

Supporting Coping with Parkinson’s Disease Through Self-Tracking

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ABSTRACT

Self-tracking can help people understand their medical condition and the factors that influence their symptoms. However, it is unclear how tracking technologies should be tailored to help people cope with the progression of a degenerative disease. To understand how smartphone apps and other tracking technologies can support people in coping with an incurable illness, we interviewed both people with Parkinson’s Disease (n=17) and care partners (n=6) who help people with Parkinson’s manage their lives. We describe how symptom trackers can help people identify and solve problems to improve their quality of life, the role symptom trackers can play in helping people combat their own tendencies towards avoidance and denial, and the complex role of care partners in defining and tracking ambiguous symptoms. Our findings yield insights that can guide the design of tracking technologies to help people with Parkinson’s Disease accept and plan for their condition.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI.**

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KEYWORDS

Symptom tracking, personal informatics, health informatics, Parkinson’s Disease, coping with chronic disease, quality of life.

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1 INTRODUCTION

Parkinson’s disease (PD) is a neurodegenerative disease whose prevalence increases with age [70, 75] and reaches 2.6% in people 85-89 years old [70]. Within the US, about a half a million people live with PD [62], a number which is expected to grow to nearly a million by 2030 [49]. PD can be treated with a variety of medications, but not cured.

People with PD (PwP) struggle with a variety of symptoms, including motor and cognitive impairments that can reduce people’s quality of life [62]. The motor symptoms tremor, bradykinesia (i.e., slow movement), and rigidity (i.e., stiffness around joints) are the cardinal features of PD and perhaps what it is best known for, but PwP can also experience a large range of other motor symptoms such as speech impairment, a shuffling gait, and dystonia (a type of muscle cramp), as well as non-motor symptoms such as gastrointestinal problems, dementia, psychosis, and sleep disorders [12]. The rate of progression of symptoms is highly variable

between individuals [81], and not all individuals develop the same symptoms [61]. In addition, symptom severity fluctuates in the short term and can be impacted by factors like stress [44]. As a result, living with PD is characterized by "the experience of living with and managing unpredictability," with the knowledge of eventual loss of independence [28].

Although the symptoms of PD can be quite disabling, the impact of the disease on people's quality of life is not fully explained by severity of symptoms [8, 25, 44]. Researchers have suggested that this is because the types of *coping strategies* used affect PwP's quality of life [8, 25, 44]. *Coping* is the performance of cognitive and behavioral strategies to manage stress [80], and individuals can use more than one coping strategy in response to a given situation, for example by changing from one strategy to another [20]. Researchers have used a variety of frameworks to classify and evaluate individual coping strategies across populations [80], but in the context of PD, coping strategies geared towards problem-solving, meaning the application of logical problem-solving techniques to improve a situation, have been associated with improved quality of life [8] and greater well-being [44]. These strategies are called "positive" or "adaptive" coping strategies, and include behaviors like making and carrying out a plan of action, and coming up with solutions to a problem [21]. By contrast, coping strategies geared towards avoiding or denying the situation have been associated with worse quality of life in PwP [8] and worse psychological adjustment to the disease [44], although other studies suggest that denial can sometimes be adaptive [38, 39] and a balanced approach with a mix of the two may be best in the context of PD [78]. Examples of escape-avoidance coping include strategies like refusing to believe that something has happened, and fantasizing about how things might be different [21]. Coping strategies associated with lower quality of life are often called "negative" or "maladaptive."

Although HCI researchers have explored how self-tracking supports self-management of chronic illness (e.g. [3, 45, 48]), more work is needed to understand the role tracking technologies can play in helping people cope with progressive decline. In other contexts, researchers have noted that self-tracking applications fail to keep up with changes in users' lives [18]. Given the constant change of life with PD, and the impact that the strategies PwP use to cope with that change can have on their quality of life, it is important to understand how technologies designed to support people in managing their illness can influence PwP's strategies for coping with decline in their condition.

We explored the following research question: how can tracking technologies be designed to help people cope with progressive decline? To investigate this question, we interviewed both PwP and their care partners (friends and family members who help the PwP manage their disease) about their symptom-tracking practices and their attitudes towards symptom-tracking. We included care partners because PwP often work with care partners to manage their illness [66]. In this paper, we illustrate how self-tracking technologies can support PwP and their care partners cope with disease progression by helping them pursue positive coping strategies and combat their tendencies towards maladaptive avoidance. We also describe how ambiguous symptoms in PD can cause tensions between PwP and care partner. Finally, we discuss design implications for creating tracking technologies for PwP and their care partners.

2 BACKGROUND AND RELATED WORK

To understand how self-tracking can fit into life with PD, it is important to understand how PD is currently evaluated and treated. We give some general background on the evaluation and treatment of PD to contextualize our findings. We also summarize some of the related work in HCI on self-tracking in the context of chronic disease and on support for PD.

Evaluation and Treatment of Parkinson's Disease

PwP see their clinicians (often neurologists and movement disorder specialists) in appointments spaced months apart. Clinicians typically evaluate patients using a scale called the Unified Parkinson's Disease Rating Scale (UPDRS), a questionnaire with items measuring a variety of symptoms of PD [24]. Although non-motor symptoms significantly impact quality of life [7, 9], neurologists typically focus on evaluating and treating motor symptoms [7].

To control their motor symptoms, many PwP take drugs like levodopa which are known for being very fast-acting, and lasting for anywhere from 2-6 hours [67]. As the drugs wear off, symptoms resurface, leading many PwP to experience "on" and "off" periods, when the drugs are either working or not working [62]. PwP also must balance the benefits of the treatment with side effects like dyskinesia, meaning involuntary movement related to levodopa [89]. Exercise can also give PwP temporary relief from pain and temporary improvement in some motor function [90]. PwP also sometimes manage their symptoms by taking medication in conjunction with Deep Brain Stimulation (DBS), a device implanted in the brain that uses electric currents to help PwP manage their symptoms, and which can drastically reduce the amount of medication needed [88]. However, even with appropriate use of these kinds of treatments, PD remains incurable, and the symptoms will eventually progress.

