Exploring Crowdsourced Self-Care Techniques: A Study on Parkinson's Disease

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Abstract

Living with Parkinson's Disease introduces a range of significant challenges into one's daily life. While medical interventions exist to overcome some of these challenges, patient self-care techniques often form an essential complement to the treatments recommended by medical doctors. Knowledge on these self-care techniques often originates from those living with Parkinson's themselves or their close caregivers, as they have the knowledge and experience required to assess self-care techniques. This so-called 'patient knowledge' is usually exchanged in peer meetings or discussion forums. Although vital to the Parkinson's Disease community, this information is often difficult to access due to its unstructured format and the difficulty of navigating through online forums. We present an online tool that allows for contributing, assessing, and finally discovering Parkinson's Disease self-care techniques. The custom discovery tool was populated with self-care knowledge by over 300 people with Parkinson's and dozens of their carers, spanning areas such as daily well-being and using assistive equipment. Then, we invited patients to explore the discover features in a smaller scale trial. While well-received, our deployment highlighted several challenges that we further discuss in this paper. Overall, our study contributes to crowdsourced digital health solutions

and provides both design and research implications to this challenging domain with a vulnerable user group.

Keywords: crowdsourcing, Parkinson's Disease, self-care, knowledge base

1. Introduction

Parkinson's disease (PD) is a chronic neurological disorder caused by progressive loss of neurons in the central nervous system (Jankovic and Tolosa, 2007). That leads to decrease in dopamine levels, which manifests as a wide variety of both motor and non-motor symptoms (Jankovic and Tolosa, 2007). Motor symptoms, such as tremors, bradykinesia, rigidity, and postural instability, impact daily activities (Jankovic, 2008). For example, moving around, eating or getting dressed may be difficult (Hariz and Forsgren, 2011). Non-motor symptoms include *e.g.* autonomic dysfunction, cognitive impairment, and depression (Weintraub et al., 2008).

Often, PD affects negatively one's quality of life (QoL). Andrejack and Mathur (2020) describe that QoL of those living with PD is influenced by three main elements. These are the availability and quality of professional health care, support from family, friends and peers, and the ability to engage in *self-care*, i.e. modifying one's lifestyle to cope with the condition as well as actively seeking to mitigate any potential symptoms through various means, typically at home (Andrejack and Mathur, 2020).

The symptoms challenge daily life, and living with these challenges issues various forms of self-care (Nunes and Fitzpatrick, 2018). Further, the effectiveness of self-care techniques is subjective and can thus vary a lot between subjects. Typical sources for self-care information are online forums, peer group discussions, or practically any information media that allow people to exchange ideas and experiences (Attard and Coulson, 2012; Preece, 1999). To this end, the best experts on self-care are people living with a given condition: the patients and their direct personal caregivers and family members. These individuals possess valuable 'patient expertise', practices, and methods that outline how to best manage the condition. However, the information as collected in current online sources is often presented in an unorganized structure (*e.g.*, a forum post among a long list of topics), and may not always be easy to find (Hosio et al., 2018).

To support PD patients in sharing and identifying self-care techniques, we set out to collect knowledge related to PD self-care and create a repository

for PD self-care techniques. Our study does not aim to provide or substitute clinical interventions or under any condition to replace guidance given by medical doctors and other clinicians. Instead, we seek to offer users the ability to share knowledge among peers and discover actionable information related to PD self-care. Specifically in this paper, we document and evaluate a crowd-powered repository of self-care techniques. In the first phase, we deployed a public online website which enabled individuals to propose and assess self-care techniques. In the subsequent second phase, we built and evaluated an online self-care technique repository, named PDCareBox, the content of which was based on the previously collected data. Through extensive collaboration with a broad range of PD organisations, we collected data from over 300 people with Parkinson's and their caregivers and explored the potential of such an online tool to serve the PD community through crowdsourced contributions from its own members.

Our contributions are;

- An evaluation of a crowdsourced solution for PD self-care techniques, based solely on contributions from PD patients and caregivers;
- Design implications for similar crowdsourced self-care tools based on our preliminary evaluation;
- An open, accessible, online community-contributed repository PDCare-Box to contribute and identify PD self-care techniques;
- We release PDCareBox as a public service online as well as open source its code to support future work in the digital health domain.

We show that crowd-contributed self-care strategies for Parkinson's Disease are actionable and understandable, and that they can contribute a useful resource for others living with PD. We highlight the potential and the challenges of the developed tool and discuss in detail our experiences as well and barriers encountered when attempting to reach this vulnerable and globally distributed community. Put together, our study contributes to crowd-powered digital health solutions and provides a public self-care technique repository based on data from one of the largest academic crowdsourcing studies among the PD population.

2. Related work

2.1. Self-care of a chronic condition

Self-care is defined *e.g.* by the UK Department of Health 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 improving self-care is seen as important in supporting people with chronic conditions (Department of Health, 2006). The Middle-Range Theory of Self-Care of Chronic Illness (Riegel et al., 2012) defines self-care as "*a process of maintaining health through health-promoting practices and managing illness*". The theory divides self-care into self-care maintenance, self-care monitoring, and self-care management. Self-care maintenance targets maintaining physical and emotional stability with the chronic illness, including actions such as lifestyle changes and adherence to the treatment, *e.g.* medication adherence (Riegel et al., 2012). Self-care monitoring focuses on recognizing changes to a condition, with monitoring body functions, feelings, and symptoms (Riegel et al., 2012). Self-care management is reacting to these results, determining if actions are needed. For example, the patient may decide whether to take extra medication when their symptoms worsen (Riegel et al., 2012).

