

Perceived Self-efficacy in Parkinson's Disease Through Mobile Health Monitoring

Citation for published version (APA):

Theis, S., Schäfer, D., Haubrich, C., Brandl, C., Wille, M., Kotz, S. A., Nitsch, V., & Mertens, A. (2020). Perceived Self-efficacy in Parkinson's Disease Through Mobile Health Monitoring. In C. Stephanidis, M. Antona, Q. Gao, & J. Zhou (Eds.), HCI International 2020 – Late Breaking Papers: Universal Access and Inclusive Design. HCII 2020: 22nd HCI International Conference, HCII 2020 Copenhagen, Denmark, July 19–24, 2020 Proceedings (pp. 749-762). Springer. https://doi.org/10.1007/978-3-030-60149-2_57

Document status and date:

Published: 25/09/2020

DOI:

[10.1007/978-3-030-60149-2_57](https://doi.org/10.1007/978-3-030-60149-2_57)

Document Version:

Publisher's PDF, also known as Version of record

Document license:

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Perceived Self-efficacy in Parkinson's Disease Through Mobile Health Monitoring

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Abstract. Parkinson's disease (PD) is one of the most common neurodegenerative diseases. The non-specific symptoms lead to a diagnosis years after the actual onset of the disease. However, the earlier a diagnosis can be made, the more effective therapies are. Here we present and evaluate a smartphone app prototype supporting an early diagnosis with patients ($N = 20$). Since self-efficacy is decisive for the patient's handling of the disease, the mobile diagnostic app should optimally support a patients' self-efficacy. In this regard, a mixed-methods study revealed significant negative relationships of depression (BDI-FS) and technical competence belief ($\rho = 0.46, p < 0.05$) and technical commitment ($\rho = 0.48, p < 0.05$). Qualitative results revealed that PD patients confirm a PD diagnosis app as enriching their daily lives and imagined that the app could have an impact on their self-efficacy. Patients believed that the awareness and knowledge about the disease enhances their self-efficacy and reduce emotionally charged uncertainty as well as to let them regain a sense of control through active self-management.

Keywords: Parkinson's disease · Self-efficacy · eHealth · Health-app · Mixed methods · Affective states

1 Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease after Alzheimer's disease with around 6.1 million people suffering from it [15]. At the time of diagnosis, most patients are around 60 years old, while in five to ten percent of patients, the disease is already noticeable between 20 and 40 years of age but often unrecognized. Many early symptoms are not necessarily associated with PD. Therefore, a definitive diagnosis tends to occur relatively late in the neurodegenerative disease process. In fact, PD actually starts many years before cardinal symptoms occur. Cardinal symptoms include slowed movement (bradykinesia), resting tremor, muscle stiffness (rigor), immobility (akinesia), and postural instability [33]. Despite the validated diagnostic criteria,

patients are often misdiagnosed [37]. Consequently, the main aim of the PCompanion project was to develop a mobile, patient-oriented screening and monitoring system for the early diagnosis and management of PD. Such a tool should benefit the reliability of the diagnosis, the treatment quality, the prognosis, and above all the PD patients' quality of life. User-centered development processes ensure the best possible use of a mobile monitoring app for patients. Here, the mechanisms of action between humans and technical systems are examined and harmonized early and iteratively.

An important human factor in dealing with serious neurodegenerative diseases such as Parkinson's disease is the so-called *self-efficacy*. People who believe that they can cope with new or difficult situations based on their own abilities are highly self-efficient. They expect to act successfully in order to reach desired goals [1]. The psychologist Albert Bandura first described the concept of self-efficacy in 1977. He explained that at the core of self-efficacy lies in the expectations people have of their own control and handling of situations and how they can influence them. These expectations affect both the kick-off and persistence of their coping behavior [1, 2]. This means dependent on how strong people believe in their own abilities, they deal differently with a difficult situation. They either show approaching or avoiding behavior [24, 32]. According to Bandura there are four main sources that shape a persons' self-efficacy: (1) Enactive mastery experiences as the most influential source. They describe situations in which people successfully handle obstacles or achieve a goal. (2) Vicarious experiences, which are experiences in which people observe role models that they identify with and then transfer, observed success to their own probability of success. (3) Verbal persuasion, which stands for encouragement and feedback from other people. (4) Physiological and affective states as the assessment of one's own capability also depends on sensations. Another source of influence is thus the assessment of physiological and emotional states in challenging situations [2].

