make more informed decisions, utilizing concrete evidence rather than the patient’s explanation and appearance at a singular appointment.⁴⁹ Online digital health platforms have the potential to streamline this process and should be considered as another tool for physicians to utilize when working to treat and diagnose patients, especially when combined with proper patient education and training.

Although sites like “PatientsLikeMe” facilitate self-tracking and provide a platform and information for

patients, it is the patient who must collect accurate data and report it to the physician, and ultimately up to the physician to correctly diagnose and offer treatment for the condition. Clinicians should widen their perspective on patient self-tracked data and consider care strategies in light of patient data along with traditional medical approaches. Although self-tracking can help patients better understand and manage symptoms, professional medical oversight must not be overlooked in order to ensure patient safety, and to ensure that the effect of interventions is interpreted meaningfully. Indeed, some patient interface portals that developed rapidly during the Covid-19 pandemic include features to allow patients to upload at least basic activity records, such as pedometer or activity level summaries.

Benefits of N-of-1 in PD

There are a number of reasons why those like Krejci and Riggare have employed self-tracking to improve their quality of life, nearly all of which are also reasons to consider PD an excellent opportunity for self-experimentation. First, PD displays unique symptoms from person to person, meaning a “one treatment fits all” approach may not be the optimal way to treat PD.⁵⁰ Furthermore, the personalization of self-quantification means people can investigate their own most severe symptoms and determine interventions to help alleviate these symptoms. Second, the information collected by those tracking their condition can be used in a clinical setting to help physicians provide more personalized and effective treatment.^{28,50} As physician support is not always immediately available, self-tracking also enables people with PD to manage their disease on their own or in conjunction with their physicians, and discover what interventions work best for them, as David Walden did for his mother. Similarly, self-tracking is aiding those with various chronic diseases outside PD. One such example is atrial fibrillation, in which remote monitoring devices are being used to continuously collect data for patients and physicians to use for care decisions.⁵¹ Lastly, the main use of self-quantification within PD is the possibility that it will help to enhance health-related quality of life among others with PD through community and scientific sharing.

PD is a “highly individual” condition in the sense that often PD presents itself differently in each patient. As such, those with PD could potentially benefit from the personalized treatments provided by patient driven N-of-1 studies.^{24,25} Due to the nature of PD, conditions do not always manifest the same way in each patient, and as a progressive disease, the stages patients are in vary a lot in their frequency of on-and-off states.¹² This translates into the need for frequent changes of medications and lifestyle choices to manage symptoms. As such, treatments are likely to be most effectual when they are tailored to the individual. An N-of-1 design in conjunction with personal

digital health offers a way that this can be implemented by the patient, by creating a hypothesis rooted in personal experience, and testing the effect on an individual basis. Through self-experimentation for self-care, those with PD can monitor and observe what treatments have the greatest effect on them and share this information with their physicians. Physicians may be able to gain greater insight into a patient’s condition with such information and provide more effective treatment.⁴⁶ Although more research is needed to develop robust and scientifically sound methods of patient initiated self-experimentation, the approach could potentially be used in clinical settings to help advance research, or improve treatment for those with PD.²⁴ Techniques such as multilevel models, meta-analysis and integrated data analysis may help to advance scientific understanding of these data at the population level.

Another trait of PD that makes it conducive to tracking is its chronic nature, as the condition can last many years or decades. The length of PD provides an opportunity for long term digital self-tracking and experimentation which has been described as a self-catalyzing process, as one discovery often leads to another or to a new question to investigate.⁵² For those with PD, tracking their conditions over an extended period of time could help pinpoint interventions that work or lead to new discoveries that build upon the previous discoveries.

PD self-tracking is promising because many of the symptoms typically manifest themselves as external motor or speech issues which can be tracked numerically and simply, as Riggare has demonstrated in some of her studies.²⁵ The wide range of symptoms also allows for large amounts of data to be collected and analyzed, although deciphering large amounts of data can be difficult.¹⁸ Along with this, certain aspects of each symptom can be expanded on further, allowing for more personal or targeted tracking. For example, a self-quantifier with PD could track something as specific as the effects of protein consumption on rigidity, or something more general such as day-to-day rigidity. The usefulness of self-quantifying depends largely on what and how one is tracking, but PD’s range of quantifiable symptoms makes it a very attractive disease for study with N-of-1 self-tracking.

The main reason people use self-experimentation within the PD community is to further understand their condition and improve their quality of life.¹³ Riggare and Krejci conducted their work with the aim of improving their own lives, while Walden worked to improve his mother’s quality of life. Digital health and self-experimentation offers a chance to do exactly this.

Through self-experimentation, one can design or modify interventions to target specific symptoms based on what they find helps. For example, Riggare aimed to alleviate her LID through the use of nicotine.²⁵ This pattern is seen in the cases of PD self-tracking that we have reviewed

and they demonstrate the effectiveness that self-quantification can have for those with PD. Self-tracking allows those with PD to scientifically and personally manage their condition and discover techniques to improve their quality of life. Self-trackers like Riggare and Krejci have repeatedly demonstrated the potential digital health and self-experimentation holds for those with PD and have made it clear that their research can be expanded upon in citizen communities and in conjunction with medical researchers. As self-tracking technology advances, tracking is becoming less burdensome and more automated, allowing for self-quantifying that is accurate and less intrusive, thus encouraging use.⁵³ As new methods and technology for self-tracking become more readily available for personal digital health trackers, current challenges such as limited research training, variable willingness, and high burden may be ameliorated. The degree and precision to which self-tracking is able to improve the quality of life of people with PD has increased as self-tracking has become more accessible and digitalized.³² Although the future of PD self-tracking is difficult to pinpoint, current trends in research suggest that digital self-tracking will continue to expand the scope and accessibility of such work and an increase in personal digital health trackers managing their own disease is expected.

