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TECHNOLOGICAL SUPPORT FOR PARKINSON'S DISEASE PATIENTS' SELF-CARE

UNIVERSITY OF OULU GRADUATE SCHOOL;
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**TECHNOLOGICAL SUPPORT FOR
PARKINSON'S DISEASE PATIENTS'
SELF-CARE**

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Abstract

Parkinson's disease (PD) is an incurable neurodegenerative disorder. It is estimated that more than 9 million individuals globally suffered from PD in 2020, and the number of patients is predicted to exceed 12 million by 2040. PD is the fastest growing neurological disorder, with the ageing population being a fundamental driver. PD motor and non-motor symptoms have a significant impact on patients' life. From the patient's perspective, the three most prevalent symptoms are tremors, slowness, and stiffness in the early stages, and varying medication effect ("wearing-off") in the later stages. Self-care is an essential part of living with a chronic condition. Self-care refers to all actions that aim to minimise the disease's impact on daily life.

Self-care activities can be categorised into maintenance, monitoring, and management. The objectives of this thesis were to create new applications for supporting daily life with PD, i.e. enhancing self-care on all three categories.

First, we implemented a mobile application, STOP, to enable patients' self-assessment and aid in medication adherence. STOP is evaluated with PD patients. The STOP application provides a medication journal to support medication-timely adherence. We demonstrate that accelerometer data from STOP are useful for tremor detection. In relation to this, we introduce the Tremor Intensity Parameter (TIP), calculated with the metrics characterising the accelerometer signal in the time-frequency domain. We digitised the traditional spiral drawing used in the assessment of PD and extended it with a square drawing task. We found the drawing performance differed with PD patients and age matching controls. We found PD patients receptive to digital tools – such as STOP – to track their medication intake and symptoms. The possibility of sharing the data with medical personnel to improve and assist their own care would motivate the use of digital tools. In future, we assume the use of digital monitoring tools will increase among PD patients if care personnel utilise the collected data, which requires interoperability with medical databases and standardised data formats.

As a second application, we collected and assessed community-contributed self-care techniques, and established and evaluated an open online repository, the PDCareBox, for PD self-care practice data. The peer-provided data is actionable and understandable, and in a daily life context, supplement clinical information of PD. The PDCareBox provides an organised way to share and discover the knowledge gained by the experience of living with PD.

Keywords: eHealth, mHealth, Parkinson's disease, self-care, sensor data, smartphone

Kuosmanen, Elina, Parkinsonin taudin itsehoidon tukeminen teknologian avulla.

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Tiivistelmä

Parkinsonin tauti on parantumaton hermostoa rappeuttava sairaus. Vuonna 2020 maailmanlaajuisesti arvioitiin olevan yli 9 miljoonaa Parkinsonia sairastavaa, ja määrän ennustetaan ylittävän 12 miljoonaa vuoteen 2040 mennessä. Väestön ikääntymisen myötä Parkinsonin taudista on tullut nopeimmin yleistyvä neurologinen sairaus. Taudin motoriset ja ei-motoriset oireet vaikuttavat merkittävästi potilaan elämänlaatuun. Taudin alkuvaiheessa kolme yleisintä oiretta ovat vapina, hitaus ja jäykkyys, ja myöhemmissä vaiheissa vaihtelu lääkevasteessa.

Itsehoito on tärkeä osa elämää kroonisen taudin kanssa. Toimia, joilla yritetään vähentää sairauden vaikutuksia päivittäiseen elämään, kutsutaan itsehoitokeinoiksi. Keskitason teoria kroonisen sairauden itsehoidosta jakaa itsehoidon kolmeen osa-alueeseen: ylläpitoon, seurantaan ja hallintaan. Tämän väitöskirjan tavoitteena oli löytää uusia sovelluksia tukemaan Parkinsonin potilaiden arkea, eli tehostaa itsehoitoa näillä kolmella osa-alueella.

Kehitimme mobiilisovelluksen STOP oireiden itsearviointiin ja lääkityksen aikataulun seurantaan. Sovellus evaluoitiin Parkinsonin potilaiden käytössä. Osoitimme, että kiihtyvyyssanturin dataa voidaan käyttää vapinan havainnointiin. Määrittelimme aika- ja taajuustason tunnuslukujen avulla laskettavan Tremor Intensity Parameter (TIP) -parametrin kuvaamaan vapinan voimakkuutta. Teimme digitaalisen version perinteisestä spiraalin piirtotehtävästä, jota käytetään Parkinsonin taudin arvioinnissa. Sovellus tarjoaa myös neliön piirtotehtävän. Parkinsonin potilaiden ja vastaavan ikäisten verrokkien suoritus piirtotehtävissä eroaa. Tutkimuksessa saatiin selville, että Parkinsonia sairastavat ovat valmiita käyttämään digitaalisia työkaluja, kuten STOP, lääkityksen ja oireiden seurantaan, ja ovat halukkaita jakamaan kerätyt tiedot hoitohenkilöstön kanssa hoidon laadun parantamiseksi. Uskomme, että tulevaisuudessa Parkinsonia sairastavat käyttäisivät enemmän digitaalisia seurantatyökaluja, jos hoidossa hyödynnettäisiin kerättyä dataa. Tämä vaatisi yhteensopivuutta potilastietokantojen kanssa ja standardoituja dataformaatteja.

Toinen kehittämämme sovellus on avoin online-työkalu PDCareBox Parkinsonin itsehoitokeinojen hakuun. Työkalun itsehoitokeinot on kerätty ja vertaisarvioitu Parkinsonin potilailta joukkoistamalla. Vertaistuetettu data on toimintakelpoista, ymmärrettävää ja arkipäivän kontekstissa, ja se täydentää lääketieteellistä tietoa Parkinsonista. PDCareBox tarjoaa organisoidun tavan kokemukseräisen tiedon jakamiseen.

Asiasanat: eHealth, itsehoito, mHealth, Parkinsonin tauti, sensoridata, älypuhelin

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List of abbreviations

PD	<i>Parkinson's disease</i>
MDS	<i>Movement Disorder Society</i>
UPDRS	<i>Unified Parkinson's disease Rating Scale</i>
AUC	<i>Area Under Curve</i>
PV	<i>Peak Value</i>
F0	<i>Fundamental Frequency</i>
F50	<i>Central Frequency</i>
SF50	<i>Frequency Dispersion</i>
TIP	<i>Tremor Intensity Parameter</i>

List of original publications

This thesis is based on following original publications, which are referred to in the text by their Roman numerals (I–IV).

- I Kuosmanen, E., Kan, V., Vega, J., Visuri, A., Nishiyama, Y., Dey, A. K., ... & Ferreira, D. (2019, October). Challenges of Parkinson's disease: User Experiences with STOP. *In Proceedings of the 21st International Conference on Human-Computer Interaction with Mobile Devices and Services* (pp. 1–11). doi: 10.1145/3338286.3340133
- II Kuosmanen, E., Kan, V., Visuri, A., Hosio, S., & Ferreira, D. (2020, April). Let's Draw: Detecting and Measuring Parkinson's disease on Smartphones. *In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (pp. 1–9). doi: 10.1145/3313831.3376864
- III Kuosmanen, E., Wolling, F., Vega, J., Kan, V., Nishiyama, Y., Harper, S., van Laerhoven, K., Hosio, S. & Ferreira, D. (2020). Smartphone-Based Monitoring of Parkinson Disease: Quasi-Experimental Study to Quantify Hand Tremor Severity and Medication Effectiveness. *JMIR mHealth and uHealth*, 8(11), e21543. doi: 10.2196/21543
- IV Kuosmanen, E., Huusko, E., van Berkel, N., Nunes, F., Vega, J., Goncalves, J., Khamis, M., Esteves, A., Ferreira, D. & Hosio, S. (under review). Exploring Crowdsourced Self-Care Techniques: A Study on Parkinson's Disease.

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1 Introduction

1.1 Background and motivation

Parkinson's disease (PD) is a progressive chronic neurological condition that manifests as a decrease of dopaminergic neurons. The diverse motor and non-motor symptoms heavily affect coping in daily life (Hariz & Forsgren, 2011; Jankovic, 2008). Its motor symptoms such as tremors, bradykinesia, rigidity, and postural instability affect everyday activities like eating or getting dressed (Weintraub, Comella, & Horn, 2008). The non-motor symptoms, on the other hand, include autonomic dysfunction, cognitive impairment, and depression (Weintraub et al., 2008). PD is usually diagnosed at an older age; the first symptoms typically appear after the age of 60 (Wong, Gilmour, & Ramage-Morin, 2014).

The UK Department of Health defines self-care of a chronic condition as “*the activities that enable people to deal with the impact of a long term condition on their daily lives, dealing with the emotional changes, adherence to treatment regimes, and maintaining those things that are important to them – work, socialising, family*”, and efficient self-care is essential for people with chronic conditions (Department of Health, 2006). In addition to medical self-care actions (e.g. taking medication), the term self-care covers mundane activities such as how to get dressed or cook with the symptoms (Nunes & Fitzpatrick, 2018). According to the Middle-Range Theory of Self-Care of Chronic Illness, self-care actions can be categorised under three key concepts: self-care maintenance (efforts towards maintaining physical and emotional stability); self-care monitoring (monitoring of symptoms and health); and self-care management (reacting to changes in status, i.e. decision making) (Riegel, Jaarsma, & Strömberg, 2012). The outcome of the self-care of chronic conditions is maintaining quality of life and perceived control of the disease (Riegel et al., 2012). Effective self-care may also reduce mortality, hospitalisation, and healthcare costs (Iovino et al., 2020). Self-care is often a joint effort of the patient, the caregiver, and other family members (Iovino et al., 2020), with different roles (Pina et al., 2017).

Health monitoring with mobile devices offers low-cost flexibility in time and place (B. M. Silva, Rodrigues, de la Torre Díez, López-Coronado, & Saleem, 2015). We carry smartphones with us most of the time, they are affordable, and the number of smartphones is increasing among the elderly (Berenguer et al., 2016). In the US, 67% of people over 65 report using the internet, 42% own a smartphone (Anderson & Perrin, 2017). We can therefore say that smartphones provide a platform for tracking patients'

symptoms and daily life. Measuring health with sensors, wearables or smartphone sensors is common today, and people are used to collecting data about themselves (Bietz et al., 2016; Hoy, 2016).

With PD, technology-based monitoring has been used in diagnosis, monitoring, and delivering therapy (Espay et al., 2016). Smartphones provide a variety of sensors for the unobtrusive tracking of PD. The sensors can offer real-time, continuous, and objective data and could supplement in-clinic evaluations, which rely primarily on subjective measures (Espay et al., 2016). Unobtrusive monitoring has an opportunity to (partly) replace the current manual tracking on symptom variation (Espay et al., 2016). For example, the smartphone or wearable sensing has been utilised in the assessment of impaired gait, tremors, handwriting, vocal impairment, and speech problems (Zhang et al., 2020). It is essential that the technology measures metrics relevant to the patients, with an acceptable benefit-to-burden ratio (Espay et al., 2019). Furthermore, the collected data must be analysed and transformed into clinically useful information about the disease status (Espay et al., 2019; Pasluosta, Gassner, Winkler, Klucken, & Eskofier, 2015). According to a European survey, less than half of PD patients had prepared a list of symptoms for a visit to a clinic, and more than a third felt they were “left out” of decisions related to their treatment (Bloem & Stocchi, 2015).

Knowledge of mundane self-care actions related to maintaining health status in daily life is gained from the experience of living with the disease. This “patient expertise” is often actionable information in the context of daily life (Hartzler & Pratt, 2011). This knowledge, i.e. information related to self-care, is typically exchanged in peer meetings or in online discussion forums. Support group participation may help in accepting the disease and coping with it (Charlton & Barrow, 2002). Online communities may supplement the clinic visits and assist in understanding the treatment more thoroughly through information sharing (Johnson & Ambrose, 2006). However, finding information via message boards and discussions can be challenging, because the information can be difficult to identify in the threads, especially if there are a lot of posts (Hartzler & Pratt, 2011). An organised way of collecting and searching for the self-care information gained from living with the disease is needed.

Considering the aforementioned aspects, this thesis sets to investigate how to advance PD self-care using technologies based on smartphones and crowdsourcing-based information management.

1.2 Objectives and expected results

Our research agenda is **to explore technological support for the self-care of PD**, with self-care defined as all actions that aim to manage daily tasks with PD. The Middle-Range Theory of Self-Care of Chronic Illness specifies three key concepts for self-care: self-care maintenance; self-care monitoring; and self-care management (Riegel et al., 2012). We focused on these three key concepts for self-care in our studies. Our objectives are to:

O1: Create novel applications for supporting PD self-care.

O2: Investigate the applications using the lens of the Middle-Range Theory of Self-Care of Chronic Illness.

To accomplish the objectives, we investigate three research questions:

RQ1: Which aspects of PD self-care should be considered when designing for people with PD?

For O1, we start by understanding our target population better. We study the challenges PD poses to patients' daily lives. We investigate the limitations of current solutions used by PD patients in self-care. We identify the design implications of PD symptoms for interaction with mobile and online applications.

RQ2: Can we use mobile technology to monitor PD in daily life?

Smartphones are ubiquitous, affordable and contain multiple sensors for data collection. Previous research has shown that many PD symptoms can be quantified with smartphone data collected in laboratory settings. For O2, we study if data collection using smartphones outside laboratory confinement is feasible, and how smartphone sensor data collected in real-life can be used in assessing and quantifying PD symptoms.

RQ3: How can we best collect and share self-care knowledge gained from the experience of living with PD?

Self-care techniques develop overtime for those living with PD. Peer-provided information is often exchanged in peer meetings and online discussion forums but is hard to find. For O1 and O2, we study how to provide a structured way of sharing and discovering self-care information.

1.3 Articles, contribution and author's role

This thesis includes four original articles (one under review) for relevant peer-reviewed, international conferences and journals in the Ubiquitous Computing and Human–Computer Interaction field. Table 1 summarises which articles contribute to the research questions.