In the case of chronic diseases, the outcome of self-care is maintaining the quality of life and the perceived control of the disease (Riegel et al., 2012). It may also reduce mortality, hospitalisation, and healthcare costs (Iovino et al., 2020). Self-care is often a collaborative endeavour between patients and carers (Nunes and Fitzpatrick, 2015), and for example, in the case of PD, most of the patients have an informal, dedicated caregiver (Schrag et al., 2006). Caregiver participation facilitates self-care (Iovino et al., 2020), and family members may often have different roles in self-care (Pina et al., 2017).

Each chronic condition has unique self-care techniques. Nunes and Fitzpatrick (2018) identified four main types of self-care activities in PD, namely: taking medication, exercise, adapting lifestyle, and accepting the disease's consequences. Medication plays a crucial role in managing daily life for many people with PD. Participants had different strategies for maintaining their medication schedule, such as using alarms or using the placement of the medication as a reminder. Exercising was seen as another important aspect of self-care, enhancing movement control and wellbeing. Adapting lifestyle refers to adjustments due to a worsening condition, either permanently (*e.g.*, lose

driver's license) or temporarily (*e.g.*, cancel a visit to a friend) due to daily symptom fluctuation related to varying medication response or environmental factors. Accepting the consequences of PD can be considered as a coping strategy. The condition is degenerative, hence the consequences are inevitable, and many motor symptoms change one's appearance (Jankovic, 2008). Nunes and Fitzpatrick further highlight that PD self-care activities take considerable work and are integrated into daily life. For example, for some people, hoovering can be considered as exercise to maintain their physical capabilities, and hence considered as self-care. This highlights the daily life context related to self-care activities.

Miertová et al. (2014) interviewed and observed two persons with PD and their families, to identify the PD self-care activities through Activities of Daily Living scale. They identified problems and the corresponding solutions used, *e.g.* use of a drinking straw to avoid spilling liquids. By focusing on the experiences of only two persons, a large number of different self-care techniques were found. In addition, the authors found that for a numerous issues the solution was the help of relatives. The high number of identified practical solutions highlight the potential of collecting self-care techniques through the experiences of the people living with PD (both patients and their caregivers). National Parkinson Foundation has also shared practical aids for Activities of daily living (Cianci et al., 2006).

Finally, Tuijt et al. (2020) identified seven themes related to the self-management of PD, which are: medication management, physical exercise, self-monitoring techniques, psychological strategies, maintaining independence, encouraging social engagement, and providing knowledge and information. A meta-synthesis by Haahr et al. (2021) identified 18 categories related to coping with PD, and they were divided into three main themes: staying independent, focusing on the present, and avoiding unpredictable challenges.

2.2. The Internet as a self-care information source for PD

While healthcare professionals provide reliable and valuable information with regards to medical and clinical treatment, information to support everyday self-care activities is often sought after from other sources. According to a European survey, 64% of people with PD searched for information on the treatment and management options from PD organizations and 62% via the internet, although specific content is often missing – with more than 40% highlighting a lack of information on fatigue, diet, and pain management (Bloem and Stocchi, 2015). However, the information provided through these sources

can vary wildly in terms of content and trustworthiness. Generally speaking, the trustworthiness of online portals that provide health-related data increases via the size of the community, and through self-correcting and improvement of content (Bloem and Stocchi, 2015). It is notable, however, that more than half of PD patients consider the various online information sources as very helpful in dealing with their medical situation (Stocchi and Bloem, 2013).

In a study relevant to our paper, Riggare et al. (2019) studied knowledge acquisition among PD patients in Sweden. Of the 346 persons with PD who responded to the online survey, 36% indicated to find disease-specific knowledge by themselves through the internet, 29% received information via patient organisations, 25% from healthcare professionals, and 5% from other patients. A total of 91% of surveyed patients felt that obtaining knowledge about PD is important for them, although just over half (55%) of respondents expressed that they had been able to obtain the information they require. A recent study among 190 PD patients by Marxreiter et al. (2020) found out that approximately 75% of the respondents use the internet for accessing disease-related information in Germany.

Fox and Brenner (2012) studied internet use by caregivers of chronic conditions, they found that 79% of caregivers have access to the internet and that the large majority of them (88%) search for health-related information on the internet. Caregivers are furthermore more likely to use both in-person and online social relationships for acquiring health-related information than age matched non-caregivers (Fox and Brenner, 2012).

These prior works highlight the value of online approaches in providing people living with PD with practical information on coping with PD on a daily basis. In this paper, we build on existing knowledge within the PD community to provide a structured way to discover relevant self-care techniques.

2.3. Peer-provided health data in online communities

A variety of eHealth solutions have been designed for exploring peer-generated content in different contexts, *e.g.* weight loss (Hosio et al., 2020), different chronic illness (Berkanish et al., 2022; Hossain et al., 2021), mental health (Fortuna et al., 2020) and hospital admission (Haldar et al., 2020). Online communities have emerged which help patients to increase their understanding of their treatment through sharing insights (Johnson and Ambrose, 2006). In such support groups, patients often share and find operationalisations of coping mechanisms, including instructions and routines, to better manage their condition (Huh and Ackerman, 2012). Charlton

and Barrow (2002) studied self-help groups for PD patients and found that participation in such a support group may help both in accepting the disease as well as in finding ways to better cope with it. Other work shows that participation in an online PD support group can improve patient quality of life (Lieberman et al., 2005, 2006). Online forums may serve as an important source of disease-specific information in areas where medical personnel might have limited knowledge or experience with the condition (Zhou et al., 2014).

