Attitudes Towards Long-Term Tracking in Parkinson's Disease

Sonali R. Mishra

University of Washington
Seattle, WA 98195, USA
srmishra@uw.edu

Woody MacDuffie

Sage Bionetworks
1100 Fairview Ave N
Seattle, WA 98107
woody.macduffie@sagebase.org

Predrag Klasnja

University of Michigan
105 S. State St.
Ann Arbor, MI 48109
klasnja@umich.edu

Eric Hekler

University of California San Diego
9500 Gilman Dr.
La Jolla, CA 92093
ehekler@ucsd.edu

Larsson Omberg
Michael Kellen
Lara Mangravite

Sage Bionetworks
1100 Fairview Ave N
Seattle, WA 98107
larsson.omberg@sagebase.org
mike.kellen@sagebase.org
lara.mangravite@sagebase.org

Abstract

The symptoms of Parkinson's Disease are highly variable, and people with Parkinson's Disease have much to gain from symptom tracking. But since the disease unfolds over a long period of time, people with Parkinson's Disease must track symptoms over decades to maintain a clear picture of their health. We interviewed 17 people with Parkinson's Disease and 6 caregivers of people with Parkinson's Disease to understand their attitudes towards long-term tracking. Here we discuss some potential challenges to long-term tracking and suggestions for encouraging long-term tracking of Parkinson's Disease symptoms.

Author Keywords

Parkinson's Disease; personal informatics; chronic disease; long-term tracking.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI).

Introduction

Roughly one million Americans live with Parkinson's Disease [3], the second most common neurodegenerative disorder [20]. Parkinson's Disease progresses slowly, but in the short term symptoms are highly variable [7], and long-term progression varies greatly between individuals [18].

Tracking symptoms can help people with chronic disease better understand their disease and identify things that make their symptoms better or worse [9]. Self-monitoring for Parkinson's Disease has been linked to improved medication adherence [5]. In the context of Parkinson's Disease, which changes slowly over the course of decades, people must track symptoms over an extended period of time. We sought to understand the attitudes of people with Parkinson's Disease

towards symptom tracking over the long term. In this paper, we discuss participants' attitudes towards long-term tracking, potential pitfalls to long-term tracking, and suggestions for supporting long term tracking among people with Parkinson's Disease (PwP). We define long-term tracking as tracking over a time period ranging from 6 months to life-long.

Related Work

HCI researchers have studied several ways to support or measure aspects of Parkinson's Disease, including information seeking behavior [18], activity tracking [15], exergaming [13], passive sensing [6,8], self-experimentation [19], individual symptom management [12,14], and others [11,16]; however, self-tracking of Parkinson's Disease symptoms has not been extensively studied. Instead, researchers have examined the value and requirements of self-tracking in relation to other chronic diseases (e.g. [1,4,9,10]). Most work on self-tracking for chronic diseases has focused on short-term tracking. But chronic diseases are long-term experiences, and the experience of Parkinson's Disease in particular remains dynamic, slowly evolving over decades. Given that self-tracking has the potential to improve care—it has been linked to better medication adherence in Parkinson's Disease [5]—understanding how to support long-term self-tracking in the context of this condition is crucial.

Methods

To understand the attitudes of PwPs towards long-term tracking, we interviewed 17 PwPs, ranging in age from 48-74 and in years since diagnosis from 1-19. We also interviewed 6 caregivers of PwPs ranging in age from 26-65. We asked participants about their symptom tracking habits and needs, including their current digital and analog systems, and showed participants a scenario of a person tracking and viewing the results of a finger tap test over six months (see Fig. 1). We asked participants open-ended questions about their responses to this scenario and how such data might be valuable to them. We further asked about their attitudes towards long-term tracking in general, not necessarily contained to 6-month intervals.

Long-term tracking: attitudes and pitfalls

In general, participants responded positively to the prospect of long-term tracking of their condition. For example, P08 felt that monitoring long-term trends would be valuable for planning major life decisions. As a result of his condition, he had retired early and decided to "[g]et in my fun travel now …. [since I'll be] less capable then. … My Parkinson's isn't getting any better." Being able to monitor his condition over the long term would help him make other major life decisions in future. However, participants' responses highlighted several potential pitfalls to long-term tracking: the inevitability of gradual decline and the possibility of diminishing returns.

Long-term tracking and gradual decline

Although most participants thought monitoring long-term trends would be motivating even in the face of decline, a couple of participants found the prospect of measuring their disease progression to be without value or even discouraging. P01 compared monitoring long-term progression of his condition to "measuring your net worth. It's [sic] might be interesting information but it's also kind of meaningless, because maybe half of your wealth is in your home, that doesn't mean you can use it or you can go on vacations all over the world…." Another participant, P10, had stopped tracking in part

because she didn't want to have to think about her symptoms every day. C05 was concerned that her grandfather would simply not track at all because he did not want to accept the possibility of decline.