Article I presents a smartphone application, STOP, which is designed to enable patients' self-assessment and medication intake time tracking. The STOP application has been evaluated by PD patients during a one-month long trial, including three interviews, and this article describes the analysis of the interviews. We present the challenges PD poses to daily life and smartphone use (**RQ1**). Our participants were willing to use digital tools such as STOP to track their symptom status and medication intake. They were also ready to share such data with medical personnel to improve their care (**RQ2**). The STOP application provides a means for medication-timely tracking (**RQ2**). **Author contribution:** The author of this thesis designed the field trial, conducted the interviews in Finland, and led the writing. The author also analysed the collected data with the help of the co-authors.

Article II presents two digitised drawing tasks for a smartphone, an Archimedean spiral, and a square (**RQ2**). We collected digital drawings from people diagnosed with PD and from age matching controls and quantified the drawing performance using the following metrics: speed; time; accuracy; crossing rate; radial and angular velocity (only for the spiral); sampling rate; and gaps in the drawing. We found a statistically significant difference between people with PD and the controls in drawing accuracy. **Author contribution:** The author of this thesis co-designed the formula for error calculation in the drawings, conducted the evaluation with the second author, took the main responsibility for data analysis, and led the writing.

Article III focuses on tremor evaluation and medication effect detection of accelerometer data collected during the trial of STOP and presented initially in Article [I] (**RQ2**). To characterise the signal in the frequency domain, we calculated features from periodograms generated using Welch's method. We introduced the Tremor Intensity Parameter (TIP) to represent the tremor symptom severity. In our study, TIP correlated significantly with the self-reported tremor score in the Unified Parkinson's Disease Rating Scale part II. To study the medication effect, we compared the accelerometer data from the game sessions played before and after the medication intake. We found statistically significant differences between these game sessions for the patients suffering from rigidity and bradykinesia. **Author contribution:** The author of this thesis analysed the accelerometer data with the second author and led the writing. The author specified the formula of the Tremor Intensity Parameter (TIP).

Article IV presents the establishment of a repository of community-contributed self-care techniques for Parkinson’s disease. In the first study phase, the PD self-care techniques were collected and assessed by people living with PD (both patients and their informal caregivers) around the world. In the second phase, an online repository for the collected data was set up and evaluated by people living with PD. The project’s contributions are the public online repository for discovering PD self-care techniques provided by people living with the PD, with design implications for the tool itself and generally for such community-contributed repositories (**RQ3**). The UI was enhanced to follow the design guidelines for people with PD. **Author contribution:** The author of this thesis planned and conducted the study with the other authors, analysed the collected data, and led the writing.

Table 1. Summary of how articles contribute to the research questions of this thesis.

Research question	Articles
RQ1: Which aspects of PD self-care should be considered when designing for people with PD?	I
RQ2: Can we use mobile technology to monitor PD in daily life?	I, II, III
RQ3: How can we best collect and share self-care knowledge gained from the experience of living with PD?	IV

1.4 Thesis outline

Chapter 2 describes the previous research on the topic. First, an overview of Parkinson’s disease and the self-care of PD is presented, and the previous work on the technology used in PD self-care and open data sets on PD are introduced. Chapter 3 introduces our research methods and materials and provides an overview of the studies and the created applications. In Chapter 4, the main results of Articles I-IV are presented. Finally, in Chapter 5, the implications of our findings in the domain of supporting Parkinson’s disease self-care are discussed by revisiting the research objectives and research questions. Chapter 6 concludes the manuscript.

2 Related work

2.1 Parkinson's disease

2.1.1 *Prevalence and cause*

Parkinson's disease (PD) is the second most common neurodegenerative disorder after Alzheimer's disease (Lang & Lozano, 1998). PD manifests as the progressive loss of neurons in the central nervous system, creating decreased dopamine levels, and leading to abnormal brain activity (Jankovic & Tolosa, 2007). PD occurs throughout the world, and its cause remains unknown (De Lau & Breteler, 2006; World Health Organization, 2006). Genetic factors increasing the risk of PD were identified, but they are attributed to less than a fifth of PD cases (Bhat, Acharya, Hagiwara, Dadmehr, & Adeli, 2018; Emamzadeh & Surguchov, 2018). Environmental factors, e.g. exposure to environmental toxins or pesticides, heavy metal accumulation and oxidative stress, contribute to the risk of getting PD (Bhat et al., 2018; Emamzadeh & Surguchov, 2018). The generally estimated prevalence of PD is 0.3% of the entire population and about 3% of people over the age of 65 have PD (Lang & Lozano, 1998; Sveinbjornsdottir, 2016).

2.1.2 *Diagnosis and follow up*

The diagnosis of Parkinson's disease is based on clinical criteria (Lang & Lozano, 1998), and such criteria are defined by different institutes. They are based on detecting a combination of the cardinal motor symptoms (bradykinesia, rest tremor, rigidity, and postural disturbances), associated with exclusive factors (suggesting other diagnoses) and supporting criteria (Jankovic, 2008; Postuma et al., 2015).

The status of PD is assessed during clinical visits by the specialist, typically 2-3 times per year (Bloem & Stocchi, 2015). A variety of rating scales is used to evaluate the status and longitudinal progression of PD (Ramaker, Marinus, Stiggelbout, & Van Hilten, 2002), such as the Unified Parkinson's Disease Rating Scale (UPDRS). UPDRS consists of different sections of self-reported and observational measures, requiring a trained specialist to perform the assessment (Jankovic, 2008).

2.1.3 Stages and symptoms

PD is categorised as mild, moderate and advanced stages, according to the severity of symptoms (Bhat et al., 2018). In mild PD, the motor symptoms occur on one side of the body. There are slight changes in posture and facial expression, and the patient may experience some difficulties in walking (Bhat et al., 2018). In a moderate stage, the motor symptoms are bilateral, the balance and coordination are deteriorated, and the patient experiences freezing episodes (Bhat et al., 2018). In the advanced stage, cognition impairment with hallucinations and delusions occur, walking is significantly challenging, and the patient requires constant assistance (Bhat et al., 2018).

The motor symptoms affect the ability to cope with daily tasks. The cardinal symptoms of PD are bradykinesia, tremors, rigidity, and postural disturbances. Bradykinesia manifests as slowness of movement and decrementing amplitude in sequential, continuous tasks (Jankovic, 2008; Postuma et al., 2015). Tremors are involuntary, rhythmic movements of a body part (Bhatia et al., 2018), PD tremors are often located in limbs and may be asymmetric. Rigidity is muscular tension, increased resistance during movement, and it may be associated with pain. Rigidity in e.g. neck or back muscles may affect posture, causing a “stooped” posture (Jankovic, 2008). PD may cause postural instability, as the postural reflexes get slower (Jankovic, 2008). In addition, PD may see the onset of freezing of the gait, which can often lead to falls (Simuni & Pahwa, 2009), and changes in speech or handwriting. PD may affect automatic movements, i.e. blinking, smiling or hand swinging while walking.

The non-motor symptoms of PD can be categorised into autonomic dysfunction (such as sweating or gastrointestinal problems), sleep disturbances (e.g. daytime sleepiness, vivid dreams, nightmares), cognitive and psychiatric disturbances (e.g. cognitive deterioration and dementia), and sensory symptoms (usually pain) (Jankovic & Tolosa, 2007; Sveinbjornsdottir, 2016).

From the patient’s perspective, in the early phase of PD (less than six years since diagnosis) the five most problematic symptoms are slowness, tremors, stiffness, pain, and loss of smell and/or taste (Politis et al., 2010). In the later phase, the most common problems are fluctuating response to medication, mood changes, drooling, sleep problems, and tremors (Politis et al., 2010).

2.1.4 Treatment

As of 2021, there is no cure for PD. A patient’s treatment is focused on alleviating symptoms (Lang & Lozano, 1998). Treatment may include medication, surgery, and

therapy, and the treatment is adjusted as the disease progresses (Davie, 2008). Each medicine has side effects, e.g. dyskinesia, and the medication tends to lose effectiveness over time (Davie, 2008). Dyskinesia is involuntary movement and is most often related to medication dosage and timing (Simuni & Pahwa, 2009). Some PD medication also causes hallucinations (Simuni & Pahwa, 2009). The response to individual medication doses may vary; the phases in medication response may vary (“on-off fluctuation”) or the medication effect may end earlier than expected (“wearing off”). Surgical treatments, such as a Deep Brain Stimulation (DBS), may be highly effective with long-term results but they are suitable only for accurately selected candidates. PD patients may benefit from various therapies, e.g. physical, occupational, speech and cognitive behavioural therapy (Davie, 2008). Rehabilitation for different symptoms maintains physical ability, alleviates muscle stiffness and improves mobility and gait (Bhat et al., 2018). Regular exercise is recommended for all PD patients.

A medication regimen is always tailored according to the patient’s symptoms and needs, taking into account the individual’s response to medication (Simuni & Pahwa, 2009). The assessment of PD status on current practice considers neurological examination during clinical visits and information provided by the patient or caregiver (Tzallas et al., 2014).

2.2 Self-care of chronic conditions

2.2.1 *Defining self-care*

Self-care refers to activities (decision making and actions) to maintain or promote health in daily life (Richard & Shea, 2011). For example, eating healthily and exercising regularly are common self-care activities. Self-care contributes to the quality of life (QoL), which is a subjective perception of an individual’s current state of daily life, including physical, emotional and social aspects of life (Andrejack & Mathur, 2020; Bonomi, Patrick, Bushnell, & Martin, 2000; Theofilou, 2013).

In chronic conditions, self-care expands to disease management (e.g. medication) and to overcoming the challenges in daily life caused by the disease, including actions of informal caregivers or family members. Each chronic condition has unique techniques for self-care, depending on the characteristics of the disease, and successful self-care can increase the perceived control of the disease (Riegel et al., 2012). The term “health-related quality of life” is often used in connection with chronic diseases, emphasising the experience of the disease and the effect of treatment on life (Bonomi et al., 2000).

2.2.2 *The Internet as a modern self-care information source*

The internet provides a platform for information sharing and peer support, and there are specific forums for several chronic conditions. Sixty-six per cent of adults with no chronic conditions and 44% of the adults with one or more chronic diseases use the internet to obtain information about health or medical issues (Fox & Purcell, 2010). About 70% of caregivers of those with chronic conditions search for health-related information on the internet (Fox & Brenner, 2012). A European survey of people with PD studied the information sources for the PD treatment and management options (Bloem & Stocchi, 2015). While 64% of people with PD sought such information from PD organisations, almost as many, 62%, used the internet and 62% obtained it from friends (Bloem & Stocchi, 2015). This highlights the importance of peers and the internet as PD-related information sources.

The information provided by peers is known to differ from the clinician's expertise (Hartzler & Pratt, 2011). The patient gains experiential knowledge by managing the condition in daily life, whereas the clinician's expertise is based on education and practical experiment (Hartzler & Pratt, 2011). Furthermore, the focus is often different. Patient expertise covers daily self-care practices offering actionable advice, in contrast with the knowledge-oriented and prescriptive information on medical topics provided by clinicians (Hartzler & Pratt, 2011). Clearly, patients can offer information in the context of daily life, complementing the information provided by professionals (Hartzler & Pratt, 2011). Previous work has shown how patient knowledge can be collected via ethnographic studies and collecting techniques of daily practices (Attard & Coulson, 2012; Pols, 2014).

Peer information is often exchanged in online discussion forums, and the online communities help in understanding treatment more thoroughly (Johnson & Ambrose, 2006). Finding the information on online discussion boards is often challenging due to long discussion threads (Hartzler & Pratt, 2011). Moreover, to assess the credibility of the provided information, new users need to build a relationship with the information providers and familiarise themselves with their characteristics and expertise level, and this is often time-consuming (Mamykina, Nakikj, & Elhadad, 2015). There is a lack of a structured way of sharing and finding peer-provided information.

2.2.3 *Self-care technologies*

Self-care technologies can support in understanding the physical impacts of the condition and increasing the experienced control of the disease (Nunes et al., 2015). Self-care tools

can be divided into seven non-exclusive categories according to their purpose: tracking health-related data; medication reminders; supporting therapeutic activities; suggesting self-care activities; providing condition-related information; interaction with other patients and carers; and remote interaction with medical care (Nunes, 2017). Published papers on the technology used in PD assessment have increased significantly in recent years (Deb, Bhat, An, Ogras, & Shill, 2021), and mobile monitoring can be utilised in diagnosis, symptom monitoring, treatment response prediction, and rehabilitation (Deb et al., 2021; Rovini, Maremmani, & Cavallo, 2017). Various technologies are applied, *e.g.* smartphones, wearables, optical motion trackers, and audio or video recording. Even though non-motor symptoms, especially depression, significantly affect the quality of life from the patient's perspective, the technology mainly offers solutions for tracking motor symptoms (Kuopio, Marttila, Helenius, Toivonen, & Rinne, 2000; Stamford, Schmidt, & Friedl, 2015).

2.2.4 Parkinson's disease self-care

Overview

An ethnography by Nunes and Fitzpatrick (2018) investigated PD self-care activities in four categories: medication intake; exercise; adapting lifestyle; and accepting the consequences of PD. People with PD often take medication several times per day, and the medication enables daily activities. Nunes and Fitzpatrick (2018) identified strategies for medication adherence, *e.g.* using reminders or placing the medication. Participants described exercising regularly to increase their wellbeing and improve movement control. The progressing condition demands life adjustments, *e.g.* adapting lifestyle. Changes may be permanent (*e.g.* losing one's driving licence) or temporary (*e.g.* missing a visit to the library because of fluctuations in symptoms). An accepting attitude towards the consequences of PD is a way of coping with a degenerative condition. According to the paper, PD self-care takes time and effort, and the activities are often integrated into everyday life. For example, some consider normal housework such as cleaning to be physical exercise, and it can thus be interpreted as part of self-care.

Miertová, Tomagová, Jarošová, and Kiabová (2014) wished to determine PD self-care techniques in the scope of Activities of Daily Living. They observed and interviewed two people with PD and their families, and identified issues and the corresponding solutions used, *e.g.* the use of plastic dishes to avoid breakages. They managed to collect many self-care techniques by studying the experiences of only two families. This

reveals the potential to use the daily life experience of people living with PD to identify self-care techniques for PD.