Hartzler and Pratt (2011) studied how patients' expertise differs from clinicians' expertise. Patient expertise is defined by personal experiential knowledge as obtained through daily management of one's personal condition, whereas the source of clinician expertise is education and practical experiment. Hartzler and Pratt (2011) identify that patient expertise focuses on daily coping strategies and offers actionable advice, whereas the clinical expertise is more knowledge-oriented and prescriptive, focusing on medical topics. Hence, patients can offer important information that substantially differs from knowledge typically provided by clinicians, with a particular focus on personal issues experienced in the daily life context (Hartzler and Pratt, 2011). Prior work has shown how patient knowledge can be collected via ethnographic studies and by collecting techniques of daily practices (Pols, 2014; Attard and Coulson, 2012).

As the online communities are often driven by patients rather than medical professionals, the accuracy of the information has sometimes been raised as a concern. To overcome this potential issue, Attard and Coulson (2012) proposed that health care professionals could ensure the accuracy of the information in online support groups. However, Visser et al. (2016) pointed out that there exist norms for behaviour in communities in which both professionals and patients co-exist that would hinder the openness of such a system. Visser et al. (2016) argue that patients would not want to ask too many questions, and also that the type of questions asked would change. Further, users would not want to complain too much or make knowledge claims about their own disease in their contributions.

Lederman et al. (2014) studied how users evaluate the credibility of information in online health forums. They stated that three types of information can be found from these forums, experiential (experiences with a condition), scientific (*e.g.*, research-based information about the condition, treatment), and non-medical factual information (*e.g.*, insurance policy regarding the condition). They further focused on users' credibility evaluation on the experiential and scientific information. They identified five criteria for

the credibility assessment; reference credibility (credibility of cited external sources), argument quality (logical soundness based on common sense), verification (confirming from several sources), contributor's literacy competence (the way that a message is written), and crowd consensus (group opinion regarding the validity of an experiential statement). The used criteria depend on information type; argument quality, verification, and contributor's literacy competence are used in forming an assessment of both experiential and scientific information. In addition, in validation of scientific information, reference credibility matters, and in validation of experiential information the crowd consensus matters.

Despite the benefits of these patient-driven message boards, some challenges also arise. Information can easily get lost in threads, especially if the volume of posts is large (Hartzler and Pratt, 2011). Another issue is the aforementioned correctness of the information, with prior work highlighting that the trustworthiness in online portals increases by the size of the community through self-correction (Bloem and Stocchi, 2015). Further, new users need to build a relationship with other forum members in order to get familiar with other users' characteristics and their expertise level, a process that might be time-consuming (Mamykina et al., 2015). In the tool presented in this paper, we allow users to discover self-care techniques via pre-defined criteria, thereby allowing both recent and older contributions to the surface based on their relevance to the user's query.

2.4. Crowdsourcing in healthcare

Crowdsourcing has been utilized in a range of healthcare-related applications, including diagnosis, surveillance, nutrition, and education (Wazny, 2018; Créquit et al., 2018; Prpic, 2017). In a review on the use of crowdsourcing in health and medicine, Ranard et al. (2014) classify crowdsourcing tasks into four groups according to the type of task: problem-solving, data processing, surveillance/monitoring, and surveying.

In our work, we focus specifically on manual crowd contributions, in which individuals contribute knowledge of their illnesses to support others. Hosio et al. (2016) contributed an online decision support tool, named AnswerBot, for this specific goal. AnswerBot enables the collection and assessment of solutions for a variety of problems and has been successfully utilised for the identification of suitable treatments for lower back pain (Hosio et al., 2018) as well as weight loss methods (Hosio et al., 2020). Lower back pain and weight loss as a health issue have similarities, as there is no 'golden solution' that

works for all. Similarly, coping with PD is also a process in which patients need to find self-care techniques that work appropriately for them (Nunes and Fitzpatrick, 2018).

Crowdsourced healthcare solutions also extend beyond the academic realm. Two popular platforms in this area are PatientsLikeMe[1] and StuffThatWorks[2], in which users can explore information statistics on several conditions based on community-contributed data. Through aggregate data, PatientsLikeMe allows users to find other patients with similar conditions or treatments, and subsequently to share their experiences (Brubaker et al., 2010). Users of the website experienced an increase in their knowledge of their symptoms, a better understanding of treatment side effects, and experienced the peer support as beneficial (Wicks et al., 2010). The StuffThatWorks forum[2]ollects data about the treatments and symptoms of different conditions, intending to utilise machine learning to identify the most effective treatments. The website's data is currently not available for the general public and is shown only to registered users with a diagnosed condition in their profiles.

In this paper, we also focus on the collection of crowdsourced data. In contrast to the discussed prior works, which focus on treatment and symptoms, our solution aims to offer actionable information for people with PD and their caregivers in a daily life context through self-care techniques. Using this approach, we hope to reduce the required effort for the user in identifying what actionable steps they can take as based on information that is typically presented to users in other sources.

3. Overview of the study

This study was conducted in two consecutive phases. In the first phase, the self-care data was collected and assessed. In the second phase, the participants discovered these self-care techniques through the established tool. The whole study was carried out in English, and due to that the recruitment activities focused mainly on English-speaking countries. The study procedures follow the guidance of our university and the Finnish National Advisory Board on Research Ethics, according to which a formal ethical review for this study (both phases) is not required (National Advisory Board on Research Ethics,

[1] patientlikeme.com
[2] stuffthatworks.health
[2] c

2019). In practice, this is due to the study not being classified as invasive and has no real medical intervention, focusing on information discovery. Next, Sections 4 and 5 describe the study's phases in detail, covering the apparatuses, recruitment, participants and the results. Lastly, we discuss the findings of both phases in Section 6.