Figure 1: Excerpt of scenario used in interviews. A character with Parkinson's Disease wonders how they have been doing over the last 6 months and reviews data from a finger tap test.

Independent of their interest in monitoring their long-term progression, participants were concerned about how the disease itself would gradually rob them of the ability to monitor their condition. P01 participated in studies as often as he could out of fear that he would eventually develop apathy as a symptom of the disease. Other participants were concerned about their current or future abilities to log symptoms on a mobile app, citing worries about accessibility and occurrence of symptoms that they could not monitor themselves, such as sleep-related symptoms. C01 was additionally concerned about the cognitive changes some PwP experience, like increasing forgetfulness, that might impact PwPs' ability to track their symptoms.

Long-term tracking and diminishing returns
Participants' descriptions of their interests and experiences tracking their symptoms implied that they would get diminishing returns from ongoing tracking. First, most of the questions participants asked about their symptoms could be answered over a short time period. For example, participants asked whether and for how long their medications worked, and whether specific triggers made their symptoms worse. Because the medications and triggers in question can have visible effects in less than an hour or even immediately (for example, with stress), these questions could be answered with some confidence over a fairly short time period. Second, participants were most interested in tracking when something was changing about their condition, but their condition could be relatively stable for long periods of time: for instance, P09 had not seen her neurologist in a year because she had been told not to come back until "things change," and nothing had. Taken together, these findings suggest that users may experience diminishing returns over long periods of tracking: after an initial high-value period during which users might track their symptoms and medications more intensely and answer many questions, the system might ask users to invest the same amount of effort for less value. One participant, P10, described tracking her symptoms early on and then stopping because she had already learned what she needed to know: after an initial period of consistent tracking, she was now "very aware" of her symptoms and had stopped tracking her symptoms on any system because it was no longer worth her time.

Supporting long-term tracking

Framing of long-term tracking

Participants who responded positively to the long-term tracking scenario thought that seeing a decline over time would "motivate [them] to intervene" (P08). For instance, C05 felt that her grandfather would be more receptive to insights about his disease progression if they were framed as a way to preserve his autonomy. These findings suggest that systems can help users to think about the ongoing value of tracking by highlighting its value for helping people maintain independence as long as possible.

Inclusion of other stakeholders

Because PwPs may not be able to track all their symptoms themselves (e.g. sleep symptoms), a challenge which may grow worse with time, systems geared towards long-term Parkinson's Disease symptom tracking can be designed to include other stakeholders, like caregivers, who can participate in tracking or reflection. Existing research has found that other stakeholders, like family members, sometimes participate in the tracking process [17]. Our interviews suggest that designing to include stakeholders here may motivate tracking: for instance, C01 had already convinced her husband, P01, to gather data about his symptoms on her behalf. Additionally, participants like P02, wanted to contribute data to researchers studying Parkinson's Disease, even if the data did not benefit them directly. Allowing participants to collect data for the benefit of the larger community, rather than just for themselves, may motivate long term tracking.

Diminishing burden for diminishing returns

Because participants may experience diminishing returns with long-term tracking, we also suggest that designing systems that require less input as time goes on may better support long-term tracking. One way to deploy this strategy is to establish the minimum amount of data needed to be meaningful, either in terms of the amount of data collected or the time interval at which it is collected, and invite participants to meet only this minimum standard over the long term (e.g., asking participants to check in every few months). Thus if the rewards of tracking diminish over time, so too does the burden, although participants remain free to invest more in tracking if they return with new questions, e.g. if they wish to iterate on self-experimentation [2].

Future Work

This study was done as part of the mPower study, a study to measure the variability of the symptoms of Parkinson's Disease. As part of this study, we will investigate the efficacy of the 'diminishing burden' strategy for promoting long-term engagement.

Conclusion

People with Parkinson's Disease can benefit from symptom tracking systems, but more work is needed to understand people's needs for long-term tracking. In this paper, we identify potential pitfalls for long-term tracking and suggest strategies for supporting this behavior.

Acknowledgments

References

1. Amid Ayobi, Paul Marshall, Anna Cox, and Yunan Chen. 2017. Quantifying the body and caring for the mind: Understanding self-tracking in multiple sclerosis. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*, ACM, 6889–6901. http://doi.org/10.1145/3025453.3025869

2. Nediyana Daskalova, Karthik Desingh, Alexandra Papoutsaki, Diane Schulze, Han Sha, and Jeff Huang. 2017. Lessons Learned from Two Cohorts of Personal Informatics Self-Experiments. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies* 1, 3: 1–22. http://doi.org/10.1145/3130911

3. Parkinson's Foundation (Reviewed by Ahmad Elkouzi). 2018. Statistics. Retrieved February 6, 2018 from http://parkinson.org/Understanding-Parkinsons/Causes-and-Statistics/Statistics