Self-Tracking in the Context of Chronic Illness

HCI researchers have studied self-tracking in the context of several chronic illnesses, including diabetes [46, 48], bipolar disease [4, 50, 51], chronic pain [19], multiple sclerosis [3], migraine [82], irritable bowel syndrome [33], and others. Much of this work has focused on how tracking tools support self-management, for instance by helping people understand how different factors affect their illness and gain a sense of control [3, 33, 52], as well as gather data to share with clinicians to manage their care [14, 60, 94, 97] or even conduct clinical screenings on themselves at home [32]. Researchers have also investigated how family members can participate in tracking symptoms [74], and how tracking systems can better help patients communicate their symptoms with family members [29]. Recently, researchers have also explored how tracking technologies can help users contribute knowledge to shed light on "enigmatic" diseases [54].

Researchers have found that self-tracking supports a variety of goals in addition to self-management of health. For instance, people suffering from migraines use self-tracking in part to gain recognition from their clinicians [82]. Mamykina et al. found that people self-tracking for diabetes management also used the system to aid in identity construction [47], while Matthews et al. found that manual and automated tracking could have different impacts on people with bipolar disorder's identity construction [50]. MacLeod et al. found that self-tracking enabled people to develop a sense of curiosity and exploration, and that people valued being able to generate data for medical research [45].

However, most of the work on self-tracking has focused on conditions where health outcomes can be controlled or at least stabilized through behavior (e.g. diabetes), or where there is no expected decline (e.g. bipolar disorder). By contrast, degenerative conditions like PD mean that people diagnosed must expect their condition to worsen over time, no matter what they do. Although degenerative conditions have been studied in the literature [3], more work needs to be done to understand how the design of tracking technologies can help or hurt people dealing with the inevitable progression of a degenerative illness.

HCI Research on Parkinson's Disease

Researchers in HCI and health informatics have done much work on developing systems to measure and monitor the symptoms of PD, including mobile phone systems [2, 40, 63, 64, 96], image processing of handwriting [73], wireless and wearable sensors [27, 30, 42, 43, 53], and many others. Much of this work has focused on the development of the systems, and has been instrumental in demonstrating the potential of

technology to successfully monitor the symptoms of PD in a quantified way. Researchers have also highlighted how mobile technologies have the potential to improve the quality of life of PwP by monitoring non-motor symptoms through markers like social interactions [87] and the amount of distance a PwP travels in a day [40]. However, these systems often do not provide data back to the PwP, although some offer data to clinicians [17, 27, 59].

Other work has examined how PwP themselves could or do use tracking or other technologies to live with and manage their disease. Researchers have examined how to support PwP in staying active and maintaining correct posture through exergaming [23, 41, 56, 85], as well as how to help PwP communicate with clinicians [60, 65, 72, 95] and conduct self-experimentation [79]. McNaney et al. have investigated how technologies can help people become more aware of PD symptoms like soft speech and drooling [55, 57] and how systems like Google Glass can be used to notify PwP when their medications are wearing off or when they are experiencing freezing symptoms (when a person is temporarily unable to move) [58]. Several researchers [58, 68, 92] have also noted the need for accessibility in tracking technologies designed for PwP. Vega et al. found that PwP preferred paper-based diaries for self-report for a variety of reasons, including that it was easier for people to physically enter information, and that their paper-based diary was designed to reduce user burden [92]. However, mobile technologies have also been found valuable for self-tracking. In a clinical deployment of a self-tracking app designed to be used in conjunction with clinicians, Lakshminarayana et al. found use of the app led to improved medication compliance and quality of clinician consultations [37].

Some researchers have found that PwP desire not just medicalized symptom trackers, but technologies for self-care, meaning technologies that help people live their lives beyond merely tracking symptoms [67]. Nunes et al. found that PwP desired technologies that could help them focus on everyday tasks like medication taking and exercise [67]. In addition, researchers have stressed the importance of designing to support active collaboration between PwP and care partners in self-care [66, 67, 72], because care partners collaborate with PwP in every aspect of self-care [66].

Although researchers have found that technology for PwP must adapt to people's changing condition [85?], little work has been done on how tracking technologies can be designed to help people cope with this change. McNaney et al. found that PwP can be reluctant to track their decline [56], underscoring the fact that tracking technologies are not neutral recorders of a person's condition, but something that

users interact with actively in changing contexts [67] that influence them psychologically. More work must be done to investigate how tracking technologies should be designed to help people with PD understand and approach the inevitable progression of their disease.

3 METHODS

To understand how symptom trackers could support or hinder PwP in confronting decline, we conducted interviews with both PwP and care partners. We included care partners in our sample because PD requires work from care partners as well as from the person diagnosed [66, 67]. Participants were recruited through several channels. First, we recruited people from a local PD exercise class by attending the class, describing the study, and inviting class members to participate. This was done with permission from the class instructor. Second, we recruited participants through social media and word of mouth. Third, we recruited people by reaching out to participants in two separate studies involving PD mobile apps, both taking place in the United States. For these participants, study organizers reached out to potential participants with information about the study, and people interested in participating contacted us. Fourth, we recruited new participants through snowball sampling by asking people who had already agreed to participate if their primary care partner would also be willing to participate, or if they knew any other PwP or care partner who might be willing to participate. Members of the research team discussed themes arising from the data as interviews progressed, and recruitment continued until we reached saturation. Note that we use the term "care partners" rather than the more usual "caregivers" because many participants strongly disliked the word "caregiver". In total, we interviewed 17 PwP, including 12 men and 5 women. PwP participants ranged in age from 48-74 (mean 61.2, median 61), and had been diagnosed between 1 and 19 years previously (mean 7.9 years, median 7 years). We interviewed 6 care partners, all women, ranging in age from 26-65 (mean 53.6, median 58, with age for one care partner not reported). In some cases, we interviewed care partners of interview participants (P01-C, P02-C, P03-C, P08-C); in others, we interviewed care partners but did not interview the PwP (P12-C, P14-C). Four care partners were the PwP's primary care partner (their spouse in all cases) (P01-C, P02-C, P08-C, P14-C); one was the PwP's granddaughter (P12-C); and one was the PwP's workplace assistant (P03-C). Since P03-C chose to participate as part of P03's interview rather than independently, in total we conducted 22 interviews rather than 23 interviews.