Self-efficacy also shows strong positive relationships with other psychological constructs such as self-esteem, neuroticism, and control [20]. Of further note are significant negative relationships with mental illnesses such as depression and anxiety [4, 31]. Additionally, related measures such as affective states and health-related quality of life (HRQoL) seem to relate to self-efficacy [9]. Thus, not surprisingly, self-efficacy has been considered in the context of several chronic diseases such as cancer, cardiovascular disease or PD, which we here focus on [4, 6, 18, 22, 29]. The effect of self-efficacy has been shown to play a relevant role in the self-management of Parkinson's disease and the quality of care [10, 12, 34]. Researchers such as Mulligan et al. (2011) have already approached the topic of self-management in PD. They describe that PD patients regard self-management programs such as seminars as enhancing self-efficacy and a useful intervention to improve their everyday life. In a recent review Linares-del Rey et al. (2019) reported and evaluates several studies on the use of health-apps for PD patients. Although the authors considered many apps as useful, methodological limitations made it questionable whether the apps truly offer any benefits [23]. Therefore, the focus on an iterative process to determine the user requirements as well as considering their evaluation and experience working with the health-app is very important. Furthermore, emphasizing on how improved self-efficacy could result in better HRQoL by rebuilding patients' belief that they handle their disease better is important. Therefore, the aim of

the here presented project was to tackle these issues by means of a prototype of a newly developed mobile health-app named Parkinson Companion (PCompanion). Patients of German Parkinson self-help organizations, physicians, and caregivers took part in the iterative process of the PCompanion development. Central to the current study were patient-meetings to evaluate the first prototype of the Parkinson monitoring app. More specifically, the present study aimed to develop general implications and design recommendations with special regard to self-efficacy for managing PD. To understand how the application might benefit PD patients' self-efficacy, one first needs to consider influential variables such as technical commitment. Even more older adults use mobile technology [25, 35] there is still a fraction that does not use this technology. On the one hand, not using mobile technology may result from not accepting them as useful or too complicated to use [11]. On the other hand, non-use may also result from low technically-related self-efficacy or lack of experience in dealing with this technology [14]. Furthermore, differences in age, gender, level of education, and affective and depressive states have to be taken into account when investigating and developing health-related technical devices [9, 13]. On basis of these facts the central research questions (RQ) of this study were:

RQ 1: How do PD patients feel about the app's prototype, the properties of the app, and what would have to be developed to achieve positive influence on self-efficacy?

RQ 2: What are the relationships between self-efficacy and other factors such as depression, affect, and technical commitment?

2 Method

2.1 Monitoring System

The monitoring system consists of a smartphone diary app, a sensor device, and a web-platform. An electronic health file system based on the Elektronische Fallakte (EFA), stores diary and sensor data to later train machine-learning algorithms that identify REM-sleep behavior disorder (RBD) and predict diagnostic probabilities. The EFA ensures German data protection requirements. The clickable prototype of the smartphone diary app was created using the Software Balsamiq Mockups 3. Figure 1 illustrates the four main sections of the app and their underlying functions. In addition to the diary app, the optional sensor system as shown in Fig. 2 records sleep and vegetative functions. A ten-channel device monitors respiratory pressure, snoring, blood oxygen (SpO_2), pulse rate, body posture, activity (sleep/wake determination), continuous positive airway pressure, bi-level positive airway, pressure, periodic limb movement, electrocardiography, electroencephalography, electrooculography, and electromyography. Bluetooth then transfers data in real time to the web platform.

2.2 Questionnaires

A self-constructed sociodemographic and health-related questionnaire based on Hoffmeyer-Zlotnik and Warner's sociodemographic questionnaire modules for comparative social surveys was used [19]. Typical variables are gender, age, and education