Ethics in PD self-experimentation

Although useful in many instances, some ethical challenges have arisen in self-experimenting and self-tracking. Self-trackers are not necessarily bound to ethical guidelines of institutions around human participants. Many institutions do not have a lot of experience in evaluating the arguments inherent to self-trackers individual rights versus institutional norms. This ambiguity has produced some issues for those conducting N-of-1 studies within the PD community.⁵⁴ The point at which independent self-tracking requires ethical review is not clear-cut. Some have suggested that the self-tracking community ought to police itself, while others have suggested that self-tracking conducted by those associated with institutions ought to receive ethical review, as has occurred in a remarkable situation around Riggare's case, considered below.^{54,55} For routine self-trackers without institutional affiliations, with their own personal goals, and with no scientific objectives, institutional standards of review most likely will not apply (though legal standards very well may apply in various situations and jurisdictions). Research performed by a sole personal digital health tracker operating on their own is not necessarily covered under typical ethical review standards, and these cases tend to not get reviewed for intentional or unintentional reasons.⁵⁵

One notable example that highlights these potential special ethical issues within the PD community and the lack of proper regulations surrounding them, is

Stockholm's Karolinska Institute's decision to reject Sara Riggare's dissertation; Riggare has written about her dissertation committee's decision, as described in her personal blog.⁵⁴ She outlines the committee's reasoning for rejecting her defense application on the grounds that some of her research used in the defense did not receive human subjects/ethics approval from an IRB. She argues that her research involved low risk everyday activities that should not necessarily have required a full ethical review.⁵⁴ The dissertation committee considered Riggare to be a doctoral student in a research group, managed by her supervisors and deemed such research groups cannot perform human subjects research without ethical review, even if the participant is a member of the research group.⁵⁶ In this case, the academic setting in which the self-tracking was conducted as a research product dictated the nature and the authority structure determining ethical risks of human participants. In other settings, when the products are not under the auspices of a research institution, it is much less clear what ethical processes should be adhered to.

Instances like this highlight the need for work on ethical guidelines for digital health and self-tracking and self-experimentation. Riggare's case, and the challenges associated with it, demonstrates how institutional ethical guidelines were clearly not written with self-experimentation in mind. Additional consensus on what requires ethical review in self-tracking is needed. These types of ethical issues are especially notable in PD self-tracking as many ordinary self-trackers are not undergoing any ethical review when engaging in self-tracking practices. It is important to try to ensure that such self-trackers are producing valid results and improving their understanding of their condition while simultaneously maintaining their safety and adhering to ethical standards. Ethical guidelines must be applicable to the research they were designed for and in this instance the lines between ensuring the safety of the research participant and hindering research are not clear cut. The novelty of these cases underscores the need for clear guidelines surrounding ethical self-experimentation.⁵⁶ Recent scholarship on ethical concerns in the arena of personal enhancement is also relevant for consideration in that the similar freedoms and accompanying moral risks may exist in self-experimentation for disease management as they do in enhancement studies.⁵⁷

Conclusion

The unique nature of PD has made it an ideal clinical space for the use of digital health. David Walden's case was an early example of how personal digital health could improve the health outcomes of those with PD. Kevin Krejci's case reflects the move towards automation of tracking and how the field is decreasing the burden of tracking. Presently, Sara Riggare is researching the process of PD self-experimentation in which she highlights the fact that the movement is becoming more sophisticated and targeted

in terms of what data is being generated, which in turn produces findings with increasingly valuable insights.¹³ It is reasonable to suspect that as more meaningful insights are created and more technological advances occur, self-tracked findings may be used in clinical settings more often and potentially guide physicians and patients alike in making more informed care decisions.

Finally, the potential impact of self-tracking and self-experimentation practices in scientific inquiries in the digital health domain is great. This arena requires patient input and personal digital health efforts, especially in the case of patients with PD, who inherently have the engagement needed to ensure patient input and compliance to their own protocols. The combination of these features may produce both collective scientific inquiry and enhanced medical care for patients. We respect and value the efforts of self-trackers like those chronicled in this article and we encourage researchers and patients alike with PD and other diseases that carry the potential for self-inquiry to consider these practices and develop in their own studies.

Acknowledgements: We acknowledge David C. Walden for the contribution of records.

Contributorship: AB and TW conceptualized and wrote the draft of the manuscript. CS and TW edited and contributed. TW received ethical approval and was the contact of Dave Walden. TB provided clinical insight and review. All authors agree on the findings.


Declaration of conflicting interests: The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.


Ethical approval: According to the author's university IRB policy, this work is considered non research and does not require human subject review.


Funding: The authors received no financial support for the research, authorship and/or publication of this article.

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