Interviews were conducted either in person or remotely over video conference, based on the participant's availability and preference. Participants were drawn from all over the United

States. We asked participants questions about a variety of topics, including: their current symptom tracking habits, such as what kinds of things they found important to track and why tracking these things were important to them; how they prepared for clinic visits and what kinds of questions they had about their symptoms; and what kind of information they thought was most important to capture about symptoms, such as objective measures (where possible), notes about the context, and other data points. As mentioned earlier, members of the research team met regularly to discuss emergent themes from the findings. Through discussion of the first few interviews (P01, P01-C, P02, P02-C, P03, P03-C), we identified four potential use-cases of self-tracking technologies that we wanted to explore further: tracking long-term progression, sharing tracked data with clinicians to manage medication, self-tracking to identify factors that affected symptoms, and having a care partner track symptoms for someone with PD.



Figure 1: Excerpt from a storyboard used in interviews. A PwP wonders how they have been doing over the last 6 months, takes a finger tap test, and views a declining trend in results from the last 6 months. The last square in the figure has an empty thought bubble so that interview participants could voice their own reactions.

To help us explore these themes with participants, we created four storyboards and added them to the end of the interview protocol (see Fig. 1 for an excerpt from a storyboard and auxiliary materials for all storyboards). Starting

with P04, we began the interview by asking our original interview questions, but partway through the interview would show participants the storyboards and walk them through the four use-cases as represented in the storyboards. After introducing each storyboard, we asked participants about their reactions to the storyboard and what value or challenges this use case represented for that participant. Using the storyboards enabled us to focus the interview on themes relating to long-term tracking, viewing data about decline, and involving care partners in symptom tracking. In addition, because three of the storyboards prominently featured a particular symptom tracking metric—the finger tap test (a test in which the user taps on two circles on the screen with alternate fingers for a set period of time, yielding metrics like total tap count as well as more abstract measurements like the user’s accuracy in hitting the circles)—they helped us discuss with participants the value of different types of symptom tracking measures. Interviews were recorded and transcribed. One member of the research team analyzed the data using an inductive thematic coding process [71]. Specifically, one member of the team began by conducting open coding [15] on the transcripts, then discussed themes in the data with other members of team and iteratively refined the codebook. Because our focus was not to understand the differences between PwP’s needs and the needs of care partners, but rather to get a holistic picture of what role symptom tracking technologies could play for PwP, we analyzed data from PwP and care partners together and present them as one participant pool. In the findings, we include both PwP and care partners in the term “participants” unless otherwise specified. This study was approved by Western Institutional Review Board.

4 FINDINGS

Participants’ current tracking habits were mixed: some currently tracked their symptoms, some did not. Most of those who did not track cited as a reason the lack of good tools for doing so. Overall, our participants were enthusiastic about the potential of self-tracking for helping them to approach their disease with a problem-solving orientation as it changed over time. Moreover, participants saw certain kinds of self-tracking technologies as a way to help them combat their own tendencies towards avoidance coping strategies and to confront their current condition honestly. However, participants experienced symptoms they could not track themselves, and sometimes struggled to differentiate symptoms that were caused by PD from symptoms that arose from other causes or even from everyday life. Participants discussed how care partners could aid in tracking ambiguous symptoms, but also how such aid could lead to tension in the determination of what counted as a symptom of PD. Below we give a more detailed report on our findings.

Current Tracking Habits and Attitudes Towards Tracking

Some of our participants currently tracked their symptoms or had in the past, and some did not, either because they had just been diagnosed or because they simply did not see the value. Eight participants currently kept track of their symptoms through some form of journaling on paper or mobile apps. Four participants used to keep a formal log of their symptoms on paper or digitally, but had stopped because the tool was too frustrating to use and did not give them what they needed, or because they no longer wanted to. Eleven participants did not formally keep track of the PwP’s symptoms.

Overall, both participants who currently tracked their symptoms and participants who did not were enthusiastic about tracking not just symptoms, but also medications and various environmental, behavioral, and health-related factors that might affect the PwP’s symptoms. For instance, P01-C and P11 were interested in tracking how diet affected medication efficacy, and P02 was interested in tracking how low light conditions and health metrics like his blood pressure and weight affected his symptoms. In fact, only a couple of participants, like P01 and P10, did not find self-tracking valuable. P01 compared tracking the progression of his symptoms to knowing his net worth, saying it “*might be interesting information but it’s also kind of meaningless*”. P10 had stopped tracking because her symptoms were not changing very much and because she did not want to think about her symptoms every day. Other participants who did not track, however, cited the lack of good tools for tracking symptoms. Most did not know that mobile apps for tracking PD symptoms existed at all; the few who had tried some out generally did not find them satisfactory. For instance, P06 had tried several PD tracking apps, but ultimately rejected them because they cost money, were designed for clinicians, and/or did not let him retrieve data in a time period useful to him, instead restricting his data retrieval to the last week. Some of the participants who did not track their symptoms regretted this choice, and wished that they had been self-tracking earlier in the illness. For instance, P03 said that some of her symptoms had improved and she wished she had data “*because I would have an idea of what’s going on*.” However, she was concerned that, “*because I’m starting so late in the game, and there’s no easy way for me to track*,” it would be impossible for her to start now.