In relation to the above, a review of PD self-management strategies identified seven themes: medication management; physical exercise; self-monitoring techniques; psychological strategies; maintaining independence; encouraging social engagement; and providing knowledge and information (Tuijt et al., 2020). A meta-synthesis of coping strategies introduced three main themes: staying independent; focusing on the present; and avoiding unpredictable challenges (Haahr, Groos, & Sørensen, 2021).

Monitoring PD with smartphones

Smartphones are used for PD symptom assessment and diagnostics, and for body motion analysis (Klimova, 2017; Rovini et al., 2017), utilising the smartphone's internal sensors or wearables. A recent review (Linares-Del Rey, Vela-Desojo, & Cano-de La Cuerda, 2019) of apps in PD divided them in two; apps useful for PD, and apps designed for PD. The apps designed for PD were further categorised as information apps, assessment apps and treatment apps. Information apps provide disease-specific information for patients and their families, and/or for health care personnel. Assessment apps provide a means for symptom or disease status evaluation, e.g. gait or speech analysis. Treatment apps contain guidelines for patients or health care professionals related to medication or rehabilitation.

Many studies focus on tremors. A tremor is defined as “*an involuntary, rhythmic, oscillatory movement of a body part*” (Bhatia et al., 2018), and it can be categorised based on its activation conditions into rest and action tremors. An action tremor is subdivided into kinetic, postural and isometric tremors (Bhatia et al., 2018). PD patients may experience rest, kinetic or postural tremors. A tremor is considered as a rest tremor if it is present in a body part that is not being voluntarily activated (Bhatia et al., 2018). A tremor during a voluntary movement is called a kinetic tremor. A postural tremor appears while retaining a posture against gravity (Pierleoni, Palma, Belli, & Pernini, 2014). A tremor can be characterised by its frequency and amplitude. The frequency of a rest tremor is 3–6 Hz; a postural tremor occurs at 6–9 Hz; and a kinetic tremor at 9–12 Hz (Pierleoni et al., 2014).

Estimates of the prevalence of tremor types vary in different studies. A recent study (Gupta, Marano, Zwebber, Boyd, & Kuo, 2020) states that almost 80% of PD patients suffer from tremors. In more detail, approximately 58% experience rest tremors, about half have postural tremors, and a little more than half have kinetic tremors (Gupta

et al., 2020). The prevalence of different tremor types overlaps, i.e. a person may experience multiple types of tremors.

Tremor severity is usually assessed by a health professional visually with specific tasks during clinical visits, using tools such as the MDS Unified Parkinson's Disease Rating Scale (MDS-UPDRS) (Goetz et al., 2008). The examiner evaluates the amplitude of postural, kinetic and rest tremors in centimetres during defined tasks (Goetz et al., 2008). In addition, the examiner evaluates the constancy of tremors, i.e. the share of evaluation period when the tremor occurs (Goetz et al., 2008).

Smartphones and wearables provide an unobtrusive and objective means to detect and quantify tremors, with the potential to detect novel phenomena assisting in the identification of biomarkers for PD progression (Espay et al., 2016). It has been shown that the PD tremor can be assessed via accelerometer-based data in a controlled environment (i.e. laboratory), either using a smartphone's internal sensor (Barrantes et al., 2017; Bazgir, Frounchi, Habibi, Palma, & Pierleoni, 2015; Bazgir, Habibi, Palma, Pierleoni, & Nafees, 2018; Duque, González-Vargas, Egea, & Rojas, 2019; Kostikis, Hristu-Varsakelis, Arnaoutoglou, & Kotsavasiloglou, 2015; LeMoyne, Mastroianni, Cozza, Coroian, & Grundfest, 2010; Woods, Nowostawski, Franz, & Purvis, 2014) or wearables (Bermeo, Bravo, Huerta, & Soto, 2016; Locatelli & Alimonti, 2017; Pierleoni et al., 2019, 2014). LeMoyne et al. (2010), Barrantes et al. (2017), Duque et al. (2019), Kostikis et al. (2015), and Bazgir et al. (2018) attached the smartphone to a glove during measurements. LeMoyne et al. (2010), Barrantes et al. (2017) and Duque et al. (2019) focused on classifying PD tremors and essential tremors. Kostikis et al. (2015) evaluated the severity of the patient's rest and postural tremors. Bazgir et al. (2015, 2018) classified tremors as rest tremors, postural tremors and kinetic tremors. In a study by Woods et al. (2014), the subjects held a smartphone during the measurements, and a statistically significant difference between participant groups with PD and with essential tremors was detected.

One of the tests used in the diagnosis of PD and assessing the disease after the diagnosis is a spiral drawing task. Traditionally, the task is conducted with pen and paper and is evaluated visually by a trained specialist. In previous research, solutions offer the spiral drawing and analysis using a tablet (Pullman, 1998; Saunders-Pullman et al., 2008; Smits et al., 2014), or smartphone (Graça, e Castro, & Cevada, 2014; Sadikov et al., 2014). Other shapes (e.g lines, circles) have also been utilised for PD symptom assessment (Dounskaia, Van Gemmert, Leis, & Stelmach, 2009; Kotsavasiloglou, Kostikis, Hristu-Varsakelis, & Arnaoutoglou, 2017; Smits et al., 2014). The aim of the studies were to quantify the spiral drawing (Dounskaia et al., 2009; Pullman, 1998; Sadikov et al., 2014) to distinguish people with PD from healthy individuals (Graça et

al., 2014; Kotsavasiloglou et al., 2017; Smits et al., 2014) or those with PD tremors from those with essential tremors (Sadikov et al., 2014).

In common with many chronic diseases, medication non-adherence decreases the effectiveness of a medication-based treatment (Grosset et al., 2009). Medication logging can be used to measure (Farmer, 1999; Jimmy & Jose, 2011; Osterberg & Blaschke, 2005) and even increase (Dayer, Heldenbrand, Anderson, Gubbins, & Martin, 2013; van Berge Henegouwen, Van Driel, et al., 1999) medication adherence. A variety of technical solutions focus on medication management, targeting the improvement of medication adherence (e.g. Dalgaard, Gronvall, and Verdezoto (2013); Hayes, Hunt, Adami, and Kaye (2006); J. M. Silva, Mouttham, and El Saddik (2009)). However, smartphones provide a way to manage medication adherence (Cubo et al., 2017; Dayer et al., 2013; Kassavou et al., 2020; Santo et al., 2016) utilising software functionalities (e.g. notifications, logs). In addition to medication, self-reports have been used in PD care to track motor fluctuations (Hauser, Deckers, & Leher, 2004; Lyons & Pahwa, 2007; Nyholm, Kowalski, & Aquilonius, 2004; Papapetropoulos, 2012; Reimer, Grabowski, Lindvall, & Hagell, 2004) and record falls (Ashburn, Stack, Ballinger, Fazakarley, & Fitton, 2008).

Self-evaluation and sensing have been combined as smartphone applications and platforms in some studies. ParkNosis (Sahyoun, Chehab, Al-Madani, Aloul, & Sagahyroun, 2016) aims for an early diagnosis of PD by conducting a spiral drawing test on a smartphone, a tremor assessment with a smartwatch, tapping tasks, and an assessment questionnaire. Lakshminarayana et al. (2017) designed a Parkinson's tracker app with self-monitoring features, a medication log with a reminder, and games for monitoring finger tapping receptivity and cognition. They showed that such an app could improve medication adherence, and the collected data could enhance the quality of clinical consultation. Arora et al. (2014, 2015) studied PD-diagnosed and healthy participants, and used an Android application to monitor voice changes, gait, posture, finger tapping, and response time. With the collected data, they estimated the symptom severity as UPDRS points.

Research methods and limitations in PD self-care studies in HCI field

Self-care practices occur daily, and understanding self-care is traditionally achieved via surveys, interviews, by observing (in person or via camera), thematic analysis or ethnographic studies. For example, to understand PD self-care, Nunes and Fitzpatrick (2018) interviewed 10 patients and 10 carers, and conducted an online ethnography with a large, public, online PD forum. Attard and Coulson (2012) analysed PD online

discussion groups, with the aim to study online communication between patients, not self-care or life with PD. Miertová et al. (2014) focused on changes in self-care of two PD patients. Data was collected with semi-structured interviews, and structured observation of the patients. In addition, they interviewed family members and analysed medical records. Tuijt et al. (2020) and Haahr et al. (2021) applied literature review and synthesis for gaining insight to PD self-management and coping strategies.

When studying how to quantify PD symptoms, it may be difficult to define a ground truth for the measurements. In the clinical settings, the symptoms are often assessed using official scales, such as UPDRS, by trained clinicians. We introduced seven studies focusing on tremor assessment in the section 2.2.4. These studies were all conducted in controlled environments. When compared to real-life studies, the data quality is often void of daily activities interference, perhaps collected with same device in surveillance of the researcher, and the number of observations is limited. In the introduced tremor studies, the number of participants varied from two (LeMoyne et al., 2010) to 52 (Barrantes et al., 2017; Bazgir et al., 2015, 2018), and the number of recordings per participant varied from two (Barrantes et al., 2017) to 12 (Woods et al., 2014).

Studying the impact of medication, especially measurements in ‘off’-state, often requires patient surveillance by medical personnel. It would be risky to ask a PD patient to travel to the lab for measurements without medication. In the study by Kostikis et al. (2015), two participants were hospitalized during a night for the measurements of medication effect. In everyday life, data collected in before and after medication intake does not cause any extra risk for the participant.

2.3 Open data sets on Parkinson’s disease

Validated biomarkers of PD have not been identified yet, hence clinical scales and patient-reported outcomes are in core of PD care (Espay et al., 2016). While the research for identifying biomarkers continues, the opportunities of digitally collected sensor data have been acknowledged (Espay et al., 2016). Projects aiming to understand PD better and to identify markers for the disease progression offer open data sets for scientists to work with.

mPower is a series of studies, started at 2015, targeting to understand PD symptom variation, i.e. the frequency, degree and impacting factors of the variation. Data is collected with a smartphone app through surveys and tasks from participants diagnosed with PD and healthy controls (Bot et al., 2016; Sage Bionetworks, 2016a, 2016b). During the study, the participants first complete a one-time baseline survey about their demographics. Standard surveys (Parkinson Disease Questionnaire 8 and a subset

of MDS-UPDRS) are submitted upon participants' onboarding and once per month throughout the study. During the study, the participant is expected to complete activities on the app three times per day for two weeks, every three months up to two years (unless choosing to quit earlier). People with PD conduct activities before and after medication, and whenever they feel compelled to. The control group are free to select any time of the day to complete the tasks.

In the first study, mPower 1.0, the memory is tested with a short visuospatial game. A tapping task assesses dexterity, in which the participant taps the screen of the phone that is placed on a flat surface. During the voice task, participants record 'aaah' for 10 seconds with steady volume. The gait and balance is evaluated with the walking activity, where the participants walk straight line back and forth and stand still, with the smartphone in their pocket. In the mPower 1.0 data set, 6805 participants have filled the demographics survey (filled only once). The number of unique participants for other tasks varies between 968 and 5826 (Sage Bionetworks, 2016b). Hence, the amount of data is large. The data collection continues as mPower 2.0 study, the phonation data is no further collected via voice task, but a tremor measurement (participant holds the phone for 15 seconds) is added (Sage Bionetworks, 2016a).

The Personalized Parkinson Project aims to establish an open dataset for identifying biomarkers for PD progression and treatment response in early phase of PD (Bloem et al., 2019). The study started in late 2017 and is still ongoing. 520 people diagnosed with PD joined the 2-year study. The participants are assessed three times a year in a clinic visit, including motor and neuro-psychological tests, collection of bio specimens, magnetic resonance imaging and ECG recordings (Bloem et al., 2019). In addition, data is collected through a bracelet, the Verily Study Watch, continuously through the whole research time. The watch is used for passive data collection of physiological data (acceleration/orientation, pulse rate, electrodermal activity, electrocardiogram) and environmental data (barometric pressure, relative humidity, environmental temperature, and ambient light level) (Bloem et al., 2019).

3 Research methods and material

3.1 Contextualizing our approach

In self-care research, the concept of self-care must be defined, and interventions should be based on theory (Jaarsma et al., 2021; Nunes et al., 2015). This thesis follows the Middle-Range Theory of Self-Care of Chronic Illness in the definition of self-care and uses the theory as an overarching lens. Having introduced the theory, we review the motivation for our method selection based on the related work. Finally, we give an overview of the developed applications and the related studies.

3.1.1 *The Middle-Range Theory of Self-Care of Chronic Illness*

Middle-range theories were introduced in sociology by Robert K. Merton in 1940s (Hedström & Udehn, 2009) and were later adapted to other disciplines, e.g. archaeology (Raab & Goodyear, 1984) and nursing (Smith & Liehr, 2018). In nursing, middle-range theories focus on specific phenomena related to the caring–healing process, and guide everyday nursing practice, with an intersection with research (Smith & Liehr, 2018). A middle-range theory is “*a set of related ideas that are focused on a limited dimension of the reality of nursing*” (Smith & Liehr, 2018). It consists of concepts and relationships between the concepts, depicted as a model (Smith & Liehr, 2018). Middle-range theories on nursing are widely used: more than 90 middle-range theories have been proposed since 1980 (Smith & Liehr, 2018).

According to the Middle-Range Theory of Self-Care of Chronic Illness (Riegel et al., 2012), the self-care of a chronic condition is defined as “*a process of maintaining health through health-promoting practices and managing illness*”. The theory identifies key concepts for self-care: self-care maintenance; self-care monitoring; and self-care management. Self-care maintenance aims to maintain physical and emotional stability with the chronic illness through actions and practices that aim to maintain or improve health, such as diet, exercise, sleep, and adherence to treatment (Riegel, Jaarsma, Lee, & Strömberg, 2019; Riegel et al., 2012). Self-care monitoring targets the recognition of changes in condition by tracking bodily functions, emotions, and symptoms (Riegel et al., 2012). To detect changes, the patient needs an awareness of the disease and an understanding of sensations, and knowledge gained from experience and education (Riegel et al., 2019). Self-care management analyses and counters these results, deciding on what actions are needed (Riegel et al., 2019, 2012). For example,

the patient may choose to adopt a different diet, take a painkiller, contact a nurse for instructions. The theory identifies factors affecting self-care, i.e. motivation, experience and skill, culture, habits, confidence, reflection, cognitive and functional capabilities, symptoms, support, and access to care (Riegel et al., 2019). Symptoms affect the motivation for self-care, either increasing or decreasing, as well as the motivation to seek professional health care (Riegel et al., 2019). The processes defining self-care are reflection and decision making (Riegel et al., 2012). These dimensions of self-care refer to the patient's knowledge acquisition, as well as to decisions on committing to self-care actions. Previously, the theory has been used in studies of the self-care of various chronic diseases, such as diabetes and asthma (Buck, Shadmi, Topaz, & Sockolow, 2021).