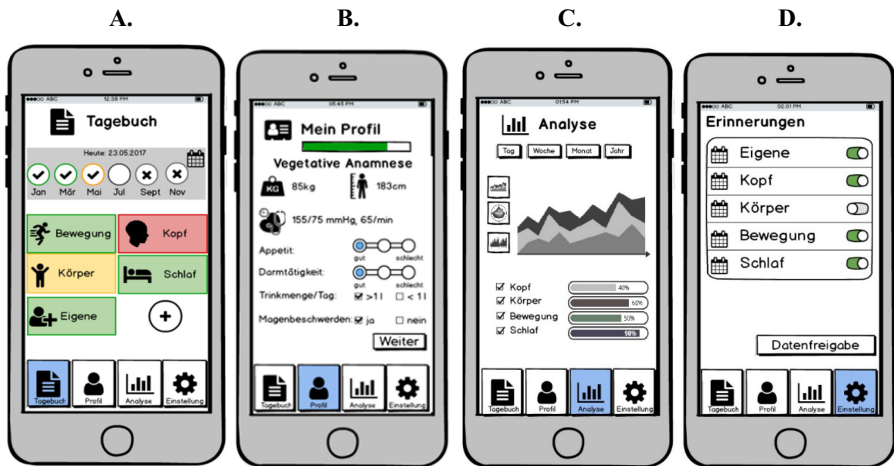


Fig. 1. **A.** Diary function to fill in medical questionnaires based on the four main symptoms of PD. **B.** Profile function to offer the user insight into relevant personal health information that is stored in their electronic case file. **C.** Analysis function to inform the user about the symptom progression over different periods derived from the diary entries. **D.** Setting function to allow the user to set reminders for filling in the diary or taking medication and to adjust data sharing with their MDs.



Fig. 2. Sleep and vegetative sensors.

but also health-related variables such as disease duration and medication intake. This questionnaire supports better classification of the qualitative data.

The PANAS measures both transient positive affective (PA) and negative affective (NA) states [8, 36]. The questionnaire consists of 20 adjectives that describe different sensations and feelings. Each of these 20 items can be answered on a 5-step Likert scale where one indicates “not at all” and 5 “extremely”. For each affect dimension (PA and NA) a mean value is calculated. Higher scores for PA or NA represent a greater degree of positive or negative affect at the time of measurement, respectively. This test checks for possible influences of the affective state on the results.

The BDI-FS is a short version of the Beck Depression Inventory II, which screens for depression [5, 21]. The questionnaire consists of seven items with answers of four statements that best describes both the patients' current situation as well as that of two weeks ago. Total scores of 0-3 indicate minimal depression, scores of 4-6 mild depression, scores of 7-9 moderate depression, and scores of 10-21 severe depression. Given that there is a relationship between depression and self-efficacy, we included this test to check for possible influences.

The SES6G is the German version of the self-efficacy scale to manage chronic disease [17, 30]. The scale consists of six items with a 10-step Likert scale ranging from one ("not at all confident") to 10 ("totally confident"). A higher mean value of given answers represents higher self-efficacy in dealing with chronic disease. This scale is included to test the patients' self-efficacy in dealing with their disease.

Technology Commitment (T-Comm) is a short scale measuring someone's readiness to use technology [28]. The scale consists of 12 items with a 5-step Likert scale where one means "not true at all" and 5 "completely true". The scale is composed of three different facets of technology commitment. These include technology acceptance (T-A), technology competence belief (T-Comp), and technology control belief (T-Con). A total score is the sum of all item values but also for one scale or dimension. This scale was included to check whether there are any age differences or relationships to other outcomes.

2.3 Participants

Advertisement in clinics, visits of the local Parkinson sports group, as well as e-mails distributed by the local Parkinson self-help group leaders or advertisements in hospitals facilitated the recruitment of participants. A sample of 20 participants (14 females, 6 males) was included in the analysis (see Table 1). The mean age of the sample was 64 years, the youngest participant was 37 and the oldest 82 years old ($SD = 12.1$). The average duration of PD was 6.75 years with a minimum of one year and a maximum of 20 years ($SD = 5.3$). The majority of the participants had vocational training (35%). Only two participants had a lower secondary school education (10%) and three a secondary school education (15%). Four participants had a high school diploma (20%) and another four a university degree (20%). Furthermore, the majority of the participants already used a computer (85%), a smartphone (65%), and/or a tablet PC (60%).

2.4 Procedure

The participants had a choice whether they wanted to use university facilities or do the study at home. Before starting the testing procedure, the participants had to read an information letter and sign an informed consent form. The four-step test procedure lasted approximately one and a half hours. First, the participants filled in questionnaires. Second, the interviewer presented the PCompanion application explaining all attributes and functions. The interviewer answered questions on behalf of the participants. Then the participant interacted with the prototype before the semi-structured interview conducted with the help of an interview outline (see Table 2). Interviews were in German and recorded by a dictation machine, lasting 45 min on average. After filling in the remaining