Self-Tracking to Support Planful Problem Solving

Participants saw tracking technologies as tools that could help them plan for changes in their condition over the long

and short term. For the long term, participants wanted symptom trackers to help them monitor their long-term progression to help them view decline as something to be planned for rather than a black box. For the short term, participants wanted tools that could help them work with clinicians between visits on changes to their medications. Some participants also felt that the framing of data was important for helping PwP adopt a problem-solving orientation to change in condition. These sentiments reflect the need for 'planful problem solving' (i.e., the application of "logical problem-solving strategies" to improve a situation), which has been associated with higher health-related quality of life in PwP [8]. Participants saw tracking technologies as tools that could help them apply planful problem solving strategies to changes in their condition.

Self-Tracking Over the Long Term. Participants knew that change would happen to them sooner or later: their symptoms would eventually progress. To deal with that change, some participants wanted tracking tools that could help them identify and plan for problems as soon as they developed. As P19 put it, "... don't sit back and let the disease happen to you." To "slow the progress of the disease, if possible," P19 researched and tried out new techniques to control his symptoms, and tracked his symptoms for clinical studies and his own purposes.

In the long term, some participants wanted to track their progression because in order to plan for it. A few participants were not interested in tracking their progression, like P01 quoted earlier. However, even though progression in PD can be difficult to predict, other participants wanted data to offer them guidance in making long-term planning decisions. For example, P05 commented, "I just happen to be one of those that wants to know my state of decline. I'm 61 years old. I've got a grandson that's four and another grandson that's 20 months. Do I need to make sure and do things with them sooner versus later? And [tracking] helps me make lifestyle and preparation decisions, probably a little more succinctly than I would otherwise." Similarly, P03 wanted to map out her progression so that she could predict when "you're gonna be useless. Then there might a point that you wanna intervene before you become useless, right?"

Self-Tracking Over the Short Term. PwP often see their clinicians in appointments months apart or more. Participants wanted tracking technologies that could help them track their symptoms against their medications so that they could work with their clinicians between visits to adjust their medication as their needs changed. Self-tracking systems were tools that could help them take action to solve issues that arose with their medication. For example, P18, who tracked his symptoms and medication extensively using a variety of

tools, said he had gotten started with self-tracking because his neurologist "didn't know how to tweak things [related to medications and DBS] to ... help with [my] symptoms". Participants also worried that relying solely on their neurology visits to resolve problems would leave them helpless to resolve issues for long periods of time. As P15 said, "I think that if it's [limited to] visits, I think that's too long a period of time. ... there needs to be a shorter feedback period. ... as a patient, I don't want to be mis-medicated for any longer than I need to be." Similarly, P18, who had recently gotten DBS and was still trying to find the right medication regimen to fit his new situation, wanted to be able to "record stuff either right there [in the clinic] or even when you're not there and be able to take that to your doctor and have [your DBS and treatment] being able to be changed"

To make adjustments to their medications, participants needed fine-grained data about their symptoms. For instance, P11 envisioned a tool that would help her measure her on and off periods by letting her measure her symptoms several times over the course of a few hours, so that she could see exactly how long it was before her medications began to work and wear off. P08 similarly needed a tool that would measure exactly how bad his symptoms were in quantifiable terms: "I don't want it to just be oh are you shaking or not shaking, I want to know how much". However, participants also needed to be able to capture contextual information about their symptoms. For example, P04's notes for his clinician contained rich contextual detail. He wrote as a note on his phone to share with his doctor, "The tremors when left hand is idle but not when [doing] a task, some shoulder or arm pain but only when resting on my elbows."

Framing Data to Support a Problem-Solving Orientation. A couple of participants suggested that how data was presented to the user was important for supporting a problem-solving orientation. While many participants, like P18, preferred raw data that they could interpret themselves, participants like P11 and P12-C stressed the importance of framing data about decline in a way that highlighted actionable insights. P11 felt that symptoms should only be tracked in context of controllable factors like exercise, saying, "... when you do a test like [the finger tap test], it needs to be associated with ... something that they're ... either choosing to do or choosing not to do. ... I mean at least if they get worse and they're doing it, you can say, well, it would be worse. [sic]" P12-C had found that her grandfather, who had PD, was more receptive to her help when she helped him solve a problem rather than simply pointing it out: "... we described it as, 'Here's some new shoes, but you can still be independent with them. I'm not like taking away your independence. ... I got you better shoes.'" P12-C felt that framing bad news in terms of actionable insights was

more conducive to problem-solving than simply presenting data showing a "downward spiral".

In summary, participants saw self-tracking technologies as tools that could help them plan for changes in their health over the long and short term, reflecting a desire to use self-tracking to support planful problem-solving type coping strategies to respond to changes in their condition. In addition, some participants thought the framing of data was important for nudging people towards positive coping strategies in the face of changes in their health.

Self-Tracking to Escape 'Escape-Avoidance' Coping

Several participants in our study spoke of the need for data that they could not game or override. They worried that they would unconsciously try to portray themselves as better than they actually were when tracking their symptoms, and wanted self-tracking systems that could *objectively* record their symptoms. Some participants also hoped that self-tracking data could help them convince someone close to them (a care partner or the PwP themselves) to accept the reality of PD. Participants' desire for objective data about their symptoms spoke to a desire to combat unconscious tendencies towards denying the reality of their symptoms, or 'escape-avoidance coping,' which has been linked to lower quality of life in people with PD [8]. Participants wanted objective self-tracking systems to help them accept the reality of their current state.