4. Phase 1: Self-care data collection

4.1. Apparatus

We built an online tool for collecting and assessing PD self-care techniques from the global PD community. The technical solution is based on AnswerBot, a flexible decision support tool that has been deployed across a number of problem domains (Hosio et al., 2016). The tool was implemented using HTML, JavaScript, PHP, and MySQL. Participants were directed to a website in which the study was introduced and, after consent was received, provided us with their demographic details as well as their connection to PD (patient, caregiver). Following this, participants were asked to share their daily self-care techniques and practices, and to assess the techniques submitted by others based on the pre-set criteria, namely: *sociality*, *affordability*, *effectiveness*, and *familiarity*. These four criteria were selected as a result of a workshop among

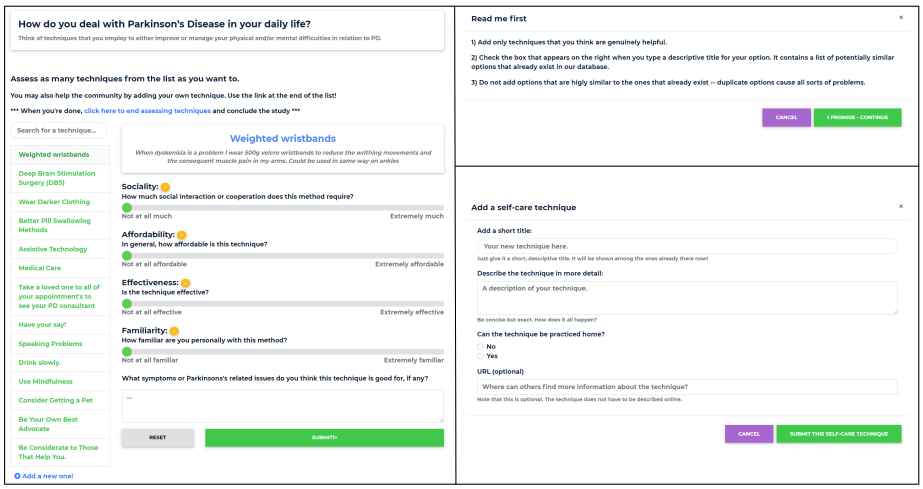

Figure 1: On the left, the interface for assessing a self-care technique. When submitting, the text in the top-right box is shown to the user, and the technique is submitted with the form on the bottom-right box.

the research team, as based on the disease's impact on life and informed by prior work on crowdsourcing treatments for low back pain (Hosio et al., 2018). PD may cause stigma (Nunes and Fitzpatrick, 2015) and bring discomfort in social circumstances (Hariz and Forsgren, 2011), as such the level of 'sociality' required by the technique is relevant. PD, similarly to other chronic illnesses, causes financial costs for the patient, *e.g.* medication, assistive equipment or rehabilitation (Wong et al., 2014). As such, financial resources might be strained — pointing to the importance of a solution's affordability. When considering patient treatments or self-care solutions, effectiveness is of obvious importance. Finally, as PD patients are often presented with a range of techniques throughout their life, familiarity was added as a final criterion.

Fig. 1 shows the specific look and feel of the user interface (UI) as well as the detailed descriptions of these criteria. The UI displays the list of submitted techniques sorted in descending order with the techniques with the least accumulated ratings on top of the list. Participant assessment was collected via a slider input (0-100), and the user may choose to assess 1-4 of the criteria. The use of such sliders for assessing arbitrary options has been shown as highly intuitive and easy to use in other contexts (Hosio et al., 2016). Further, we followed the suggestions by (Matejka et al., 2016) in the slider implementation: The value in is shown in real-time when moving the slider handle, and there are no tick marks on the axis. In addition, the participant was asked which symptom or PD-related issue the technique is suitable for through an open-ended text field. The interfaces for the collection and subsequent assessment of self-care techniques are shown in Fig. 1. When submitting a technique, participants provided a title and description, indicated whether the technique could be practiced at home, and provided an optional hyperlink to provide additional details. The participants were allowed to submit as many techniques as they wanted. In order to bootstrap the system and to avoid the cold-start problem, we manually inserted five self-care techniques that we obtained from Parkinson's UK and Parkinson's Foundation web site before offering the tool to the general public.

4.2. Recruitment

We invited both people with PD and their personal caregivers to join the study. There was no reward for participating, but the participants were offered a chance to join a raffle of five Amazon gift cards ($100). In order to recruit participants, we engaged in extensive contact with several organisations and foundations related to PD, supplemented with Facebook groups and bloggers.

Table 1: Participant details. Note, in the case of caregivers the disease-specific data refers to the person for which they act as caregiver. The categories for education level are primary education, secondary education, vocational degree, bachelor's degree, master's degree, PhD, or above. The categories for work status are work full time, work part-time, unemployed, and retired.