3.1.2 Motivation

Our objectives for this thesis were to create novel applications for supporting PD self-care, and to investigate their fit in the Middle-Range Theory of Self-Care of Chronic Illness key concepts for self-care. Self-care is an essential part of living with a chronic condition (Department of Health, 2006; Riegel et al., 2012), and each chronic condition has specific self-care activities and techniques, depending on symptoms and the treatment regimen.

Medication is adjusted for each PD patient, but the analysis of the medication effect relies on the patient's description. The clinical follow-up of PD is based on visual assessments, e.g. tremor amplitude and prevalence are evaluated visually using evaluation scales such as UPDRS. The specialist sees only a snapshot of the patient, and the data provided by the patient are highly subjective and prone to bias (Tzallas et al., 2014). There is a lack of objective, quantitative monitoring data.

As self-care is performed in the context of daily life, we wanted to utilise devices and technology suitable for daily life and that were already familiar and in common use among people with PD. Smartphones are ubiquitous and often already available. Using an existing device requires less effort to learn how to use the application. As many people use smartphones, it does not cause a stigma (Nunes et al., 2015). We therefore selected smartphones as a platform for monitoring.

Previous studies of tremor quantification using a smartphone (Barrantes et al., 2017; Bazgir et al., 2015, 2018; Duque et al., 2019; Kostikis et al., 2015; LeMoyne et al., 2010; Woods et al., 2014) show that tremor evaluation based on the accelerometer signal is feasible. These studies were conducted in lab conditions, following a given task. It remained unclear if the measurements could be conducted in real-life conditions without

supervision, with different devices and varying conditions. Moreover, all the studies attached the smartphone to a glove, with the exception of Woods et al. (2014). It is impractical to use a glove in daily measurements, because the glove is obtrusive, and attaching the phone to the glove may be difficult for someone with PD.

We designed a smartphone application called STOP to monitor medication-timely adherence and symptom levels. Our aim was to determine if the data collection was feasible “in the wild”, and if the collected data could be utilised in symptom assessment. We provided the measurements in the form of a game, without any extra equipment. The STOP application was evaluated in a field trial (Study 1, Articles I and III).

We enriched the functionality of the STOP application with digitised spiral and square drawing tasks. Previous solutions for digitising the spiral drawing assessment were conducted using a stylus or a digital pen. Again, to ensure accessibility, we decided to provide the tasks to be conducted using only a smartphone without extra equipment, and the drawing was performed with a finger. The drawing tasks were evaluated as a lab experiment in the local PD Association meeting (Study 2, Article II).

While clinicians often focus on treatment and symptoms, self-care is centred on daily activities, i.e. self-care maintenance. Self-care knowledge is gained by living with PD, and this experience is exchanged via online or face-to-face discussions among peers, but there is no organised way to collect and discover this expertise. As the second application, we built the online repository PDCareBox for daily self-care techniques. Our target was to provide a structured way to collect and discover the self-care information in the form of self-care techniques (Study 3, Article IV).

Next, we present the research approach and the applications in more detail.

3.2 Study 1: STOP field trial

In the field trial of the custom-built mobile software STOP, authentic PD patients used the STOP application with their own devices in naturalistic settings. We collected data through interviews, and using the STOP application (consent, questionnaire, sensor data). In Article I, the qualitative data from the interviews were analysed by creating an Affinity Diagram (an HCI method to synthesise qualitative data into themes (Holtzblatt & Beyer, 2016)), and the data collected by STOP were analysed by using adequate statistical tests (e.g. Mann-Kendall test, Kendall tau-b correlation test). In Article III, we analysed the collected sensor data using signal processing methods (e.g. linear interpolation, Welch’s method) and statistical analysis (e.g. Wilcoxon rank-sum test).

3.2.1 STOP mobile application for monitoring PD

The STOP application was created specifically to track PD symptoms and support medication logging. The STOP application utilises the AWARE framework (Ferreira, Kostakos, & Dey, 2015) for data collection. AWARE allows secure storing and transmission of data. The application is provided for both Android and iOS, and it collects data via a smartphone's sensors. Related guidelines are considered in the design: Nunes, Silva, Cevada, Barros, and Teixeira (2016); Vega et al. (2018); W3C (2010); Siek et al. (2011). The application core functionalities implemented in the first release are: an accelerometer-based game that quantifies patients' hand tremor, a medication journal for medication intake time logging, and a daily survey for overall PD symptom severity reporting.

Accelerometer-based ball game

Previous research has shown that a smartphone's accelerometer sensor can be utilised to quantify PD tremors in lab conditions (Barrantes et al., 2017; Bazgir et al., 2015; LeMoyné et al., 2010).

The STOP application leverages the accelerometer in the tremor and the hand's motorics assessment, implemented as a brief ball-balancing game: the smartphone is held horizontally on the palm of the hand, screen up, for the pre-set time. The user tries

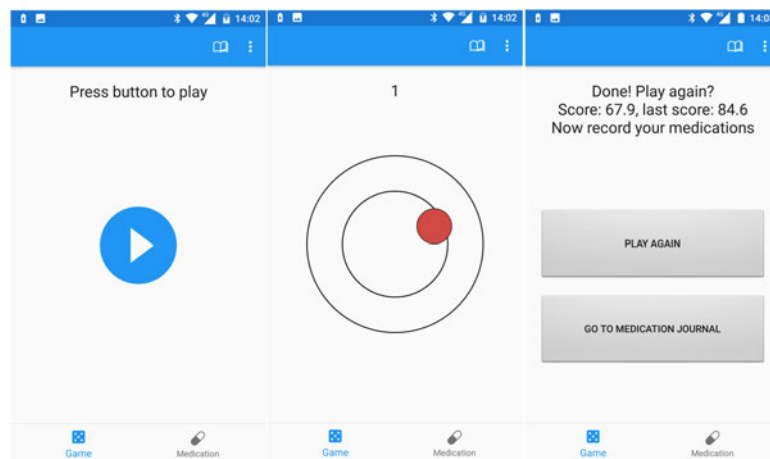


Fig. 1. The screen flow of the ball-balancing game. After pressing the play button, the user aims to keep the ball in the centre of the middle circle by keeping the smartphone horizontally flat for a predefined time. The score (range 1-100) based on the performance is shown after the game session. Reprinted with permission from Article I © ACM, 2019.

to keep the ball in the centre of the screen, inside the inner circle (Fig. 1), as still as possible. During the game session, STOP records the data from the accelerometer, linear accelerometer (acceleration without the force of gravity), gyroscope and rotation sensors, the position of the ball in relation to the inner circle's centre, and screen pixel density. The app provides a success score, calculated based on the ball's distance between the centre of the screen: $score = (1 - \frac{MD}{SD}) * 100$, where MD is the mean distance between the centre of the screen (X and Y coordinates) and the ball's current coordinates; SD is the maximum screen distance possible (maximum X and Y, depending on screen resolution). In practice, the more the ball deviates from the centre point, the lower the score, with a range of 1–100.

The game is customisable. The circle size, sensitivity of the ball (i.e., the amount of motion needed to move the ball) and game duration can be modified.

Medication journal

Medication intake times can be logged in the medication journal in STOP. The journal interface is designed taking interaction limitations caused by PD into account (Nunes et al., 2016; Vega et al., 2018; W3C, 2010). The size of the actionable buttons is large, and they change colour on touch (see Fig. 2). The interactions required for timekeeping are designed to be as short as possible, as recommended by Siek et al. (2011). The medication intake time may be recorded by manual input (“Now” and “Specify time”

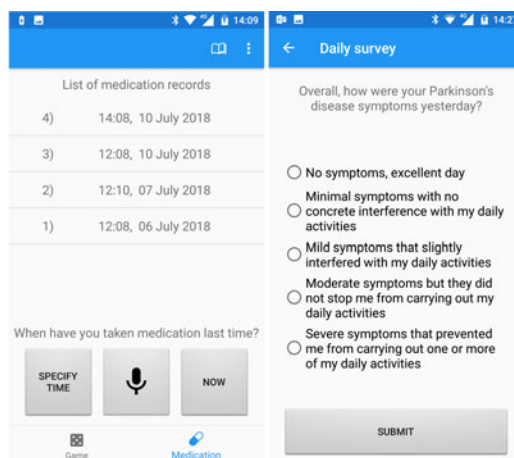


Fig. 2. On the left, the medication journal with different input options. The buttons are large, and change colour on touch (see ‘Medication’ button at the bottom). On the right, daily PD symptoms survey. Reprinted with permission from Article I © ACM, 2019.

buttons) or using voice input, e.g. by saying “three hours ago” or “yesterday 9 a.m.”. The medication journal is a retrospective tool for users, providing a view of how the prescribed medication schedule is being followed.

Daily symptoms survey

Once per day, the user is asked to rate the overall symptom level of the previous day; see Fig. 2. The five response options are:

- No symptoms, excellent day
- Minimal symptoms with no concrete interference with my daily activities
- Mild symptoms that slightly interfered with my daily activities
- Moderate symptoms but they did not stop me from carrying out my daily activities
- Severe symptoms that prevented me from carrying out one or more of my daily activities

The response options are loosely derived from UPDRS Section II (Goetz et al., 2008) and the Parkinson’s Disease Activities of Daily Living Scale (Hobson, Edwards, & Meara, 2001). These assessments provide also five response options from no symptoms to severe or extreme. The UPDRS-II scores depict PD motor symptoms’ severity and effect on daily activities. In the long run, the daily survey provides an insight into the daily variation of PD and its effects on the user’s daily life.

Notifications

Notifications remind the user to play the ball game, record medication intake time, and to commit to the daily symptoms survey regularly. Notifications are shown randomly within notification periods, one per period. The notifications for the game and medication are shown in the morning (8:00–11:59), at noon (12:00–14:59), in the afternoon (15:00–18:59) and in the evening (19:00–21:59). The reminder for the previous day’s PD symptoms survey is delivered between 10:00 and 11:00.

Data collection with STOP

The STOP application collects the following data:

- **Consent:** consent for using the collected data in research can be given and withdrawn in the application.

- **Patient characteristics:** when STOP is opened for the first time, the participant’s age, how long ago PD was diagnosed, the medication regimen, and a self-evaluation of PD symptoms using the UPDRS part II scale are filled into the app (see Fig. 3).
- **Mobile device sensor data:** collected during the ball game session from four smartphone sensors, accelerometer, linear accelerometer, gyroscope, and rotation. In addition, the distance of the ball from the screen centre is recorded.
- **Medication time data:** the user enters medication intake times in the medication journal.
- **Notification data:** the time of notification and it’s opening.
- **Feedback:** feedback on-demand about the app given by users.

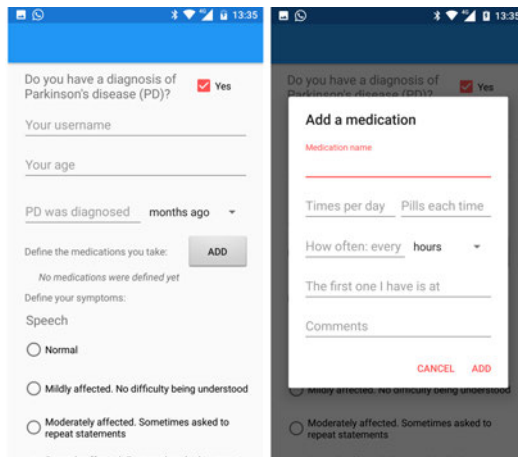


Fig. 3. On left, participant profile query. On right, medication regimen input screen. Reprinted with permission from Article I © ACM, 2019.

3.3 Study 2: Digitised drawing tasks

In the second release, the STOP application was enriched with drawing tasks. To evaluate the tasks, we employed a controlled experiment with two user groups, people with PD and an age-matching control group. Background demographics were collected using a paper questionnaire, and the drawings with the smartphone app were done using a single device and supervised by the researchers. In Article II, the quantitative data are analysed with appropriate statistical methods (e.g. Wilcoxon rank-sum test).