Self-Tracking to Combat Tendencies Towards Denial. Symptoms like tremor can be captured meaningfully in three different ways. One way is **objective** metrics, like accelerometer data from a phone, or the results of a finger tap test. Another way is with **subjective** metrics like a rating of how bad the tremor is from mild to severe, and a third is with **functionalist** metrics like a description of how specific tasks and activities of daily life are impacted by the tremor. Some participants worried that they would not accurately track symptoms without an **objective** tracking system because they would try to appear better than they were. Participants did not always trust themselves to be able to offer representative behavior to their clinicians during the periodic clinical exam. As P15 put it, "God bless my movement disorder neurologist, but she knows that I can game her. I just come in there and I can just be perfect. ... I will outperform what I normally would." This concern, however, extended beyond clinic visits to self-tracking systems. P08, concerned about "all kinds of placebo effects in Parkinson's research," wanted data "that I couldn't override". He wanted to be able to test tracking tools to make sure he could not "game" them before he was willing to trust them. P15 went further, rejecting any kind of metric other than wearable sensors because, "Us PD patients, the Parkies, we compensate all the time. That's how you learn to

live, maintain a good lifestyle. So you know, you're fighting against human nature by doing" periodic, explicit data collection instead of using continuous sensor data. P16 felt that his evaluations of not just a subjective symptom like pain but even an outwardly measurable symptom like tremor would be impacted by his surroundings. He said, "... my problem is if it's the dead of winter, I'm sitting in here and I'm in pain and having a tremor, I'll bet you that if you compare that same tremor to the spring time when the birds are singing ... I'll bet you my response is different." These statements suggest that participants felt they could not rely on themselves to accurately report their current condition, either to themselves or to clinicians.

Some symptoms could not be tracked with objective metrics. For instance, P09 experienced a symptom she called "tippiness" that was different from her actual unsteadiness, but rather "a strange perceptual thing that makes me feel unsteady, even though I'm not actually unsteady." Several participants also experienced cognitive symptoms like forgetfulness or a sense of someone standing behind them, which one participant called "the presence" (P16). For these kinds of symptoms, P01-C expressed concern that people's willingness to track a symptom would depend on how they were asked. P01-C worried that PwP's reports of the symptoms they experienced would be greatly impacted by context. Thinking about clinic visits with her husband, she voiced concern that PwP would not give clinicians accurate information if they perceived their symptoms to be "bad":

"... our doctor, who's really good, she first asked, 'Are you having hallucinations?', and then after that, she said, 'Do you ever feel like you just see something out of the corner of your eye, but you don't quite know what it is?' And of course, if you ask that question second, the person is gonna say, 'Oh, that's a precursor to hallucinations, hallucinations are bad. I don't have them, I'm going to say no to that question.' Even if they maybe have felt like there's this weird sense of something on the edge of the field of vision."—P01-C

In addition, participants were concerned that they would not always be able to take the time to take objective measures of their symptoms, even if the symptom could theoretically be measured objectively. P15 gave the example of being "in a meeting... I'm feeling unsteady. Am I going to stop and log in the app and indicate—the answer of course is no...". Participants were also not always aware of their symptoms: as P04 said, "sometimes I don't even know, I look down and I see [the tremor]. I don't even know that it's happening."

Because of the difficulty of logging symptoms at any time, P11 wanted to be able to correlate her subjective sense of

her symptoms with objective measures. As she described it:

"...I think what would be an interesting thing to know is ... do they correlate. ... So let's say today I'm having a real big problem with tremor. So that I open up the app to a point where every hour on the hour I get a prompt that says tremor, one, two or three. ... at the end of the day you could then pull that up and put over it, you know, superimposed on it, what the [objective] tremor measurement was."—P11

Dealing with Denial in Others. A couple of participants struggled not just with forcing themselves to accept PD, but with getting other people close to them to accept it. One participant, P04, hoped that symptom tracking systems could help him get his spouse to accept his condition. P04 wanted his spouse to complete the same finger tap test that P04 himself performed so that he could compare his own data to that of his spouse. P04 felt that his spouse was *"still trying to ignore it and he hasn't gotten on board with this is a life changing thing and we're just going to have to accept it and move on."* He wanted to be able to record his data side by side with his spouse's data that could help him demonstrate to his spouse the difference his symptoms made. From the other side, P14-C wanted her husband, who had PD, to accept his condition. She wanted data to prove to him that his medications made a difference to help him accept that he needed treatment:

"...he can't see that there's a difference when he takes his meds. And so if I get him to take his meds and then, say, 20 minutes later do the test again, maybe he can see that there is a change in the tremor test or the tap test. ... And so maybe I can actually show him with that, that he's actually doing better on the meds, which would be a huge help for me. ... He wouldn't be quite so resistant to taking the meds."—P14-C

On the opposite end of the spectrum, participants did not always want to admit to symptoms that they experienced, and felt betrayed when their care partners kept track of those symptoms and reported them to clinicians. P11 and P04 both complained that their care partners liked to *"tattle"* (P11) or *"rat [them] out"* (P04) at clinic visits. Anticipating this reaction, other participants felt that care partners should be able to track PwP's symptoms independently of the PwP themselves. P12-C, for instance, took care of her grandfather with PD in conjunction with her whole family. She needed a way for care partners to share notes with each other so that their collective picture could help them all decide how best to take care of the PwP, without his involvement at all. P13, herself a PwP, likewise felt that care partners needed tracking systems independent of PwP because sometimes

PwP *"tend to get really belligerent and defensive"* when confronted with their symptoms.