Metrics	**PD Patients**	**Caregivers**
Number of participants	288	31
Mean age (range min-max)	67.3 (38-86)	65.7 (44-86)
Mean years since PD diagnosis	5.7	9
Mean years since onset of symptoms	8.8	11
Women/Men/Non-binary/ Prefer not to disclose	57%/43%/0%/0%	74%/26%/0%/0%
Education: Prim./Sec./ Voc./Bac./Mas./PhD	1%/27%/21%/27%/18%/6%	0%/19%/35%/23%/16%/6%
Work status: Full time/ part time/unemp./retired	8%/9%/6%/77%	23%/13%/16%/48%

The European Parkinson's Disease Association forwarded our message to their member organisations and to their online forum. Parkinson's UK added our study to their online 'Take Part in Research' section and sent the message to their 'Take Part Hub'. The Davis Phinney Foundation shared the invitation in their email list and Parkinson Society British Columbia added our study to the Research Volunteer Recruitment page. ParkinsonsDisease.net added a post to their Facebook group. Parkinson Association of the Rockies, Parkinson Society Newfoundland and Labrador, the Cure Parkinson's Trust, Parkinson Wellness Project, and The Finnish Parkinson Association agreed to share the information with their members. We created a profile for advertising the study on Parkinson's Resource Organization's platform. Additionally, we added a post to Parkinson's UK discussion forum on their 'Research Opportunities' page and shared our post through several social media accounts.

4.3. Participant profiles

The data collection started in January 2021 and is ongoing. For the analyses of the collected data as presented in this paper (Phase 1), we took a snapshot of the database at the end of May 2021, when Phase 2 started. A total of 320 participants had submitted and/or assessed one or more self-care techniques through the website (see Fig. 1), along with the background

Table 2: The frequency of reported symptoms (as percentage). The three largest frequencies are shown in bold.

Symptom	PD %	Caregivers %
Motor symptoms		
Bradykinesia (*i.e.* slowness of movements, decrease of amplitude or speed in consecutive movements)	**69.8**	64.5
Tremor	**61.8**	58.1
Rigidity (stiff or inflexible muscles)	58.7	45.2
Postural and gait impairment	59.7	**80.6**
Mood and cognition related symptoms		
Anxiety, panic attacks	31.9	35.5
Mood disorders, *e.g.* apathy or depression	35.8	54.8
Hallucinations, illusions, delusions	9.0	32.3
Cognitive impairment	20.1	54.8
Dementia	1.0	9.7
Autonomic dysfunction and sensory symptoms		
Orthostatic hypotension (drop in blood pressure when getting up)	18.4	12.9
Constipation	49.3	**71.0**
Urinary dysfunction (urgency, retention)	48.3	58.1
Sexual issues	18.4	25.8
Sweating problems	16.0	22.6
Skin problems	17.7	16.1
Problems in eating, swallowing and control of saliva	29.5	38.7
Sleep disorders (*e.g.* insomnia, REM behavior disorder, daytime sleepiness, restless legs) and/or fatigue	**63.9**	**80.6**
Sensory dysfunction (*e.g.* loss of sense smell, loss of visual contrast or color discrimination, abnormal sensations)	39.2	41.9
Pain	43.4	41.9

demographics questionnaire. The majority of our participants were from the UK and USA, with 11 countries of origin reported. Of this sample, 288 participants were diagnosed with PD, and 31 acted as a caregiver of someone with PD. We provide an overview of participant demographics in Table 1.

In the questionnaire, we asked the participants to select their symptoms from a list based on (Massano and Bhatia, 2012). Table 2 presents the distribution of participants' self-reported symptoms. The most common symptoms reported by people with PD were bradykinesia, sleep-related issues, and tremors. On average, the participants with PD reported 6.9 symptoms per participant. The three most common symptoms reported by the caregivers

Table 3: The stages of the Modified Hoehn & Yarn scale, used to describe the progression of PD (Goetz et al., 2004), and the distribution in our sample. Note, in the case of caregivers the disease-specific data refers to the person for which they act as caregiver.

Stage	**Description**	**PD %**	**Caregivers %**
Stage 0	No signs of disease.	1.7	0
Stage 1	Symptoms on one side only (unilateral).	26.4	9.7
Stage 1.5	Symptoms unilateral and also involving the neck and spine.	10.1	6.5
Stage 2	Symptoms on both sides (bilateral) but no impairment of balance.	14.9	0
Stage 2.5	Mild bilateral symptoms with recovery when the 'pull' test is given (the doctor stands behind the person and asks them to maintain their balance when pulled backward).	14.2	19.4
Stage 3	Balance impairment. Mild to moderate disease. Physically independent.	28.8	38.7
Stage 4	Severe disability, but still able to walk or stand unassisted.	3.5	19.4
Stage 5	Needing a wheelchair or bedridden unless assisted.	0.3	6.5

Table 4: Distribution of impact of PD on daily life as based on the Parkinson's Disease Activities of Daily Living Scale (PADLS) (Hobson et al., 2001). The PADLS is used in assessing how PD affects to patient's day-to-day activities (*e.g.* housework, shopping, dressing, eating) in the last month. Note, in the case of caregivers the disease-specific data refers to the person for which they act as caregiver.

Level	**PD %**	**Caregivers %**
No difficulties	16.0	3.2
Mild difficulties	62.2	32.3
Moderate difficulties	18.4	51.6
High levels of difficulties	2.4	9.7
Extreme difficulties	1.0	3.2

in our sample were postural and gait-related issues, sleep-related issues, and constipation. On average, the caregivers reported 8.5 symptoms per participant. Of note is that our participant sample included all symptoms listed in the survey.

Furthermore, participants self-assessed their PD status (or the PD status of the person for which they act as caregiver) using the Modified Hoehn & Yarn scale (Goetz et al., 2004), see Table 3, as well as the impact of PD on their daily life with Parkinson's Disease Activities of Daily Living Scale

(PADLS) (Hobson et al., 2001), see Table 4.