Table 1. Participant profiles

ID	Age	Gender	Education	Time since diagnosis
01	69	Female	Secondary school	13 yr.
02	79	Male	Vocational training	5 yr.
03	61	Female	Vocational training	10 yr.
04	71	Female	Secondary school	18 yr.
05	82	Female	Lower secondary school	20 yr.
06	75	Female	Secondary school	5 yr.
07	67	Female	University	2 yr.
08	48	Male	High school	4 yr.
09	65	Female	University	2 yr.
10	79	Female	Vocational training	8 yr.
11	76	Male	Lower secondary school	4 yr.
12	67	Female	Vocational training	10 yr.
13	53	Male	University	6 yr.
14	37	Female	High school	2 yr.
15	51	Female	High school	5 yr.
16	55	Female	University	3 yr.
17	74	Male	High school	6 yr.
18	52	Female	Vocational training	1 yr.
19	55	Female	Vocational training	2 yr.
20	64	Male	Vocational training	9 yr.

questionnaires, participants received a monetary compensation of 20 euros. The Ethics Commission at the Medical Faculty of the RWTH Aachen approved the study with the internal file number “EK 042/18”.

Table 2. Questions of the semi-structured questionnaire

No.	Question
1	How would you rate the app as a potential enrichment for your everyday life?
2	Do you think that the app could give you the feeling of having more influence on your personal situation and more confidence to manage it? How so?
3	What do you think are influential factors that would make a patient use an app like this?
4	What does quality of life mean to you? How would you define it?

2.5 Data Analysis

Theoretical thematic analysis inspired by Braun and Clarke’s 6-step recursive process analyzed the qualitative interview data. The main advantages of thematic analysis lie in its flexibility, usefulness in working within a user-centered research design, quick learn-ability, and easy access to researchers who are new to qualitative research [7]. Transcripts were analyzed thematically. The thematic analysis is characterized by an essentialist, analyst-driven and semantic approach, which means that the process of coding was done in relation to the research questions, pre-researched concepts of self-efficacy and thus with regard to particular areas of interest. A progression from a semantic level to a level of interpretation gave rise to broader meanings and implications. MAXQDA software coded and analyzed the data. IBM SPSS V25 served the quantitative data analysis. Initially, the Shapiro-Wilk test checked all variables derived from the questionnaires for normal distribution. Bivariate correlation analysis then followed a descriptive one. Spearman’s rho addressed the normally distributed variables while Pearson’s correlation coefficient targeted not-normally distributed data [16].

3 Results

The order of the results corresponds to the order of the two research questions. Part 1 reports the participants’ impression of the PCompanion app and their thoughts on how its use might have an influence on their self-efficacy. Part 2 reveals the quantitative results of the bivariate correlation analysis between questionnaire data.

3.1 Relation Between Self-efficacy and App Usage

The majority of the sample showed a positive reaction to the app’s prototype and categorized it as a possible enrichment to their lives. The rest of the participants were either not sure about it or did not currently see an enrichment in it (see Fig. 3). With regard to self-efficacy and the app’s potential of having a positive influence on it, three main themes were generated from the interview data which are as follows: 1. Limited potential, 2. Knowledge enhancement, and 3. Influence, structure & decision support.

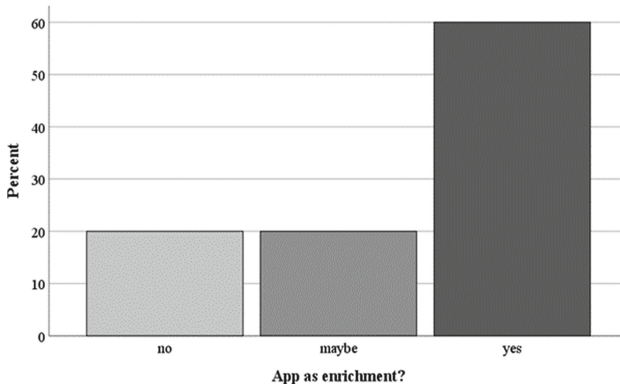


Fig. 3. Participants' considering the PCompanion app an enrichment for their daily lives.