In summary, some participants worried that they would cheat their own self-tracking systems and present their symptoms as better than they were if they did not have objective metrics that they could not beat. Concerned that they could not take the time to log objective metrics whenever they were experiencing symptoms, participants suggested that self-tracking systems could help them learn to associate their subjective feelings with objective metrics. Participants also saw value in self-tracking systems for convincing others close to them to accept the reality of PD, but some participants with PD wanted the ability to escape tracking symptoms they did not wish to admit to. As a result, some participants felt care partners needed tools to track PwP's symptoms completely independently of the PwP themselves.

Ambiguous Symptoms and the Role of Care Partners

Participants were interested in using self-tracking technologies to help them cope with changes in their condition, but they often struggled with symptoms that were unobservable (in that PwP could not observe them themselves) or were ambiguous in nature. In the first case, care partners could play a clear role. However, in the last case, tensions sometimes arose between participants with PD and care partners, because they could not always agree on whether change was happening or what it meant. As P01-C put it, *"I'd like to think that it would be possible to be graceful about changes. But if you're confused about what changes are, that's harder."* We describe each of these types of symptoms and the role of care partners in tracking them.

Care Partners and Unobservable Symptoms. Participants sometimes wanted to track symptoms that they could not actually observe themselves, such as sleep and soft speech. PwP sometimes speak very quietly without realizing it, as a result of PD. As P07 put it, *"When I think I'm talking normal ... it's not the right normal."* In these cases, some participants felt that care partners could help track symptoms. For instance, participants like P02 thought care partners were instrumental in reporting sleep symptoms—he himself relied on his wife to notice when he fell asleep while reading the newspaper, and how long he had been asleep.

Care Partners and Ambiguous Symptoms. Participants frequently wondered whether what they were experiencing resulted from PD or from another cause. For instance, P02, who had recently been hospitalized for a knee surgery, had been experiencing increased tremor in his leg, and was unsure if his condition was changing or if his increased tremor was temporary and related to his hospitalization. Participants determined if this type of symptom was due to PD

either by waiting to see if it lasted (like P02) or by testing if medication improved the symptom.

However, participants also sometimes struggled with distinguishing symptoms from everyday experience. For instance, P02 explained how knowing that swallowing issues were a symptom of PD would get "... *in the back of your mind, and at any time you have a difficulty swallowing or, say, you get a coughing spell after drinking or something like that, you're gonna attribute it to the Parkinson's when that may not be the case at all.*"

Some participants felt care partners had a role to play in identifying these ambiguous symptoms. For instance, P15 cared a great deal about data validity in tracking his symptoms, and saw his care partner as a way to validate data that could not be gathered objectively. He said, "... *I think if you ... say 'I felt forgetful today' and the caregiver can say yes or no, it validates the data.*" However, asking care partners to track symptoms was not straightforward, in part because PwP and care partners sometimes disputed whether something was a symptom at all. As P11 put it, "*Here's the thing. My husband will say to me that he thinks that I am forgetful or whatever, and I looked at him and I'm like, are you kidding me? You say that because I have Parkinson's. Am I allowed to tell him that because he's older?*" Care partners also worried about sorting symptoms out from everyday life. P01-C, for instance, observed that her husband had been having occasional difficulty parking, and could not tell if it was from PD or just his usual parking style. "*Then from the outside, then I think, 'Well, maybe that's a symptom.' Or maybe that's just his personality. ... How would I know? I'm not inside his skin. ... You can always come up with rational explanations for slightly odd stuff, so when does it become a symptom?*"

Care Partners in a Self-Tracking System

Participants had mixed views on whether care partners should be users of self-tracking systems for PD. Some participants wanted care partner participation within the self-tracking system, like P04, whose desire to compare his finger tap test data with his spouse's was discussed earlier, and P11, who thought it was valuable to be able to invite her care partner to help her track specific symptoms like sleep. However, other participants felt that care partner involvement should happen through face-to-face conversations rather than through a "*machine cold*" (P18) self-tracking system. Even P15, who thought care partners could act as guarantors of data validity, felt that he would "*not necessarily be happy*" to find that his care partner was tracking his symptoms without talking to him about it face to face. As described earlier, some participants (P13, P12-C) also hoped for symptom tracking systems just for care partners. Finally, some care partners

did not want to involve themselves in symptom tracking at all, like P08-C, who said tracking her husband's symptoms "*feels really mommyish*".

In summary, participants struggled with how to understand changes in their condition and symptoms when they were not sure exactly what the symptoms were. Participants were open to the involvement of care partners in tracking symptoms that PwP could not observe themselves, and to go by the test of time to determine whether symptoms of unclear cause were attributable to PD. However, when it came to ambiguous symptoms that were hard to distinguish from everyday experience, tension arose between participants with PD and care partners over what constituted a symptom. Perhaps relatedly, participants generally felt that care partner involvement should happen interpersonally rather than through a symptom tracker, or that care partners should have their own independent systems to track the PwP's symptoms.

5 DISCUSSION

Our findings illustrate how self-tracking technologies can play a central role in helping people with PD, a progressive disease, cope with changes in their condition. Self-tracking tools can help people plan for their decline and approach it with positive coping strategies. In addition, by including objective measures of symptoms, self-tracking tools can help people combat their own unconscious tendencies towards avoidance and face the reality of their condition. While other work has examined how to instruct users in positive coping strategies [84], our goal is not to prescribe any particular coping strategy to PwP, especially since strategies like avoidance and denial can at times be adaptive [38, 39], and people may need to adapt their coping strategies over time and changing contexts [22, 38]. Instead, our findings shed light on how self-tracking technologies can be designed to help people face changes in their condition with problem-solving strategies and regulate their own unconscious attempts at avoidance. In addition, our findings highlight the tension that can arise between PwP and their care partners over the ambiguous symptoms that are part of life with PD. Other work has discussed the need for self-care technologies to support mundane activities like medication taking, exercise, and collaboration between PwP and care partners [66, 67]. Our findings build on this literature and yield several insights for the design of self-tracking tools for PD.