3.3.1 The digital spiral and square drawing tasks

Assessing a spiral drawing performance is used to observe tremors and other abnormal movements in the assessment and diagnosis of PD (Hess, Hsu, Yu, Ortega, & Pullman, 2014; Pullman, 1998). Traditionally, the spiral is drawn with pen and paper and analysed visually. The STOP application is extended with the digital spiral and square drawing tasks, which are performed with a finger. The application provides an instruction screen that asks the user to start drawing from the centre of the spiral, and from the bottom-left corner in the square, and to follow the template. The drawing is done according to the provided template, and the drawn line is illustrated on the screen. After drawing, the user can click either “reset” to start again or “done” to save the result. The results, with the average, max, and standard deviation of error, and drawing time, are presented to the user. The touch coordinates with the time stamps are recorded from the drawing, along

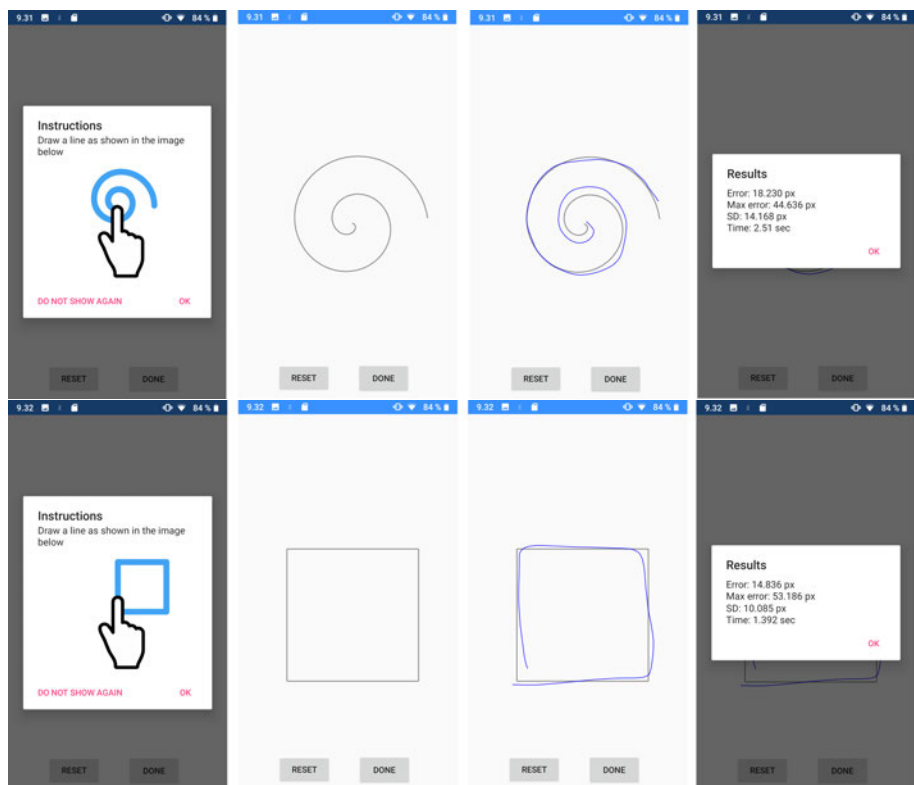


Fig. 4. The screen flow of the drawing tasks, the spiral drawing task on the top row, and the square on the bottom row. Screens from left to right: instructions; template; drawing; and results. Adapted with permission from Article II © ACM, 2020.

with the screen capture of the final drawing. The screen flow of the drawing tasks is presented in Fig. 4.

3.4 Study 3: An online repository of PD self-care techniques

In the third study, the self-care data were collected from people with PD and their personal carers in an online experiment through an online interface and online questionnaires. The created artefact was evaluated by authentic users in another online experiment. In Article IV, a thematic analysis was conducted for the data submitted by the users, and the quantitative data (i.e. the log data) were analysed (e.g. Wilcoxon rank-sum test).

3.4.1 *PDCareBox*

The repository contains two user interfaces, one for submitting and assessing the PD self-care techniques, and the other for discovering the suitable PD self-care techniques.

The technical solution utilises AnswerBot, an online decision support tool enabling collection and assessment of solutions for a given problem (Hosio, Goncalves, Anagnostopoulos, & Kostakos, 2016). Previously, AnswerBot has been applied in collecting treatments for lower back pain (Hosio et al., 2018) and methods for weight loss (Hosio, van Berkel, Oppenlaender, & Goncalves, 2020). PD self-care is often about trying different self-care techniques and finding the working ones for the patient (Nunes & Fitzpatrick, 2018). Similarly, the suitable treatment for lower back pain and a working weight loss method are often found by trying several options. There is no “golden solution” that works for all. For this use case, the UI was redesigned following the design guidelines focusing on accessibility.

The online UI for submitting and assessing self-care techniques

Figure 5 presents the online UI for submitting and assessing PD self-care techniques. In the tool, the study is first introduced, and after consent is given, the users fill in an initial questionnaire about their demographics and details of their PD status. The tool allows the user to submit their personal self-care techniques and to assess techniques submitted by others. Before setting the tool public, we added five self-care techniques obtained from the Parkinson’s UK and Parkinson’s Foundation websites.

How do you deal with Parkinson's Disease in your daily life?
 Think of techniques that you employ to either improve or manage your physical and/or mental difficulties in relation to PD.

Assess as many techniques from the list as you want to.
 You may also help the community by adding your own technique. Use the link at the end of the list
 *** When you're done, [click here to end assessing techniques](#) and conclude the study ***

Search for a technique...

- horsesriding
- ice berg breaker
- Computer programming
- Cooking, making up new recipes
- ketogenic diet
- Trail cycling
- Water and coffee fasts of 5+ days duration
- Bell ringing
- PWMI Moves
- skipping/jump rope
- exercise with Scottish Baret
- Meditation
- Strict observance of circadian rhythm
- Clock yourself app
- Far infrared sauna

[Add a new one!](#)

Weighted wristbands

When dyskinesia is a problem I wear 500g velvet wristbands to reduce the writhing movements and the consequent muscle pain in my arms. Could be used in same way on ankles

Sociality: 👤
 How much social interaction or cooperation does this method require?
 Not at all much Extremely much

Affordability: 👤
 In general, how affordable is this technique?
 Not at all affordable Extremely affordable

Effectiveness: 👤
 Is the technique effective?
 Not at all effective Extremely effective

Familiarity: 👤
 How familiar are you personally with this method?
 Not at all familiar Extremely familiar

What symptoms or Parkinson's related issues do you think this technique is good for, if any?

Read me first

1) Add only techniques that you think are genuinely helpful.
 2) Check the box that appears on the right when you type a descriptive title for your option. It contains a list of potentially similar options that already exist in our database.
 3) Do not add options that are highly similar to the ones that already exist – duplicate options cause all sorts of problems.

Add a self-care technique

Add a short title:

Your new technique here:

Describe the technique in more detail:

Can the technique be practised at home?
 No Yes

URL (optional):

Notes that this is optional. The technique does not have to be described online.

This research is an international collaboration led by University of Duisburg, with collaborators from Aalborg University, Fraunhofer University, the University of Pittsburgh, the University of Glasgow, the University of Lisbon and the University of Melbourne. [Data protection disclaimer.](#)

Fig. 5. The interface for entering and assessing self-care strategies. On the left, the user sees the list of submitted self-care techniques, and can assess the selected technique through four criteria (sociality, affordability, effectiveness, familiarity) via a slider input. In addition, the user can describe what the technique is good for with an open-ended field. If the user clicks “Add new one!”, the pop-ups presented on the right are shown. The user first sees short instructions and may then submit their own self-care technique with title, description, information if the technique can be practised at home, and an optional URL for more information. Adapted from Article IV (under review).

The submission of a new technique consists of a title and a description. The submitter also selects if the technique can be practised at home, and if a hyperlink can be provided for more information.

The list of submitted techniques is shown in descending order according to the number of ratings. The user may choose any technique for the assessment, and the assessment is collected using a slider input (0–100) for the pre-set criteria: *sociality*; *affordability*; *effectiveness*; and *familiarity*. In addition the user may describe what symptoms or issues the technique is good for in an open-ended field. We refer this input as reflection.

Discovering PD self-care techniques via PDCareBox

Figure 6 presents the UI for discovering the PD self-care techniques via the PDCareBox. At the top of the web page, the tool is introduced, and short instructions on how to search for self-care techniques are presented. The search interface allows the user to specify the desired level of 1–4 criteria: *sociality*; *affordability*; *effectiveness*; and *familiarity*. The results provide the matching self-care techniques. By clicking “Show what this is good for”, the reflections are obtained from participants during the assessment, with the assessor’s age and years with PD. After using the tool for four search rounds, a pop-up asking the user to fill in a questionnaire about their background and their experiences with the tool is shown. The link to the questionnaire is also permanently available in the PDCareBox.

The tool’s accessibility was improved from earlier applications of the Answerbot (Hosio et al., 2016, 2018, 2020) by following design guidelines for older adults (Consortium, 2021a, 2021b; Nurgalieva, Laconich, Baez, Casati, & Marchese, 2019, 2021) and



Fig. 6. The interface in the PDCareBox for discovering self-care techniques. On the left, the introduction and instructions (on top of the UI). On the right, the discovery interface. The user sets the preferred level of 1–4 criteria, and clicks “Discover best matches”, and the best matching techniques are shown. The user can click the “Show what this is good for” button, and the reflections from assessments are shown. The “Learn more” button redirects the user to the (optional) url provided by the author of the technique. At the bottom, the collaborators are introduced in the banner.

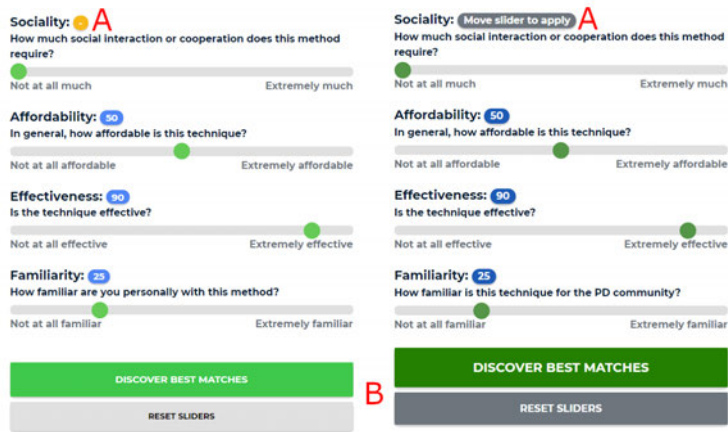


Fig. 7. The implemented accessibility enhancements in the PDCareBox search UI. On the left, the earlier version of UI, and on the right, the enhanced UI. The following improvements were made: A) a note to move the slider for applying the criteria was added; and B) the contrast ratio of the UI elements and text was increased. Reprinted from Article IV (under review).

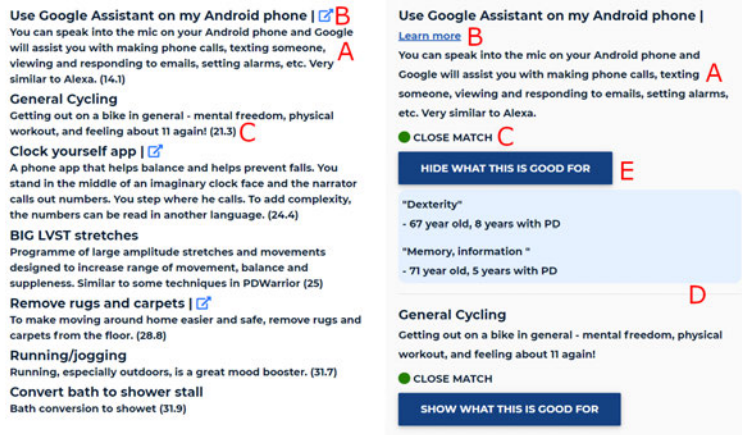


Fig. 8. The implemented accessibility enhancements in the PDCareBox results UI. On the left, the earlier version of UI, and on the right, the enhanced UI. The following improvements were made: A) The text line-height was increased from 1.2 to 1.5 and line space was increased; B) the icon was replaced by instructive text; C) a numeric goodness-of-fit indicator was replaced with a visual indicator; D) a thematic break was added; and E) a “Show what this is good for” section containing assessment reflections was added. Reprinted from Article IV (under review).

PD-specific design guidelines (Nunes et al., 2016). The implemented enhancements are introduced in Figures 7 and 8. An instructional note for operating the sliders was added to replace a hyphen indicating the criterion was not applied in the search, (Fig. 7, A). The contrast ratio of the colour in the criteria slider items and buttons was updated according to Consortium (2021b) and Nurgalieva et al. (2021) (Fig. 7, B). For readability, the text line space and font size were increased (Consortium, 2021b; Nurgalieva et al., 2021), (Fig. 8, A). Elderly users may be unfamiliar with standard icons, so the icon for URL provided by the submitter was replaced with the text “Learn more” (Nurgalieva et al., 2021) (Fig. 8, B). The unvisited and visited links were made distinguishable from each other by changing the colour of the visited links (Nurgalieva et al., 2021). The numeric goodness-of-fit indicator was replaced with a text (poor, moderate, or close) and highlighted with colours (red, yellow, or green) (Fig. 8, C). A thematic break between each technique was added to make the techniques more distinguishable (Fig. 8, D). The content of the reflections describing what the technique was good for according to the assessors can be set to visible by clicking the corresponding button. The origin of the peer-provided data is highlighted by facts about the writer, e.g. “50 years old, 10 years with PD” or “Caregiver of 50-year-old, 4 years with PD”.

3.5 Summary of the research methods used

In the studies, quantitative data were collected in the real world and supplemented with subjective qualitative data. The aim of this mixed methods approach was to holistically provide data for supporting PD self-care and to ensure our applications were usable in naturalistic settings. A summary of the research methods used in the studies is presented in Table 2.

Table 2. Summary of research methods in each study and article.

Method	Study 1 Articles I, III	Study 2 Article II	Study 3 Article IV
Field Study	X		
Lab experiment		X	
Evaluation			X
Interview	X		
Questionnaire	X	X	X
Diary	X		
Mobile data collection	X	X	
Online Data Collection			X

4 Research contributions

This Chapter presents the research contributions. An overview of the contributions per Article is presented in Table 3.

Table 3. Summary of research setup and contributions of the articles.

Art.	Research objectives	Contributions
I	Conduct a real-world trial for STOP application. Deepen the understanding of the target audience, people with PD.	User experiences of STOP collected in naturalistic settings. Design implications for next implementation iteration found. How PD affects the daily life, and to smartphone use identified (RQ1, RQ2).
II	Design and implement drawing tasks for PD symptom evaluation	Spiral and square drawing assessment with smartphone, without extra equipment, provided. Found statistically significant differences in drawing performance of participants with PD and healthy age-matching controls, and design implications for the tool (RQ2).
III	Find ways to evaluate hand tremor severity and medication effect with accelerometer signal collected by STOP.	Feasibility of hand tremor characterisation from accelerometer signal shown. Introduced Tremor Intensity Parameter (TIP). In these data, TIP correlates significantly with UPDRS II tremor score. Found statistically significant difference in accelerometer signal characteristics in game sessions played before and after medication intake among participants suffering rigidity and bradykinesia (RQ2).
IV	To establish and evaluate a repository for community-contributed PD self-care techniques.	A public, accessible, online repository of community-contributed PD self-care techniques. Design implications for the tool, and research opportunities for community-contributed data repositories (RQ3).

4.1 Designing for PD self-care

Each chronic condition has unique challenges, and **RQ1** asked which aspects of PD and self-care should be considered when designing for people with PD. For this, we studied life with PD, the implications of PD for design, and experiences with the STOP application.