4 Limited Potential

Although some participants rated the app as an enrichment for their daily lives, they were insecure about how much it would influence their self-efficacy. One reason for this was the hypothetical character of a click-prototype:

"I cannot say that. I would have to try that." (ID04)

"Yes, you would have to try that out, so to what extent anything changes at all." (ID06)

Others simply did not see any or only a limited potential either because the app would only be a nice add-on to their current way of disease management or because they could not imagine any direct influence of app use on self-efficacy:

"It wouldn't affect me. It would affect me somewhere... I would simply say, in my own data collection of information, which would at best support me." (ID11)

"That's basically when I get something right back, then I can say that helped. However, assuming that it is so distant that you have evaluated it, and then you have taken the right action, a lot of time has passed. [...] And what did it do? Nothing. Because there is no direct answer." (ID13)

Some participants even saw a danger in the use of it, because they thought it was likely that one would get too involved with the disease:

"The danger of being too busy with it and being a little preoccupied. [...] The patients see what's on the scale and think, 'oh, it's gotten so bad already. It used to be like that and now it is like that'." (ID01)

5 Knowledge Enhancement

Benefit. One argument was that the app's potential to enhance the management of PD and one's own influence, would only be possible if the use of the app also fulfilled an added value:

"If I had the feeling it made sense what I was doing. In addition, it makes sense to me if I can make it out of a social aspect or if I personally derive benefit from it. [...] I have to find some benefit in it. This means that the analysis results should offer me some-thing that I would not have come up with myself. If I recognized it then [...] it would probably be that way that you get a little bit of the feeling that you are still managing something here." (ID08)

Overview of Symptoms & the Course of PD. Many participants found it particularly helpful to gain an insight or an overview of the course of symptoms, as it could improve their understanding of their disease and possible influences:

"[...] always at 11 o'clock I feel bad or always in the night at 2 o'clock I am awake. So, you can check it very well over a few days or weeks and then you can show it to the doctor." (ID18)

"I think it's good that you can see the course, a bit like how that works. And then I can judge that better myself and maybe you can even see for yourself what has done you some good." (ID15)

Visual expressiveness & reflection. Several participants considered it helpful that the app and the insight into their health data would offer them more transparency and thus a clearer estimation of their health status.

"[...] and if I now have such an idea of 'oh look, that's black on white', that has a different power than what creeps around in my head. If you see that, then of course it can unfold a completely different power. So, I imagine it to be very helpful." (ID16)

In addition, some participants saw that the app could motivate them to take time for reflection at the end of the day and thus maybe offer them some relief:

"Yes, simply that when I have typed it in, I have it somehow off my chest [...] I find it important that I have documented it and can also show it to the doctor." (ID19)

5.1 Influence, Structure and Decision Support

Some participants also reported that they believed that the app could strengthen their influence on disease management.

"I just feel good when I think I just did my part of the job." (ID15)

In addition, the use of the app could also add more structure to the everyday life of the participants.

“I work in a very structured way and I need that, and I think that’s very important.”
(ID07)

Finally, a better understanding of the data could help them make better decisions and support them in their actions.

“The overview is there... that if I also have a doctor who works together with me in this direction, that you can really approach it in a structured way and say: ‘we have to intervene a bit more at the right spots’.”(ID18)

Influence on Self-Efficacy

Bivariate correlation analysis revealed several significant relationships between questionnaire data (see Table 3). Significant negative relationships were found between depression score (BDI-FS) and self-efficacy for managing a chronic disease (SES6G), $\rho = 0.68$, $p < 0.01$, between BDI-FS and technical competence belief, $\rho = 0.46$, $p < 0.05$, between BDI-FS and technical commitment (T-Comm), $\rho = 0.48$, $p < 0.05$, and as expected between BDI-FS and positive affect, $\rho = 0.48$, $p < 0.05$. Moreover, there was a significant positive relationship between SES6G and positive affect, $\rho = 0.45$, $p < 0.05$. In addition, we also found a significant positive relationship between education and technical acceptance (T-A), $\rho = 0.49$, $p < 0.05$, and between education and technical commitment, $\rho = 0.46$, $p < 0.05$. Interestingly, we did not find any significant relationship between age or gender and the other questionnaire outcomes (technical commitment, PANAS, etc.). However, there were significant relationships between age and other sociodemographic variables such as education (see Table 3. for more detail).

Table 3. Correlations Spearman’s rho

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. Age	–									
2. Gender	0.06	–								
3. Education	0.58**	0.07	–							
4. Duration	0.48*	0.03	0.51*	–						
5. BDI-FS	0.02	0.07	0.17	0.24	–					
6. T-A	0.21	0.19	0.49*	0.01	0.35	–				
7. T-Comp	0.33	0.05	0.28	0.03	0.46*	0.63**	–			
8. T-Con	0.11	0.19	0.16	0.07	0.28	0.57**	0.23	–		
9. T-Comm	0.25	0.07	0.46*	0.03	0.48*	0.90**	0.85**	0.56**	–	
10. SES6G	0.14	0.35	0.14	0.19	0.68**	0.19	0.24	0.21	0.27	–
11. PA	0.16	0.40	0.02	0.04	0.48*	0.24	0.22	0.04	0.23	0.45*

6 Discussion

The current study investigated self-efficacy in Parkinson's patients and the possible influence of PCompanion Health app use on it. In addition, factors such as depression, technical commitment, and age that were previously reported to show relationships with self-efficacy and app-use were considered.