Designing to Support Planful Problem-Solving

Although the rate of PD progression is highly unpredictable, participants saw self-tracking systems as tools to help them plan as best as they were able, and to resolve issues with their medications as their condition changed. These sentiments reflected a desire for self-tracking tools that would support

planful problem-solving coping strategies. To support these uses, PwP need self-tracking systems that allow them to flexibly track different types of data and review it for highly customized timeframes. Since PD progression can happen over a long term, PwP need systems that impose a low user burden. Because PwP wanted to use tracking technologies to plan for decline, researchers should also explore to what extent tracking technologies for PD and other progressive diseases should support prediction of decline, as well as how the framing of self-tracking data can help people adopt positive coping strategies to face changes in their condition.

Create flexible tracking systems. Participants set out to study their condition not just in terms of the symptoms they experienced, but in terms of the contextual factors which affected those symptoms, such as treatment and behavioral and environmental factors. To identify factors that affect their symptoms, PwP and care partners need systems that allow them to define and track a variety of symptoms and contextual factors. In this respect, self-tracking systems for PD should resemble other self-tracking systems in the literature, such as OmniTrack [36] and Health Mashups [5], which allow users to track whatever is meaningful to them and identify correlations.

Participants needed systems that could help them track over both the very short term (e.g., a matter of hours to track medication effect) and the very long term (e.g., over years to track progression). This finding implies that self-tracking systems must allow data retrieval over customizable timeframes. Since participants wanted to communicate with clinicians about their medication schedules, self-tracking systems should also be designed to facilitate patient-clinician communication, as has been examined in other work [60, 83, 93, 94, 97]. Researchers should additionally explore ways to make the burden of self-tracking bearable over the long term. Past work has found that self-trackers in other contexts abandon self-tracking when it is too burdensome [11], and that PwP in particular need low-burden self-tracking systems where data is easy to enter at any convenient time [92]. Researchers have also found that self-tracking can have the unintended effect of forcing people to dwell on the depressing fact of their illness [1], a finding voiced by one of our participants as well (P10), as described earlier. One approach researchers can explore to make self-tracking manageable over the long term is to establish the minimum amount of data needed to meaningfully track progression, either in terms of the amount of data collected or the time interval at which it is collected, and ask users to meet only this minimum standard over the long term (e.g., asking users to check in intermittently every few months), to reduce the burden of self-tracking over time. However, this approach comes with several open questions,

including how often people must measure their symptoms for progression to be detectable and how the design of intermittent tracking systems can help people stay engaged over the long term. Additionally, since PwP may need changing support over time [67] and the pace of PD progression is not easy to predict, the minimum meaningful tracking interval may change over time. More work must be done to understand how to design systems to best support intermittent tracking.

Explore Design for Predicting Decline. Participants wanted to track their symptoms in part to predict when their condition would worsen. This finding yields several implications. First, since PD symptoms vary a great deal over time and progression can be difficult to predict, PD self-tracking systems should communicate to users the limitations of their ability to detect trends. This is especially important because the high level of noise and variability in PD symptoms may contradict general assumptions about the ability of self-tracking systems to reliably detect trends. If knowledge about PD symptom progression advances to the point where systems can accurately predict decline, researchers must consider when and how to present this information to users. Since framing of self-tracking data can influence users' self-perception [10], presentation of information about disease progression must be thoughtfully designed so as not to foster a sense of helplessness and depression. In addition, our findings suggest that the optimal design will vary based on individual's values, disease stage, and family situation. For instance, some PwP are likely to prefer getting actionable recommendations alongside or instead of a prediction about decline. For these users, researchers must carefully consider how to prevent contradictory or unhelpful recommendations [5, 77], especially as symptoms can fluctuate rapidly, and a recommendation based on symptom intensity one day may not apply the following day. Additionally, users might reject system-generated suggestions if they do not agree with the system's assessment of their current state and abilities. As an alternative approach, some users might prefer that systems alert family members or clinicians to changes in the PwP's condition, especially if the PwP is highly dependent on care partners, while other users might find this function intrusive. Researchers must find ways to design systems congruent with PwP's individual values.

Designing to Help Avoid Escape-Avoidance Coping

Researchers have found in other health contexts that tracking can arouse feelings of anxiety [35, 76, 91]. Our findings show that people living with progressive diseases like PD can feel reluctance to log progression in symptoms. However, rather than simply avoiding tracking, participants feared that they might intentionally log data that misrepresented their

condition. Participants valued objective symptom measures to help them honestly confront PD progression.

The nature of data has been shown to matter for ease of logging and interpretation in other health contexts (e.g., [13, 16, 29, 86]). Our findings suggest that data type also matters in the context of progressive diseases like PD, where people grapple with their own unconscious desires to portray themselves in the rosier light, both to clinicians and to themselves. Since facing up to current disease state is an important part of what PwP see as successful life with the disease [31], it is important to design self-tracking technologies to help people confront the inevitable decline in their condition. To help PwP and care partners combat their own tendencies towards avoidance, self-tracking technologies for PD should incorporate objective metrics wherever possible. However, even the most dedicated self-trackers will sometimes encounter situations where they are not able to take objective measures of their symptoms, either because the time is not convenient or because there is no possible objective metric (e.g., for symptoms like hallucinations or P09's "tippiness"). For the first case, tracking systems may be able to help PwP log symptoms accurately by helping them understand the connection between their subjective sense of a symptom and the objective measurement of a symptom, as suggested by P11 in our findings. This finding underscores the importance of ongoing research in HCI and health informatics to develop methods for passive, continuous capture of different symptoms through mobile phones and wearable technologies (e.g., [2, 27, 42, 43, 53, 64], and others), so that users can capture data about their symptoms without interrupting their day. For the second case, researchers should explore ways to help people achieve consistency in subjective symptom tracking. One direction researchers can explore is to investigate how to assist users in creating scale anchors that make sense to them. Work in self-experimentation has found that users worry about their ability to be consistent in evaluating symptoms [34], and desire highly customized ways to record symptoms in ways that make sense to them [33]. Our findings suggest that helping users find ways to record symptoms in ways they feel they can use consistently is important in the context of progressive disease as well, so that users can hold themselves to an internally consistent rating system as their symptoms change over time. Additionally, some symptoms, like tremor, can be recorded in different ways, and users might find it more valuable or convenient to log symptoms in different ways at different times. For instance, users might find it more convenient to log a subjective rating of a tremor at work, and more valuable to log an objective metric at home. Alternatively, users may want to capture additional contextual detail about their symptoms,