In Article I, we present the qualitative data analysis from the one-month trial of the first release of STOP. The objectives of this study were to gain an understanding of PD's impact on daily life and smartphone use, collect the user experiences from the PD patients using STOP daily, and validate the data collection via the STOP application. Thirteen participants with PD from Finland and the UK were recruited for the study. The participants were obliged to use the STOP application in their daily life for one month and to join three interviews by phone or in person:

- **Initial interview:** to understand the daily life challenges of PD, and mobile device use.
- **Half-way:** STOP use feedback.
- **Debriefing:** STOP's impact on medication adherence and possible benefits of the application use.

4.1.1 Life with PD

The interviews provided an insight into daily life with PD, and how the STOP application fitted in with routines. An Affinity Diagram (Holtzblatt & Beyer, 2016) was applied in the analysis of the interviews, highlighting the concerns, experiences and strategies the participants followed.

The participants described various effects of PD on their lives. Overall, PD's motor symptoms affected most of our participants' daily lives, hampering many activities.



Fig. 9. Working with the Affinity Diagram. The interview responses were printed, using a different colour for each participant. The themes identified in the responses were written on post-it notes, and grouped according to topic.

Autonomic dysfunction, sleep disturbances, and pain also affected daily routines. The participants described how they had to plan their day and tasks to be able to cope with them. Medication and the dietary regimen dominated the day, along with the various symptoms.

Medication adherence is considered to increase the effectiveness of a medication-based treatment (Grosset et al., 2009). However, we learned that adherence was not a simple issue in PD. The participants described how they sometimes had to consciously deviate from the medication regime to ensure they were in their best condition for demanding activities like going to physiotherapy. Similar behaviour was reported by Nunes and Fitzpatrick (2018). The medication schedule was not always strict timewise. The timing of medication might be tied to e.g. mealtimes. Half of our participants used “booster medication”, an additional medication taken when needed.

Our participants described firm medication routines. People used different methods for remembering to take medication, such as smartphone reminders or a family member taking care of their medication. However, for most participants, the main reason for remembering the medication was their symptoms getting worse. It is difficult to forget to take medicines with PD, because symptoms intensify if medication intake is delayed, and the body really needs the medication. Some said they were impatient when waiting for the next medication intake. One participant pointed out that a good phase in PD might make adherence worse, because the symptoms did not force strict adherence. Although medication logging may improve medication adherence (Dayer et al., 2013; van Berge Henegouwen et al., 1999), only two of our participants felt their adherence improved during the study.

4.1.2 Implications for design due to PD

All the participants used STOP regularly and reported no significant problems in using it. The participants described how PD affected their smartphone use in general and the usability of STOP. All the participants used smartphones daily for various tasks. In addition to phone calls and SMSs, they took photos and browsed the internet, etc. As expected, PD symptoms make using a mobile device harder. Even holding the device can be difficult. The most prevalent challenge is typing, i.e. PD symptoms (primarily tremors and rigidity) cause typing and touch errors. Some described how they compensated for the issues provoked by the symptoms – for example, by using voice instead of touch or using the speaker to avoid holding the phone. Some reported that they preferred a computer for typing, and according to our results in Article IV, the internet was an important source of PD-related information. To ensure our applications’

accessibility, we applied PD-specific design guidelines (Nunes et al., 2016; Vega et al., 2018) and design guidelines for older adults (Consortium, 2021a, 2021b; Nurgalieva et al., 2019, 2021; Siek et al., 2011; W3C, 2010).

4.1.3 User experiences of STOP

In the final interview, the majority of our participants did not feel they benefited from using STOP. The joy of success in the game was mentioned as a main benefit of the app. All the participants had suffered from PD for years, and they had established routines for taking care of medication: some used alarm clocks, others had otherwise firm daily routines, so they did not feel a need for an app to assist with medical adherence. Some said that multi-comorbidity complicated the daily symptom assessment. It was sometimes difficult to distinguish what challenges were caused by PD symptoms. The game score did not reflect their perceived symptom level. They also said they did not need a tool to measure their symptom level, because they knew their body well enough, e.g. they knew when booster medicines were needed. The majority of our participants did not notice a significant difference when they compared their game scores before and after medication. However, some participants noticed a difference in their game scores according to the time of the day and their condition: stress, tiredness and agitation were experienced as decreasing the scores; concentration increased them. The game score calculation is based on the ball's deviation from the centre of the circle; it does not consider any other sensor data. Clearly, the algorithm for calculating the score is currently too simple to detect a slight variation in motor symptoms like a tremor.

The STOP trial participants indicated their willingness to use digital tools such as STOP to track the status of symptoms and medication intake. All the participants felt comfortable with sharing the collected data with medical personnel, and data sharing would motivate the use of tools like STOP even if the application itself was not useful in managing PD.

In the interviews, the participants suggested improvements. In the self-evaluation, they wanted to log much more data than we had allowed. Some wanted to add tags to the game results to indicate which symptoms they had or the context. One participant mentioned their dietary regime and wanted to include a food diary in the app. The symptom level query was presented once per day. Few participants felt they wanted to evaluate the symptoms more often due to symptom fluctuation. However, in the long run, the burden of tracking should be balanced with the benefit of use.

From the researchers' perspective, although the average age of our participants was 67, and PD caused an extra challenge in both cognitive and motor abilities, the

installation (even remotely) and use of the STOP was successful, though not without challenges. Many participants doubted they would be able to perform the tasks required by the study, as they felt they were not experienced in using smartphones. One of the participants did not know his Google password, and he could not download the app from Play Store. We sent him the installation file (apk-file) via an SMS. A technical challenge was the various smartphone models and software versions the users had. One participant had a Doro phone, a phone specially designed for the elderly. It had automatic zooming of the screen, meaning the ball game did not fit the screen. We created a special version of the app for this user. There were also some deviations in the accelerometer sampling capabilities, which led to some participants being excluded from the analysis and had implications for the signal processing in Article III. Some participants were unfamiliar with the notification functionality. They either did not know the term notification or were unfamiliar with the option of entering the application via the notification.

In summary, smartphones are an integral part of our participants' daily life, and hence we believe they can be suitable platform for a self-care tool. PD symptoms may hinder also the interaction with the smartphone in versatile ways. Our participants can and would use digital tools, such as STOP, for tracking their condition if they were able to share the data with medical personnel.

4.2 Monitoring Parkinson's disease motor symptoms with a smartphone

RQ2 investigated the suitability of mobile technology for monitoring PD in daily life. We explored ways to quantify motor symptoms "in the wild" with a smartphone.

4.2.1 Quantifying hand tremor severity and medication effectiveness

Article III focuses on tremor and medication effect detection from the accelerometer signal collected during the STOP real-world trial (see Chapter 4.1). During the study, each participants played the ball game at least four times per day, and the motion data were captured during the game sessions. The data set contains a total of 2,213 game sessions (mean 138 [SD 60.6] sessions per participant) and 1,856 medication logs (mean 107 [SD 54.9] logs per participant) recorded by participants. We categorised the participants into four groups according to the self-reported symptoms:

- Participants with no tremors, denoted as the "no tremor" group
- Participants with tremors, location unspecified, denoted as the "tremor" group

- Participants with a hand tremor, who didn't play with the affected hand, denoted as the “hand tremor” group
- Participants with a hand tremor, who played with the affected hand, denoted as the “plays with a hand tremor” group.

The participants used their own devices in the study, and the sampling rate of the smartphones varied between devices, as well as between one participant's game sessions. To obtain uniformly sampled data, we applied linear interpolation to the accelerometer signal.

PD symptoms have specific frequency bands: dyskinesia, 1–3 Hz; rest tremor, 3–6 Hz; postural tremor, 6–9 Hz; and kinetic tremor, 9–12 Hz. To characterise the accelerometer data from the game sessions, periodograms were generated using Welch's method (Welch, 1967), and the following features were calculated in a time-frequency domain:

- **area under the curve (AUC)**: expresses the total power of the signal in G^2/Hz (Barrantes et al., 2017);
- **peak value (PV)**: the maximum value of PSD;
- **fundamental frequency F0**: the frequency of maximum power (Barrantes et al., 2017; Bazgir et al., 2018; Pierleoni et al., 2019, 2014);
- **central frequency F50**: the frequency at which the periodogram is divided into two equal parts in PSD (Barrantes et al., 2017; Bazgir et al., 2018; Pierleoni et al., 2019, 2014);
- **frequency dispersion SF50** : represents the width of the frequency band around F50 containing 68 % of the total power of the signal (Bazgir et al., 2018; Pierleoni et al., 2019, 2014);
- **IF50 - F0**: the difference between F50 and F0 (Bazgir et al., 2018; Pierleoni et al., 2019, 2014);
- **Tremor Intensity Parameter (TIP)**: describes tremor severity, calculated as PV divided by SF50.

The first five features are inspired by previous research by Pierleoni et al. (2019, 2014), Bazgir et al. (2018), Barrantes et al. (2017), and we introduce the Tremor Intensity Parameter in Article III. Figure 10 illustrates the PV, F0, F50, IF50-F0, SF50 and TIP via an example.

To evaluate the validity of STOP in the tremor assessment of PD “in the wild”, we first investigated if we could detect the tremor in the accelerometer signal captured during a ball game. We compared the user groups pairwise in terms of the calculated features. The “no tremor” group had significant differences with “plays with a hand

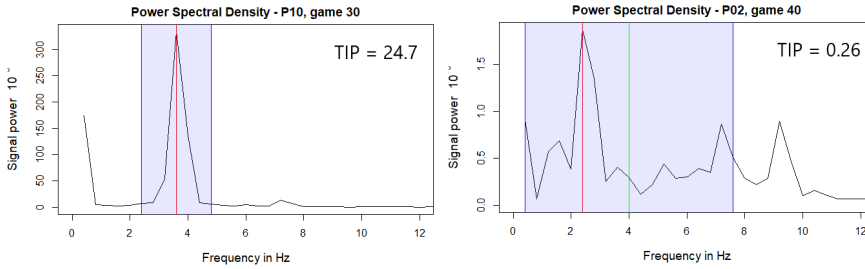


Fig. 10. The Power Spectral Density of a single game of P10 (playing with a hand tremor) and P02 (no tremor). The red vertical line represent the fundamental frequency F_0 , the green line represents the central frequency F_{50} , and the gap between the lines is $|F_{50}-F_0|$. For P10, F_0 and F_{50} are the same frequency (lines overlapping in the figure), which leads to $|F_{50}-F_0|=0$. The frequency dispersion SF_{50} is denoted with blue. P10 has a high PV and narrow SF_{50} , generating a high TIP of 24.7. The signal power of PSD is generally low for P02, and the PV is also low and SF_{50} is wide. Hence, there is a low TIP of 0.27. Note: the y-axis range differs. Reprinted with permission from Article III under the terms of Creative Commons Attribution 4.0 licence, 2019.

tremor” in all features. In a comparison of the “no tremor” with the “tremor” and “hand tremor” groups, all the features differed significantly, except for frequency dispersion SF_{50} . This parameter describes how wide the power of the signal has spread around the central frequency. When the tremor was in a body part other than the hand holding the smartphone, the power of the signal was spread in a wider frequency range and could not be differentiated from the “no tremor” case. The “plays with a hand tremor” group differed significantly from the “tremor” and “hand tremor” groups, except for fundamental frequency F_0 and central frequency F_{50} . The tremor effect was similar frequency-wise in all tremor groups, but when the tremor hand was used to play, the magnitude of the tremors differed. Specifically, we proposed TIP to characterise the had tremor from the accelerometer signal, and we found a significant difference in TIP between participants with and without tremor symptoms, as well as between participants playing with the tremor hand and those with a tremor in the non-playing hand or in other body parts. Finally, the Tremor Intensity Parameter was significantly correlated with the self-reported UPDRS II tremor score in this dataset.

We also studied if the effect of PD medication could be seen in the accelerometer signal. With the medication intake logs in the medication journal, the game sessions were labelled as “before” and “after” medication. Each participant’s “before” and “after” game sessions were compared in terms of the features listed above. Statistically significant differences were found for three participants suffering rigidity and bradykinesia, i.e. the medication effect was visible in the accelerometer signal of these participants. This is

aligned with previous research: the medication response of bradykinesia is known to be usually good (Burkhard, Shale, Langston, & Tetrud, 1999), and there are observations for improved rigidity after medication intake during laboratory tests in “on” and “off” medication states (Kostikis et al., 2015).

In summary, the accelerometer data collected by the off-the-shelf smartphones can be utilized in quantifying hand tremor. With the data collected in-the-wild, we replicated features from prior work done in a controlled environment. Further, we presented the TIP parameter for unobtrusive tremor assessment. A statistically significant difference between the game sessions before and after medication intake was found for participants with rigidity and bradykinesia, and concluded that detecting the effects of PD medication is possible. Further research is needed for validating both the TIP parameter, and the medication effect in the accelerometer signal.

4.2.2 Digitised drawing tasks

The STOP application was extended with drawing tasks for for quantifying diverse symptoms. The evaluation was performed in the local Parkinson’s Association meeting with 14 participants. Eight persons with PD volunteered (mean age 71.5 years) and six controls without PD (mean age 72.3 years). They all conducted three spiral drawings and three square drawings using the same device (LGE Nexus 5, Android 6.0), a total of six drawings per participant. We collected the drawing data as timestamped touch coordinates, and the final drawing screen captures. From the drawing data, we calculated the following metrics:

1. **Drawing speed and total time:** speed in pixels/ms, calculated as an average for each game and a point-wise speed during a drawing task
2. **Drawing accuracy (error):** the deviation of the drawing from the template, calculated in pixels for each user drawn dot
3. **Crossing rate (as percentage):** the number of occurrences when the drawing line crosses the template line, divided by the total number of drawn dots.
4. **Radial and angular velocity (only for spiral):** Radial velocity describes how much the radius of the spiral increases in pixels/millisecond and the angular velocity how much the spiral angle changes in radians/millisecond
5. **Drawing sampling rate and gaps:** PD may cause finger jumping on the screen, causing deviations in the touch screen sampling and gaps in the drawing.