4.4. Descriptive statistics of submitted techniques and assessments

We first sought to understand both our participant sample and their submitted techniques through descriptive statistics. Our participants submitted in total 115 individual self-care techniques. 24% of all participants submitted one or more techniques, 93.5% of them had PD and 6.5% were caregivers. 64.9% of all submitters were women and 35.1% men. The participants with PD submitted 87.8% of the techniques, and the caregivers the remaining 18.2%.

Table 5: The techniques with the highest assessment scores per criteria, the mean score of assessments in brackets (range 0-100). Excluded the techniques assessed by three or fewer participants.

Criteria	**Rated by PD (mean)**	**Rated by Caregivers (mean)**
Sociality	'Mind over matter, just get on with life. Live for the day.' (78.7)	'Take a loved one to all of your appointments to see your PD consultant' (73.7)
	'Be Considerate to Those That Help You.' (76.4)	'Participate in local PD Group' (62.5)
	'Table tennis' (72.4)	'Go out daily to stay active' (38.0)
Affordability	'Home exercises because of gym closures due to the pandemic' (97.8)	'Take a loved one to all of your appointment's to see your PD consultant' (96.9)
	'Better Pill Swallowing Methods (96.7)'	'Go out daily to stay active' (90.3)
	'Running/jogging' (95.4)	'Put the stiffer arm to a sleeve first' (84.8)
Familiarity	'Running/jogging' (99.9)	'Convert bath to shower stall' (100.0)
	'Convert bath to shower stall' (95.4)	'Take a loved one to all your appointments to see your PD consultant' (98.6)
	'Dance for Parkinson's' (93.4)	'Daily stretches' (94.7)
Effectiveness	'Remove rugs and carpets' (87.4)	'Take a loved one to all of your appointment's to see your PD consultant' (97.3)
	'Laughter' (85.6)	'Convert bath to shower stall' (90.0)
	'Dancing' (85.4)	'Daily stretches' (83.7)

The total number of times a technique was assessed using one or more criteria was 1052, and the total number of individual ratings was 3876. A large majority of 75.7% of participants with PD, and 80.6% of caregivers assessed one or more techniques (using one or more criteria). On average, participants with PD rated 3.3 techniques per person and caregivers 3.1 techniques per person.

Table 5 shows the best-rated techniques per each criterion. From the caregiver's point of view, taking a loved one to doctor's appointments is social, affordable, familiar, and effective. The top-3 of each criterion according to the participants with PD, is more versatile.

During the assessment, participants had the possibility to describe what symptoms or PD-related issues they believe the technique is good for through the use of an open-ended field. We will refer to this input as a participant reflection. 1121 individual reflections were submitted, an average of 9.7 reflections per technique. 69.8% of participants with PD submitted a reflection for one or more techniques, as compared to 61.3% of the carers. 38% of the participants providing reflections were men, and 62% were women.

4.5. Qualitative analysis of the techniques

4.5.1. Categorisation of the techniques

Next, we set out to categorise the submitted PD self-care techniques in order to obtain a better understanding of participant contributions. Our analysis is based on the reflective thematic analysis framework by Braun and Clarke (2012). First, two of the authors familiarized themselves with all provided techniques and coded the data. Subsequently, they formed nine categories with descriptions (see Table 6) by combining codes, and assigning the techniques to the categories. The techniques were subsequently assigned into these categories independently by two additional authors. Some of the techniques matched to multiple categories, *e.g.* 'Walking with hiking sticks' matches both with the 'Physical activity and exercise' and the 'Equipment, aids and re-organizing' categories. All authors identified what they believed to be the most suitable category for the technique, and if agreement could not be reached in a subsequent discussion, we allowed techniques to be categorised into multiple categories.

The biggest category was 'Physical activity and exercise'. Physical exercise may positively impact PD patients' daily activities, as it maintains physical abilities and alleviates both motor and non-motor symptoms (Lauzé et al., 2016; Murray et al., 2014; Cusso et al., 2016), the versatile impact of exercise

Table 6: Categorisation of the submitted self-care techniques and their respective frequency.

Category	**Description**	**Count**
Physical activity and exercise	Techniques related to keeping physically active and in good fit.	52
Well-being	Techniques aiming to improve mental and/or physical well-being, *e.g.* relaxation and symptom management, or how to stay positive when living with PD.	30
Equipment, aids and re-organizing	Techniques related to using equipment or mental models to manage activities, or to re-organize surroundings.	27
Leisure and hobbies	Techniques giving inspiration for keeping busy in free-time, having hobbies and interesting activities.	26
Medication and treatment	Techniques related to medication and treatment, and facing medical personnel.	14
Diet and nutrition	Techniques related to diet and nutrition	10
Social interaction	Techniques related to social situations.	7
Knowledge	Techniques related to knowledge and information about PD.	6
Monitoring	Techniques focusing on monitoring of health, disease status and symptom status.	2

was clearly presented in the provided reflections. The exercise was described to alleviate many motor symptoms, such as rigidity and pain, and improve balance, but also to improve mental health and alleviate stress or anxiety. Stress may worsen both the motor and non-motor symptoms (van der Heide et al., 2021), and the second biggest category, 'Well-being', offered means for relaxation and symptom management, as well as for keeping a positive mindset. Having interesting hobbies helps in keeping the mind off the disease, and often provides socializing with others. The 'Social interaction' category provides techniques for handling social situations.

Diet has also an important role in PD self-care, which is reflected in the number of 'Diet and nutrition' category techniques. In addition to symptoms related to autonomic dysfunction, some PD medication might have diarrhoea or constipation as a side-effect (Gage et al., 2011), and some medication regimens suggest low protein intake (Barichella et al., 2009).