4. Sergio Felipe, Aneesha Singh, Caroline Bradley, Amanda Cdec Williams, and Nadia Bianchi-Berthouze. 2015. Roles for personal informatics in chronic pain. *9th International Conference on Pervasive Computing Technologies for Healthcare*, 161–168. http://doi.org/http://dx.doi.org/10.4108/icst.pervasivehealth.2015.259501

5. Rashmi Lakshminarayana, Duolao Wang, David Burn, et al. 2016. Using a smartphone-based self-management platform to support medication adherence and clinical consultation in Parkinson ' s disease. *Nature Partner Journals: Parkinson's Disease*, May: 1–8. http://doi.org/10.1038/s41531-016-0003-z

6. Jacki Liddle, David Ireland, Simon J. McBride, et al. 2014. Measuring the lifespace of people with parkinson's disease using smartphones: Proof of principle. *Journal of Medical Internet Research* 16, 3. http://doi.org/10.2196/mhealth.2799

7. Max Little, Paul Wicks, Timothy Vaughan, and Alex Pentland. 2013. Quantifying short-term dynamics of Parkinson's Disease using self-reported symptom data from an internet social network. *Journal of Medical Internet Research* 15, 1: 1–16. http://doi.org/10.2196/jmir.2112

8. Jiaxin Ma, Kenichi Kameyama, and Makoto Nakagawa. 2017. Optimizing Gait Parameters and Insole Sensor Positioning for Parkinson's Disease Assessment. *Proceedings of the 2017 4th International Conference on Biomedical and Bioinformatics Engineering (ICBBE 2017)*, ACM, 1–5. http://doi.org/10.1145/3168776.3168780

9. Haley MacLeod, Anthony Tang, and Sheelagh Carpendale. 2013. Personal informatics in chronic illness management. *Proceedings of Graphics Interface 2013 (GI '13)*, Canadian Information Processing Society, 149–156. Retrieved from http://hcitang.org/papers/2013-gi2013-personal-informatics.pdf

10. Lena Mamykina and Andrew D. Miller. 2010. Constructing identities through storytelling in diabetes management. *Proceedings of the SIGCHI Conference on Human Factors in Computing*

Systems (CHI '10), ACM, 1203–1212. http://doi.org/10.1145/1753326.1753507

11. Rísin McNaney, John Vines, Daniel Roggen, et al. 2014. Exploring the acceptability of google glass as an everyday assistive device for people with parkinson's. *Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14*: 2551–2554. http://doi.org/10.1145/2556288.2557092

12. Roisin McNaney, Nick Miller, Patrick Olivier, et al. 2011. Cueing for drooling in Parkinson's disease. *Proceedings of the 2011 annual conference on Human factors in computing systems - CHI '11*: 619. http://doi.org/10.1145/1978942.1979030

13. Roisin McNaney, Patrick Olivier, Madeline Balaam, et al. 2015. Designing for and with People with Parkinson's. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*: 501–510. http://doi.org/10.1145/2702123.2702310

14. Róisín McNaney, Mohammad Othman, Dan Richardson, et al. 2016. Speeching: Mobile Crowdsourced Speech Assessment to Support Self-Monitoring and Management for People with Parkinson's. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*: 4464–4476. http://doi.org/10.1145/2858036.2858321

15. Helena M. Mentis, Anita Komlodi, Katrina Schrader, et al. 2017. Crafting a view of self-tracking data in the clinical visit. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*, ACM, 5800–5812. http://doi.org/10.1145/3025453.3025589

16. Carla Pereira, Patrícia Macedo, and Rui Neves Madeira. 2015. Mobile Integrated Assistance to Empower People Coping with Parkinson's Disease. *Proceedings of the 17th International ACM SIGACCESS Conference on Computers & Accessibility - ASSETS*: 409–410. http://doi.org/10.1145/2700648.2811394

17. Laura R. Pina, Sang-Wha Sien, Teresa Ward, et al. 2017. From personal informatics to family informatics. *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '17)*, ACM, 2300–2315. http://doi.org/10.1145/2998181.2998362

18. Sara Riggare, Pär J Höglund, Helena Hvitfeldt Forsberg, Elena Eftimovska, Per Svenningsson, and Maria Hägglund. 2017. Patients are doing it for themselves: A survey on disease-specific knowledge acquisition among people with Parkinson's disease in Sweden. *Health Informatics Journal*: 146045821770424. http://doi.org/10.1177/1460458217704248

19. Sara Riggare, Kenton T Unruh, Jasmine Sturr, and Josefa Domingos. 2017. Patient-driven N-of-1 in Parkinson ' s Disease. *Methods of Information in Medicine* 56, 99: e123–e128. http://doi.org/10.3414/ME16-02-0040

20. Sue Thomas and Doug MacMahon. 2004.

Parkinson's disease, palliative care and older
people:part 2. *Nursing Older People* 16, 2: 22–26.