The analysis shows that the group with PD had a longer drawing time and slower drawing speed. The average drawing time is 66% longer in the spiral and 39% longer

in the square. The average drawing speed (pixels/ms) is 20% lower in the spiral and 7% lower in the square. In the spiral drawing, the average radial velocity (pixels/ms) is 17% lower and the average angular velocity (radians/ms) is 25% lower. However, these differences, are not statistically significant (Wilcoxon rank-sum test). Due to smartphone's smaller screen size than a tablet, the drawing space is smaller in a smartphone, resulting in a shorter task, which may explain why the difference was not significant with this sample size.

There was a statistically significant difference between the groups with and without PD in the drawing accuracy in average and maximum error. On average, the control group was 32% more accurate in spiral drawings and 24% in square drawings. In spiral drawing, the average crossing rate of the group without PD was higher, and the average error was lower. This means the spirals of the control group were more compliant with the template. In the square drawing, the average crossing rate of the group with PD was higher, as was the average error. The control group therefore drew closer to the template with straighter lines.

In addition, the design implications of our study included improving the instructions and error calculation. Some participants corrected their drawings, e.g. drew another line closer to the template. According to our observations during the evaluation, a tremor might cause "finger jumping" on the screen, leading to a drawing concluded in parts. To avoid corrections to the drawing in future, we will instruct the user to conduct drawing without lifting a finger. If there are gaps in the drawing due to a tremor or other symptoms, the gaps in the drawing should increase the error score accordingly.

In summary, as the drawing performance of people with PD differs from age-matching controls, we see the potential of drawing tasks in quantifying PD symptoms. Again, using off-the-shelf smartphones would allow frequent assessment, and data from different kind of tasks would allow informed decisions on both daily self-care, and in long run on treatment.

After the studies with the STOP application on the scope of self-care monitoring, we set out to design for self-care maintenance, i.e. to focus on daily PD self-care practices and techniques.

4.3 PD CareBox: an online repository of community-contributed self-care techniques

RQ3 set out to explore a solution for collecting and sharing the self-care knowledge gained from the experience of living with PD. In contributing to **RQ3**, Article IV introduces an online repository of crowd-contributed self-care techniques for PD. The

empirical data collection was carried out in two study phases. In the first phase, the self-care techniques were collected and assessed. In the second phase, the people with PD used the online repository PDCareBox to find suitable self-care techniques, and evaluated the tool.

4.3.1 *Collecting the PD self-care techniques*

An online UI was built to collect the self-care techniques from people with PD and their carers (see Chapter 3.4.1). The UI allowed the user to submit their own techniques and assess the techniques submitted by others. The data collection started in January 2021, and remains ongoing. We took a snapshot of the data for Article IV in May 2021. At that point, 320 persons had shared their knowledge; 288 of them had been diagnosed with PD, and 31 were caretakers of a person with PD.

The snapshot contained 115 individual self-care techniques and 3,876 individual ratings. To obtain an overview of the techniques, we divided them into nine (partly overlapping) categories (number of techniques in the category in brackets): “Physical activity and exercise” (52); “Wellbeing” (30); “Equipment, aids and reorganising” (27); “Leisure and hobbies” (26); “Medication and treatment” (14); “Diet and nutrition” (10); “Social interaction” (7); “Knowledge” (6); and “Monitoring” (2). The technique was allowed in multiple categories, as e.g. “Walking with hiking sticks” matches both the “Physical activity and exercise” and the “Equipment, aids and reorganising” categories. From the number of techniques in each category, we can identify the most common areas of self-care, highlighting the mundane nature of PD self-care and the daily life context.

During the assessments, the participants were able to describe what symptoms the technique was good for with an open-ended field. We refer to these descriptions as reflections. In these reflections, the participants often described an emotional impact of the technique, while the technique itself was typically an actionable instruction. For example, removing rugs from the floor may increase the feeling of independence. These reflections contained the same themes as the PD coping strategies (Haahr et al., 2021) or self-management categories (Tuijt et al., 2020). Hence we can see the self-care techniques as actionable steps towards coping.

4.3.2 *Discovering the PD self-care techniques*

In the study’s second phase, we built the PDCareBox tool for discovering the submitted self-care techniques using the same criteria as in the assessments (see Chapter 3.4.1).

The tool was published in May 2021, and we invited the users to fill in the questionnaire about their experiences with the PDCareBox with some demographic details. Of 120 people who tried the tool, 23 persons decided to join the study and respond to the questionnaire by the time Article IV was written.

In the questionnaire, we asked how the users typically searched for self-care related information. We asked which information sources they utilised, and whether they specified the topic in the search or browsing in general. We discovered that the internet, especially the PD organisations' websites, was an important source of self-care-related information for the people with PD. A third said they searched for information on a specific topic, and 13% said they generally browsed for the self-care related-information in general. Our participants view of the differences between professional- and peer-provided data was aligned with the previous research (Hartzler & Pratt, 2011). The search strategy with the PDCareBox differs from a typical internet search, in which you specify what you are looking for, as well as from information exchange among peers in peer meetings, as in PDCareBox, you specify the criteria for the peer-provided information.

The users completed 1–6 search rounds, specifying 1–4 criteria for each search round. The users completed an average of 2.2 searches, with 3.1 specified criteria per search. The most popular search combinations were to use all four criteria or to specify only one of them; a majority of the searches (64.4%) utilised all four criteria, and a fifth of the searches used only one criterion. Effectiveness was the most often used criterion. It was used in more than 90% of searches. The other three criteria were specified in about three quarters of the search rounds each. The users also evaluated the usefulness of the criteria on a five-point scale in the questionnaire, and the perceived usefulness was aligned with the search statistics. The most useful criterion was effectiveness, and the order of the others followed the search statistics; the second most useful was affordability, the third sociality, and the fourth familiarity.

The users evaluated the features of the self-care techniques provided by the PDCareBox using a Likert scale. The majority perceived the techniques as understandable (91%), useful (87%), safe (78%), novel (78%), actionable (78%) and reliable (74%). We also asked if the users would make use of the PDCareBox in self-care maintenance, self-care monitoring, or self-care management. The majority (74%) would use the PDCareBox for maintenance, 26% for monitoring, and 39% for self-care management. Multiple selections were allowed, and 17% also stated they would not use the PDCareBox for any of these functions.

In summary, PD impacts severely on one's daily life. Through the experience on living with PD, one learns how to manage daily activities with the symptoms. This

actionable and practical know how on daily life context, i.e. ‘patient knowledge’, supplements information provided by clinicians. The PDCareBox is a public, continuously growing database of structured self-care techniques provided and assessed by people living with PD. The source code of the PDCareBox is freely available to future development and research in this domain.

5 Discussion

The motor symptoms of PD were first identified and described by James Parkinson more than 200 years ago (Parkinson, 2002). There have been since major advances in treatment and in understanding the causes and pathophysiology of the disease. Yet there is still no cure for PD, and the burden of PD is predicted to increase with an aging population (Del Rey et al., 2018). Technology is expected to open new ways to improve diagnosis accuracy, provide a means for monitoring and quantifying symptoms and medication response, and enable personalized medication (Del Rey et al., 2018; Klucken, Krüger, Schmidt, & Bloem, 2018). Furthermore, beyond these clinical objectives, technology also offers opportunities also to support patients' daily self-care. This thesis set out to build technology for this purpose, and to investigate it in the light of the Middle-Range Theory of Self-Care of Chronic Illness (Riegel et al., 2012).

5.1 Fulfilling the objectives

The first objective of this thesis was to create novel applications for supporting PD self-care, i.e. supporting daily life with PD. For this objective, we created the STOP smartphone application for symptom-level assessments and medication adherence tracking, and we set up an open online database, PDCareBox, for discovering crowd-contributed self-care techniques. To ensure accessibility in these applications, we followed the design guidelines for people with PD (Nunes et al., 2016; Vega et al., 2018) and for older adults (Consortium, 2021a, 2021b; Nurgalieva et al., 2019, 2021; Siek et al., 2011; W3C, 2010).

The second objective of this thesis was to investigate the created applications via the Middle-Range Theory of Self-Care of Chronic Illness, i.e. through three aspects of the self-care process: maintenance; monitoring; and management. Figure 11 presents how these applications contribute to the self-care elements. Self-care maintenance covers daily health-promoting practices and treatment adherence. Medication intake time tracking supports medication adherence, and the PDCareBox provides actionable information in the form of self-care techniques. The STOP application also provides daily symptom survey and symptom assessment tasks that support self-care monitoring. Self-care management is decision making related to the disease, reacting to signs and symptoms. The data collected by STOP can support reflection. The PDCareBox provides information for behaviour change, e.g. information about diets supporting wellbeing or ways of dealing with symptoms.

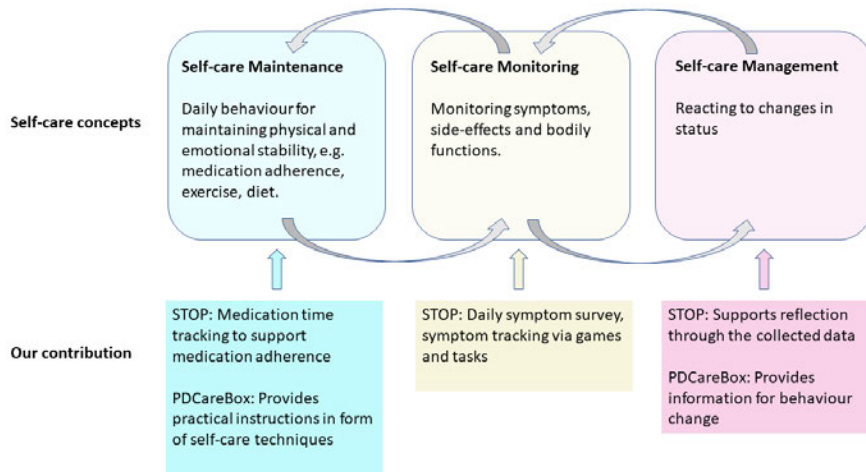


Fig. 11. The key concepts of the self-care of a chronic condition according to the Middle-Range Theory of Self-Care of Chronic Illness are self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2012). The figure illustrates how our work contributes to these self-care elements.

Next, we discuss the research questions.

5.2 Revisiting the research questions

5.2.1 *RQ1: Which aspects of PD and self-care should be considered when designing for people with PD?*

This RQ was answered by Article I, which analysed the qualitative data collected via the interviews during the STOP trial (Study 1, Chapter 4.1). First, when designing the STOP application, we applied the design guidelines for people with PD and for the elderly. The participants described their daily life with PD in the interviews. We discovered that the disease's impact on daily activities varied greatly, depending on the patient's symptom combination. Motor symptoms and autonomic dysfunction may hinder coping in daily activities and limit mobility and independence. Non-motor symptoms and the progressing disease may affect one's mental state. Symptoms such as speech problems affect communication with others. The self-care of PD consists of daily mundane actions, and the medication regimen often dominates daily life. The participants stated that living with PD required planning and re-planning when adapting to the current

status. We therefore need to design flexible applications that match the different needs and symptoms of the users and allow timely variation in use.

Our participants also described how their symptoms affected mobile device use. The motor symptoms caused typing mistakes and touch errors. The participants found ways to compensate for this, such as using voice commands, keeping the device on the table when using it, or using a stylus, as tremors diminish when holding something in the hand. In conclusion, when designing for people with PD, different interaction problems should be considered by providing alternative input options.

5.2.2 RQ2: Can we use mobile technology to monitor PD in daily life?

Previous research has shown that the sensor data collected via a smartphone in lab conditions can be used in quantifying PD motor symptoms. In answering this RQ, Articles II and III showed that quantifying symptoms using the sensor data collected in real life via a smartphone was feasible. In Article I, we discovered that people with Parkinson's were able and willing to use smartphone-based tools for monitoring PD, and the data could be collected "in the wild". The ability to communicate the results with a doctor and utilising the collected data in treatment decisions motivate the use of such tools.

5.2.3 RQ3: How can we best collect and share self-care knowledge gained from the experience of living with PD?

This RQ was answered in Article IV, which presented how an internet-based, public, community-powered crowdsourcing tool could efficiently collect and share self-care knowledge among people living with PD. The data were in structured form, enabling the future processing of the data. According to our participants, the peer-originated information differed from professionals' information, the context of the patient knowledge was often in daily life, and the information was practical and in actionable form, whereas the professionals provided more theoretical information about the medical context. This is aligned with the previous research (Hartzler & Pratt, 2011).

We discovered that the community-contributed self-care techniques were perceived as understandable, actionable, and safe. We concluded, that the community-contributed data could be utilised to produce understandable information, and as Riggare, Höglund, et al. (2019) and Hartzler and Pratt (2011) also suggest, to complement the clinical health information. The correctness of the experience-based information can be obtained

via crowd consensus (Lederman, Fan, Smith, & Chang, 2014), which is facilitated via the assessment of the techniques in our tool.

5.3 Challenges and future research

Self-care technologies are understudied in the domain of Human-Computer Interaction. Critically, a review by Nunes et al. (Nunes et al., 2015) points out that the HCI research on the development of self-care technologies often lacks a definition of what “self-care” is within the work. In nursing, the same concern is voiced by Jaarsma et al. (Jaarsma et al., 2021), who recommend that self-care be defined when planning self-care interventions. The motivation of HCI studies on self-care can often be seen from three perspectives: the self-care of the chronic condition is considered difficult; technology is expected to reduce costs; or the aim is to explore technology and understand the nature of self-care (Nunes et al., 2015). The HCI research on self-care technology design allows engagement with complex contexts and multiple actors, and the influence on medical research should be increased (Nunes et al., 2015). To achieve this, HCI research should take the theories and practices of medical and nursing research into better account. With this in mind, we used the Middle-Range Theory of Self-Care of Chronic Illness (Riegel et al., 2012) as a theoretical frame for understanding self-care in this thesis.

The development of digital tools for PD has three interest groups (i.e. stakeholders): the users, as the people living with PD; the medical personnel; and the researchers – all with different foci and needs. For example, data collection might target general knowledge about the PD characteristics or aim for better phenotyping of PD or to find markers for PD progression (Espay et al., 2016) instead of self-care. The mPower study series (Bot et al., 2016) and The Personalised Parkinson Project (Bloem et al., 2019) both offer open data sets for researchers to study the symptoms and identify biomarkers for the disease progression. The clinical treatment of PD focuses on motor symptoms and medication, but the patients often worry about the disease’s implications for their lives, how they manage their daily tasks, and the disease’s psychological impact (Vafeiadou, Vasalou, & Roussos, 2021). The research (in number of published papers) on the self-care of chronic conditions has increased recently (Nunes et al., 2015), but only rare solutions address all three domains of self-care: maintenance; monitoring; and management (Buck et al., 2021). We now discuss our views on the challenges future research will face.