beyond a simple objective marker, to communicate with clinicians about their health. Accordingly, researchers should explore ways of accommodating multiple types of data for the same symptom. Different data types can pose challenges not just for system designers, but also for users in reflecting back over their data. More work must be done to understand if different data types for the same symptom should be merged, for example, or if they should be separated within the interface of a self-tracking system.

Designing for Ambiguous Symptoms and Care Partners

Although care partners are important in any health context, they are especially important in the context of progressive, debilitating conditions like PD [66], where people know that their condition will deteriorate and they will become increasingly dependent on others. We found that while PwP and care partners were aware of this reality, there was no consensus on exactly what role care partners should assume in symptom tracking. Building on findings that care partners and patients sometimes experience conflict in managing chronic disease [6, 91] and recommendations that systems for self-care be designed to maximize the patient's autonomy [69], we suggest that self-tracking systems for PD be designed to give PwP choice over how to involve their care partners in their self-tracking. PwP should be able to choose whether care partners have any access to their self-tracking systems at all, whether they have viewing access, or whether they can add data themselves. If the latter, PwP should be able to choose exactly what kinds of data care partners can enter. If care partners are permitted to jointly track symptoms with PwP, then designers must explore ways to support merged data streams, as discussed by Pina et al. in the context of family tracking of chronic disease [74]. Researchers and designers of self-tracking systems for PD must also explore how the role of the caregiver may evolve over time, as the PwP's condition changes [66, 69].

Our findings also illustrated how PwPs and care partners struggled to disambiguate symptoms from normal occurrences. To help PwP and caregivers resolve ambiguity over what constitutes a symptom, researchers should explore ways to facilitate shared reflection over tracked data between PwP and care partners to help them jointly determine what part of their experience is due to the disease and what part of their experience is just everyday life. Shared reflection has been found to help people glean new insights from data [26] and been recommended as a way for care partners and patients to manage asymmetric values [6].

However, when symptoms are hard to differentiate from noise, researchers and designers must recognize that encouraging PwP and care partners to track ambiguous symptoms might lead people to track things they would not otherwise consider symptoms. This may especially be the case in the context of a progressive disease, where users are already on the lookout for new and worse symptoms. In addition, simple awareness of symptoms could make symptoms worse [69, 92]. Researchers must explore how to design self-tracking symptoms for progressive diseases so that they do not make chance occurrences seem like symptoms, thereby inadvertently creating the symptoms they seek to merely record. Both intermittent tracking, suggested earlier as a strategy to minimize user burden, and objective metrics may help PwP and care partners differentiate signal from noise. If tracking check-ins are spaced far enough apart, users have time to forget possible symptoms that do not recur, helping them identify patterns and distinguish disease symptoms from chance occurrences. Passive continuous monitoring, where available, may also help users distinguish symptoms from noise if they feel that the system is gathering data they cannot influence.

6 LIMITATIONS AND FUTURE WORK

Our study has three important limitations. First is the representativeness of our sample, which was largely made up of people in earlier stages of PD. In addition, we recruited in part from populations already participating in self-tracking research. Consequently, our sample population was likely biased in favor of self-tracking. Although it is unclear exactly how representative of the general PD population our sample is, it is important to understand that some PwP see self-tracking technologies as useful and valuable tools for coping with changing health. Future work must be done to gain a more representative picture of how self-tracking fits into the needs of the PD population at large, and especially how it supports people in more advanced stages of the disease. Future work must also investigate how individual characteristics like socio-economic status impact PwP's self-tracking needs, and should include the development and deployment of self-tracking tools to gain further insight into the needs of PwP. Second, care partners' roles evolve over time, as the PwP's condition changes [66]. Because our study was not longitudinal, we were unable to examine how people's attitudes towards the role of care partners in self-tracking systems might change as the PwP's condition changed. Future work must be done to understand this evolution. Third, we interviewed PwP and their care partners, but not clinicians in this study. Since our findings suggested that PwP want self-tracking technologies to facilitate communication with clinicians, future work should include research done

with clinicians to understand their communication needs and perspectives.

7 CONCLUSION

As PD progresses, PwP and the care partners who share their lives must learn to cope with the PwP's changing condition. However, not all coping strategies are created equal, and positive coping strategies yield a better quality of life than avoidance coping strategies [8]. We illustrate how self-tracking technologies can help people with PD and their care partners pursue positive coping strategies, and combat their own tendencies towards denial as the disease progresses. We also show that care partners can be instrumental in symptom tracking, but that tensions can arise between PwP and care partners when symptoms are ambiguous. Accordingly, researchers and designers should create flexible self-tracking systems for PD that incorporate objective metrics of symptoms wherever possible, and allow PwP to determine for themselves the role of their care partners in helping them track their symptoms. Thoughtful design of self-tracking systems for PD has the potential to help PwP better manage their illness and achieve higher quality of life.

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