Concerning RQ 1, the majority of the participants reported a positive impression of the current prototype. Most participants believed that using the app would enrich their daily lives and that they were interested in trying out the final product as soon as it is available. Furthermore, we established three main themes that describe the participants' view on the PCompanion prototype and its' potential to have an enhancing effect on self-efficacy. In general, relatively few statements concerned this matter. This is most likely due to the hypothetical nature of the question itself. Still, some participants immediately expressed that they cannot imagine that the app has the potential to enhance self-efficacy. Even if this argument related to health-apps in general. Moreover, some participants also worried that one might get too preoccupied with PD. Altogether, participants suggested that although for some the PCompanion might be an enrichment, this would not necessarily be due to an increase in self-efficacy but rather due to simple increase in knowledge. Interestingly, the matter of knowledge enhancement was the top argument for most participants that considered PCompanion-use as a potential self-efficacy enhancement. More precisely, they thought that this could be achieved through better insight into their personal health-status and course through the analysis function. Thus, it would improve their awareness and estimation of their illness and thereby reduce uncertainty and emotional stress. This is consistent with the findings of Mulligan et al. (2011) where PD patients emphasized that knowledge about their disease is empowering them and allows for better decision making. In addition to knowledge enhancement, some participants also considered the PCompanion's visualization of personal health data as another attribute to relieve stress as it defuses possible upsetting health-related imaginations. Altogether, this implies that the use of the PCompanion could have a positive effect on the participants' affective states that appears. Finally, entering the information into the app through the diary function could also give some participants a stronger sense of actively managing the disease than just being a passive part of it. Furthermore, some participants also stated that they would feel more at eye-to-eye with their MD through continuous access to wh health information. These two arguments support the fact that the PCompanion-use might also affect participants' sense of enactive mastery experience as it regains their control behavior and thereby enhances self-efficacy.

With regard to RQ 2, several significant relationships appeared that again support the importance of affective states in relation to self-efficacy. Namely, there were significant relationships between depression and self-efficacy for managing a chronic disease, between depression and technical self-efficacy (technical competence belief), and between depression and positive affect. This is supported by the socio-cognitive theory of Bandura [2, 3] and consistent with previous literature highlighting the impact of depression in PD [26]. Additionally, these relationships showed that depression affects self-efficacy across different domains, not only in clinical settings but also in the technology domain. Furthermore, depression also revealed to have a significant relationship with technical commitment. This implies that negative affective states might hinder the

PCompanion-use from the start. However, several participants that scored high on depression still expressed a positive attitude towards the PCompanion and even supported the potential self-efficacy enhancing effect. Hence, the connection between depression and technical commitment might be a very general one and maybe exclude PCompanion-use.

In conclusion, both the quantitative and the qualitative results underline the impact of affective states including depression, anxiety, and uncertainty on self-efficacy and thus on participants' self-management and well-being. However, while interpreting the results, several limitations need to be considered. One being that the majority of participants were also participants or members of a self-help group and frequently took part in group-sport activities. This could mean that the participants were particularly motivated and committed participants and thus individuals that might already have a higher self-efficacy than the average PD patient. Furthermore, it is likely that there are individual differences in the comprehension of interview questions as self-efficacy is a subjective topic but also because there were sometimes minor inconsistencies in the interviewer's formulation of the questions. Moreover, only one researcher carried out the analysis. Finally, only long-term use of the PCompanion app can truly offer benefits for self-efficacy can only be said after participants used the app for a longer period. The current study only worked with hypothetical questions regarding this topic, thus providing little information about the actual effect of app use. As a result, further longitudinal studies with the final product are needed to examine this question. Despite these drawbacks, the results of this study enabled us to gain in-depth understanding of PD patients' self-efficacy and in what way PD influenced this construct. Self-efficacy in turn influenced how PD patients feel, think, motivate, and behave and is thus a very important topic for the self-management of PD and the development of technical devices such as the PCompanion to support self-management.

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