Digital tools for treatment decisions

In our studies, people did not feel they needed the monitoring tools, and there were few self-care techniques related to monitoring. In a recent study of PD, with participants recruited from populations already participating in self-tracking research, approximately only a third of the participants tracked their symptoms (Mishra et al., 2019), and in a European study, less than half had prepared a list of symptoms for the clinic visit (Bloem & Stocchi, 2015).

It is difficult for a person with PD to identify reliable technical solutions, and it is perhaps partly because of this that commercial devices for tracking PD have not thus far been popular. For example, Parkinson's UK recommends a paper-based diary for monitoring symptoms. They have also set up an "Apps and devices library" providing a list of solutions reviewed by a company for reliability and a review group of people with PD for usefulness. They currently present six apps, of which two provide monitoring of symptoms. The Parkinson's Organisation (US) does not introduce any technology-based monitoring system on their webpages.

We hypothesise that designing for chronic disease may not be as profitable as wellbeing apps and devices. The potential target audience is smaller, frequently with an economic burden because of the condition and the expectation of a recommendation for use from healthcare professionals. The need for clinically useful information on the disease status has been identified in previous research (Espay et al., 2019; Pasluosta et al., 2015), and our study revealed patients' willingness to collect such data. The STOP trial participants said they would use the STOP application in data collection although they did not experience the benefit of its use in managing PD if the collected data were beneficial for the medical personnel and the improvement of their care. Healthcare systems are often incompatible with new solutions for measuring the condition, because the data format and data processing are not standardised (Kumar, Jeuris, Bardram, & Dragoni, 2020). Some clinicians may be open to taking the results of personal tools into account, but this is often not included in common guidelines for treatment. We believe people with PD will use the digital monitoring tools and applications more extensively if the medical personnel request and utilise monitoring data in treatment decisions.

Design for measuring PD "in the wild"

With its wide symptom range and varying symptom combinations from patient to patient, PD status is difficult to measure. The tools can often offer measurements for only some of the symptoms. Some PD symptoms are challenging to detect using smartphone

sensors, i.e. how to distinguish bradykinesia from fatigue or intentional slow moving (e.g. moving slowly due to fear of falling) (Espay et al., 2016). Sometimes PD tremors diminish during a goal-oriented voluntary movement, e.g. holding something in the hand (Bhatia et al., 2018; Camara et al., 2015; Gironell et al., 2018). Monitoring actions should be planned carefully to determine if the aim is to enable input without symptoms hindering the interaction, or to measure the symptom, e.g. a stylus can make phone use easier but decrease the symptom being measured (i.e. tremor).

Measuring sensor data in real life differs significantly from lab measurements. Different kinds of devices affect the results, e.g. the sampling rate may differ. The average useful life of a smartphone is 2–3 years until a replacement is required, but there is a wide range of smartphones in terms of operating systems and models. Our experience suggests that the elderly tend to update their devices more rarely, so software should be compatible with older systems and hardware. This means it becomes challenging with a slowly progressing disease to rely on these technologies for a long period unless the data are collected and stored outside the device. The user conducts the tasks by themselves without supervision “in the wild”. In our study, during the tremor measurement with the ball-balancing game, how the user played the game affected the task: some pressed the elbow against torso, some extended the hand so that it did not touch the body, some played while sitting, and some while standing. This makes comparison of data between users more difficult, and must also be considered in comparing a single user’s game sessions. Posture may affect tremor characteristics. A user with an extended hand user may have a postural tremor, and if the hand is rested on the lap, rest tremor frequencies may be prevalent. If the user considers the task a game, they may pursue higher scores by changing their position. Yet if the user considers the task a measurement, they may be more coherent in the task. In the final interview, we asked if the users had tried beating their own scores, and only one participant played several times in a row for good scores. In relation to this, we asked the participants if they perceived STOP as a game or measurement tool. STOP was primarily a game according to a third of users, and another third thought it was a tool. The remaining third did not know. The interpretation of the score will probably differ depending on the perception; if the user targets a high score or a record, they will measure the best performance, while other users who consider the task a tool will aim to measure the symptom level and focus on keeping the posture similar. Both approaches may work from the user’s perspective, but further research is needed on how the measured symptom is characterised in the sensor data while changing the measurement position.

Medication adherence is often seen as a cornerstone of medical treatment. In our study, we discovered that monitoring adherence in those with PD is far from

straightforward. Some participants described a medication regimen that was not based on timing but was tied to mealtimes, or in which medication was taken according to bodily sensations. The patient might decide to delay or advance medication intake for an occasion where they want to be at their best, e.g. in physiotherapy. Worsening symptoms often serve as a reminder of medication intake. Times of good adherence may be interpreted as worse times, while during a bad adherence period, symptoms may have been milder. The participants in the STOP field trial said they know their condition well. For example, they feel in their bodies when they need an extra dose of medicine. It is known that patients with a shorter time since diagnosis benefit more from tracking (Riggare, Duncan, Hvitfeldt, & Hägglund, 2019). We hypothesise that monitoring the symptoms more closely could also benefit people with a longer disease duration in situations where treatment is changed, or a new treatment is introduced, e.g. a medication change or dose optimisation.

Supporting reflection and decision making

The Middle-Range Theory of Self-Care of Chronic Illness defines the dimensions of self-care. Self-care can be unreflective or reflective, and insufficient or sufficient (Riegel et al., 2012). The ideal self-care is reflective and sufficient self-care, in which the patient has sufficient knowledge of self-care, and they conduct self-care activities with reflection. To improve self-care, digital tools should support reflection as decision making, i.e. self-care management. Health information should be understandable and actionable for the patient to be able to act on the provided information (Centers for Disease Control and Prevention, 2021). The information should also be in the right context. We showed that in collecting the self-care information from people living with PD, the patients and their carers, we could obtain information in the daily life context written in a common language and therefore perceived as understandable. In addition, as the information was collected in the form of techniques, it was short and actionable.

If we consider monitoring tools, the symptom level information of PD as such is not actionable data. For example, compared to diabetes monitoring actions, blood sugar levels have a target range, and the result may cause actions, i.e. if the blood sugar level is too low, sugar is required, or if it is too high, insulin is required. In PD, the acceptable symptom level is often context-dependent and personal, e.g. an acceptable tremor level depends on daily plans and preferences. A person staying at home watching TV may tolerate a higher tremor level, but the tremor will be medically tuned down for a person playing cards with friends. Interpretingly, PD monitoring results require more processing from the user, i.e. self-care management. Making sense of the symptoms

and affecting factors requires effort. Many factors affect the symptom level, such as time since last medication, environment, or stress. The medication impact may vary, i.e. some experience “on-off” fluctuation in which the medication effect wears off unexpectedly (Simuni & Pahwa, 2009).

Cognitive dysfunction is a common symptom of PD, and it typically affects frontal lobe function such as motivation and complex decision making (Simuni & Pahwa, 2009). This also hinders self-care management and making sense of monitoring results. To allow the user to understand their condition better, we should create new ways to support reflection and the analysis of the results. For people who have no tracking experience and may have issues with cognition, a conversational agent presenting supporting questions related to context and co-founding factors may help, e.g. “You got good results, what do you think was affected?”; “Your result was worse than yesterday – what is different compared to yesterday?”; “Yesterday you felt anxious, and you got the same result – how do you feel today?”. This is also supported by previous research, in which contextual information helps understand habits and environmental factors affecting overall health (Nunes et al., 2015).

When quantifying a degenerative condition, the results will of course show the deterioration, and this may be unpleasant to see (Mishra et al., 2019). The psychological effect of the worsening condition should be considered when designing for PD. We received feedback describing the logo of the STOP app (a shaking human figure with a walking stick) as depressing – a reminder of an inevitable future. The participant said the logo should be something that expressed hope.

5.3.1 Future work

We outline certain generic recommendations for future work in this area. First, when designing for PD self-care, tracking could be extended from quantifying symptoms to monitoring functioning in daily activities, as suggested by Deal, Flood, Myers, Devine, and Gray (2019), e.g. measuring how long it takes to get dressed, or how many times the person manages to put their shoes on independently. Daily activities may be interpreted as self-care, e.g. cleaning can be considered exercise, but they are not seen as important in the clinical sense (Nunes & Fitzpatrick, 2018). In Article IV, the participants described the emotional impact of a practical technique in the reflections, and raised themes related to self-care management and coping (Haahr et al., 2021; Tuijt et al., 2020). For example, removing rugs was a practical action to avoid falls, and the emotional impact was a feeling of independence, the maintenance of which was indeed a coping strategy (Haahr et al., 2021; Tuijt et al., 2020). If such daily activities

were monitored, the user would be able to affect the result, and this may serve as a motivation for achieving the goal. Furthermore, in combining the information about self-care techniques, e.g. if help is needed in putting shoes on, a recommendation system could suggest related self-care techniques such as using shoes without laces. Mishra et al. (2019) suggested predictive systems for symptom tracking. However, the problem with data interpretation is also valid in predictions: how can it communicate what the numbers mean in the future?

Self-care is often a joint effort of everyone living in the same household. Many people with PD may struggle to use technology due to motor limitations or cognitive deterioration. Caregivers and family members often provide help in using smartphones or computers, and community-driven tools could offer an easy way to register together. Piper, Cornejo, Hurwitz, and Unumb (2016) suggested suggested “family-accounts”. In addition to their roles in facilitating self-care, community-driven tools could also take different social roles in online behaviour into account. According to previous research, some people were comfortable with sharing information and instructing others, while some preferred to ask questions and seek information from others (Yang, Kraut, Smith, Mayfield, & Jurafsky, 2019). In this sense, self-care technologies should incorporate all who participate in self-care, whether online or offline.

5.4 Limitations

PD hampers daily life routines, and it is sometimes challenging to reach such a vulnerable group. Finding participants for a computer science study is difficult. People may doubt their technological skills with smartphones or computers. In addition, online instructions for the elderly on internet use tell them not to click any links from sources they do not know, which challenges online recruiting. It is therefore essential to have a trusted recruiting partner – in our case, PD organisations. Many are willing to contribute to science and appreciate the PD organisations’ evaluation and recommendation of important studies.

As the participants have volunteered for our studies, the sample may be biased towards those who are more interested in their condition and more open to trying new applications. In Article IV, the study was conducted online, and in Article I the participants were expected to have a smartphone with an internet connection, which means only those with the equipment and the ability to use these technologies were eligible.

Cultural aspects affect self-care, e.g. self-care is seen as important in cultures that value independence, while in some cultures, care and attention can be interpreted as a

sign of respect (Riegel et al., 2012). Self-care instructions and cultural beliefs may also differ in different countries. For example, bed rest is a common self-help for those with back pain, although light physical exercise is currently recommended. Most of our participants were located in Finland, the UK, and the US.

6 Conclusions

In this thesis, we have introduced two applications for supporting PD self-care. We developed and evaluated the STOP smartphone application for symptom assessment and medication-timely tracking. We established and assessed an online repository for PD self-care techniques. We investigated these applications via the Middle-Range Theory of Self-Care of Chronic Illness, which specifies three key concepts for self-care: maintenance; monitoring; and management.

During the studies, we have detected challenges due to the unique nature of PD compared to many other chronic conditions. As symptoms and the medication effect may vary for a patient during the day, as well as varying between patients, each patient develops unique self-care techniques. Monitoring symptoms is challenging; non-motor symptoms are difficult to measure, and motor symptoms may also be challenging to quantify. Collecting data in daily life was feasible, and the perceived usefulness of monitoring activities was connected to the use of the collected data in treatment decisions by the medical personnel. The interpretation of the monitoring results is not straightforward, because there are no actionable limits for the results. Patients do not need the tools to describe the symptom level. They know their bodies well enough but prefer to record their status to be shared with their doctor.

Actionable information is key for successful self-care. We see a potential to use crowdsourced data in the self-care domain: the collected self-care techniques were perceived as understandable and actionable practical instructions.

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Original publications

- I Kuosmanen, E., Kan, V., Vega, J., Visuri, A., Nishiyama, Y., Dey, A. K., Harper, S., & Ferreira, D. (2019). Challenges of Parkinson's disease: User Experiences with STOP. In Proceedings of the 21st International Conference on Human-Computer Interaction with Mobile Devices and Services (pp. 1-11).
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- III Kuosmanen, E., Wolling, F., Vega, J., Kan, V., Nishiyama, Y., Harper, S., van Laerhoven, K., Hosio, S. & Ferreira, D. (2020). Smartphone-Based Monitoring of Parkinson Disease: Quasi-Experimental Study to Quantify Hand Tremor Severity and Medication Effectiveness. JMIR mHealth and uHealth, 8(11), e21543.
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Original publications are not included in the electronic version of the dissertation.

818. Darabi, Hamid (2022) Machine learning techniques for urban flood risk assessment
819. Tervo, Nuutti (2022) Concepts for radiated nonlinear distortion and spatial linearization in millimeter-wave phased arrays
820. Nissilä, Tuukka (2022) Ice-templated cellulose nanofiber structures as reinforcement material in composites
821. Yu, Zitong (2022) Physiological signals measurement and spoofing detection from face video
822. Chen, Haoyu (2022) Human gesture and micro-gesture analysis : datasets, methods, and applications
823. Khan, Iqra Sadaf (2022) Exploring Industry 4.0 and its impact on sustainability and collaborative innovation
824. Peng, Wei (2022) Automatic neural network learning for human behavior understanding
825. Zhang, Ruichi (2022) Vanadium removal and recovery from liquid waste streams
826. Vääätäjä, Maria (2022) Prospects of the room temperature fabrication method for electroceramics : feasibility for printing techniques and integration with temperature-sensitive materials
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829. Leppänen, Tero (2022) From industrial side streams to the circular economy business : value chain, business ecosystem and productisation approach
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831. Kumar, Dileep (2022) Latency and reliability aware radio resource allocation for multi-antenna systems
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