'Medication and treatment' related techniques highlighted the importance of finding suitable treatment options and encouraging patients to be involved in treatment decisions. 'Equipment, aids and re-organizing' category provided practical tips for managing with the symptoms.

4.5.2. The content of reflections

In the reflections, which were analysed through an inductive coding process, the participants often described which symptoms the technique tackles. For example, 'going out daily' was described as mitigating stiffness and pain and improving balance, whereas 'walking with hiking sticks' was said to help with the freezing of gait, tremor, stiffness, and anxiety. It is sometimes difficult to distinguish if a proposed technique tackles a specific symptom of PD, or is more for general well-being. For example, one participant described that listening to music alleviates depression, whereas another participant highlighted how it can lift one's mood.

Although the techniques themselves might be practical, the open-ended answers also described the emotional impact in addition to the practical outcome. For example, for an instruction to remove rugs and carpets to make moving around the home easier, a participant described her feelings: "*My husband was opposed to this at first. This caused me to feel very stressed. Nevertheless, I removed the rugs and that has helped me feel empowered and safe. It is sensible for people our age (68 and 70) to think of making the home safer whether they have PD or not.*"

Independence was mentioned as a positive outcome in many descriptions. Emotional independence relates to the feeling of control over the disease. For the technique 'Be Your Own Best Advocate' participants described it as good for "*maintaining independence, spreading the load of support*", and "*helps me to feel I have some control over the disease and I can make choices. I think I can describe daily functioning with accuracy.*" Information about the disease and seeking out the best treatment furthermore increases trust in maintaining one's independence: "*A good knowledge of what's available and potentially useful in individual cases can help prolong the opportunity to be independent.*" Being able to manage independently without help on different activities was mentioned in connection with many 'Equipment, aids and re-organizing'-category techniques, such as the technique 'Convert bath to shower stall', but the physical exercise was also experienced as important to maintain motor abilities and hence preserve independence.

On the other hand, being able to rely on help from a carer was also highlighted as a positive thing. Taking the carer to doctor's appointments brought comfort and security: "*Confidence. Two views on your situation can provide a much wider picture of your day-to-day situation and therefore assist your clinician to better understand what help is needed. Feeling supported*

and not alone with something that has a big impact on your day-to-day life.[...]"Social relations and social interaction were in general experienced as important for keeping a good mood and feeling connected with friends and community, and described in reflections: "*Can benefit motor symptoms and is a great benefit to feeling positive and connected with friends and the community*"

Being able to 'get a break' or forget Parkinson's was also mentioned in many of the reflections. It was described to be important for both the people with PD and the carers. Hobbies might make you forget your disease, a table tennis player described it helps in "*Balance and hand/eye co-ordination, aerobic exercise helps general fitness. Social interaction with other players who are not, mainly, PD sufferers, helps feeling of normality and benefits my mental health.*" A carer described choir singing: "*Gives me a break from living with a PD sufferer and the constant caring and emotional turmoil.*" One participant pointed out that he actively tries to discuss also other things than his PD: "*[...] I also try to drive the conversation to their health so that it is not just me and my Parkinson's.*" Even though many feel participation in a local PD group as a good place for social interaction, some might experience it as overwhelming: "*Have been part of an active group that offered social, physical exercise and vocal help. Problem was that a very few people end up running activities for others who consider themselves unable to volunteer. It became overwhelming. As personal difficulties increase with disease progression I as carer do not want to listen to moans of others! I care for my husband but want any free time and energy to be as far away from Parkinson's as possible.*"

4.6. Participant engagement

The high level of engagement we received from participants in this study was a positive surprise to us. Several participants contacted us with various questions and suggestions. For example, one of the participants had inputted wrong dosing to a recommendation of using a food supplement, and she asked us how to correct the inputted technique – something that is not currently supported in the user-facing side of the application. Another participant wanted to verify whether their contribution was stored following a page refresh. Another technical challenge was faced by a participant receiving a security warning from the antivirus application in their computer, wondering whether the page was secure. At this time our tool did not force a redirect from 'http' to 'https', something we have since changed. Finally, one participant reached out to state that he is willing to participate in the study, but he does not

have any self-care practices in mind apart from medication. We suggested he join the study without providing new self-care techniques, as providing new data here is not mandatory - instead, he was able to browse and assess the items submitted by others.

5. Phase 2: Discovering self-care techniques using PDCareBox

In the second phase of the study, our goal was to have the community, i.e. people with PD and their caregivers, discover techniques among the knowledgebase built as a result of the first phase.

5.1. Apparatus

The users were directed through various recruitment means, much like in the first phase, to the final implementation of PDCareBox at PDCareBox.com. The page contains a short introduction and instructions on how to use the tool on top, and below that the search interface (see Fig. 2). The user specifies the desired level for 1–4 criteria, and clicks 'Discover best matches'. Operating the search interface brings up the results interface (see Fig. 3). Each result contains a 'Show what this is good for'-section which includes possible reflections obtained from participants during the assessment phase (see Fig. 3, E). The reflections are accompanied by the participant's age and years with Parkinson's Disease to emphasize the fact that these are reflections left by other people with Parkinson's or their caregivers. A new search can be started by resetting the sliders, or by simply changing the position of sliders and pressing 'Discover best matches'. After using the tool for a while (four search rounds), a pop-up reminder about the questionnaire is shown. The link to the questionnaire is also available in the PDCareBox. When entering the questionnaire, the study was first introduced and the consent was confirmed. After that, the questionnaire queried the following topics:

- Background demographics: are they diagnosed with PD, caregiver or someone else, gender, year of birth, years since diagnosis, and PD status using the Parkinson's Disease Activities of Daily Living Scale (PADLS) (Hobson et al., 2001)

- Self-care information: *e.g.* what are their typical information sources, do they search information on a specific topic or in general, how does the information from different sources (peer/professional) differ

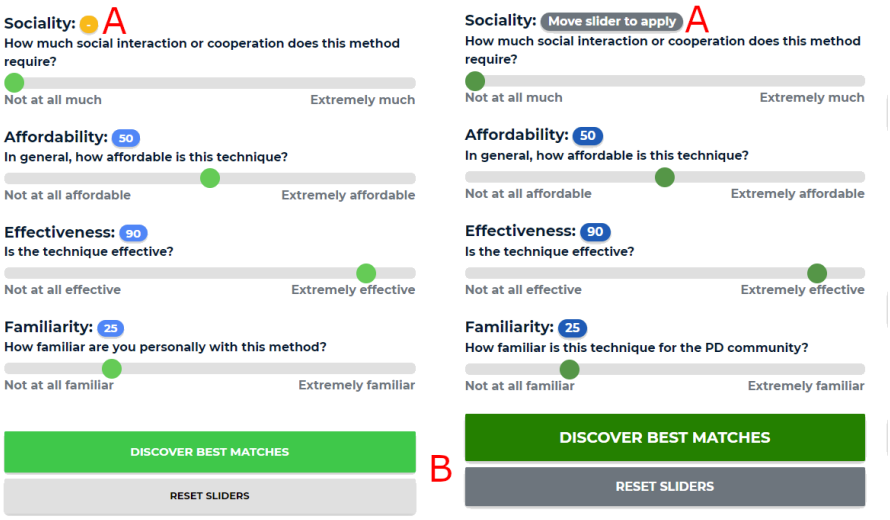

Figure 2: Accessibility improvements to user interface (UI) of the PDCareBox – original (left) compared to updated (right). The updates include A) criteria slider note, and B) increasing the contrast ratio of UI elements and text.

- Evaluation of PDCareBox:*e.g.* benefits, downsides, the usability of the search criteria, improvement ideas

For the second phase, we enhanced the accessibility of the self-care technique discovery interface used in earlier AnswerBot studies (Hosio et al., 2016, 2018, 2020) by following design guidelines for older adults (Consortium, 2021b,a; Nurgalieva et al., 2019, 2021), and also design guidelines for people with Parkinson's (Nunes et al., 2016).

PD may cause visual disabilities (Nunes et al., 2016), and these hindrances may worsen as people age. To ensure that the text is readable, the text line height of the interface was increased from baseline 1.2 to 1.5 (see Fig. 3, A), as suggested in (Consortium, 2021b; Nurgalieva et al., 2021). We increased the text font size to be 16pt at a minimum across the interface. To ensure that each of the shown techniques is distinguishable from each other, a thematic break was added in between them (see Fig. 3, D).

A high contrast between background elements and foreground text is also needed to support users for with slight visual impairments (Nunes et al., 2016; Nurgalieva et al., 2021). The colors of the criteria slider items and buttons were updated to having a contrast ratio of 4.5:1 (see Fig. 2, B), following

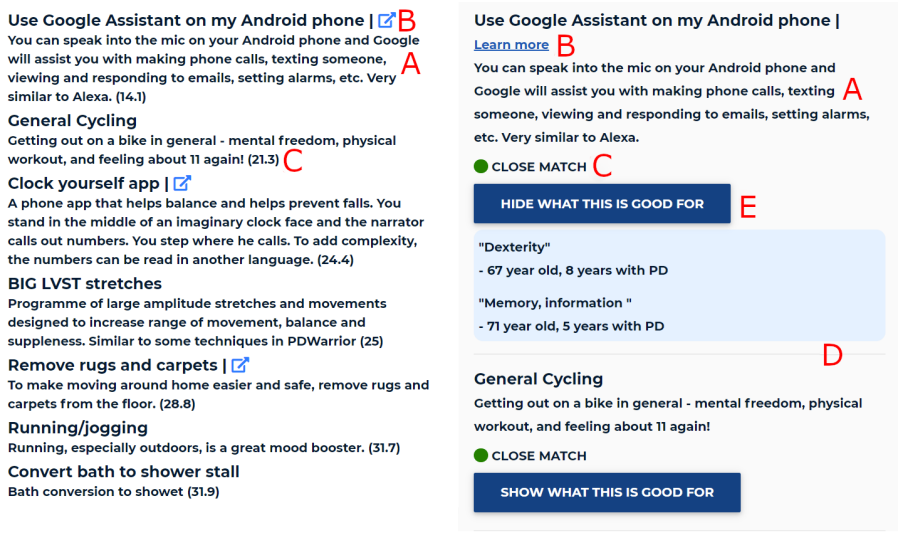

Figure 3: Accessibility improvements to user interface (UI) of the PDCareBox – original (left) compared to updated (right). The updates include A) increasing text line-height from 1.2 to 1.5, B) text in place of icons, C) more understandable goodness-of-fit visual indicator, D) a thematic break, and E) 'Show what this is good for'-section that contains reflections from the users who rated the particular self-care technique.

(Consortium, 2021b; Nurgalieva et al., 2021).

Standard icons might be unfamiliar to elder users, therefore it is advisable to reinforce these icons with words (Nurgalieva et al., 2021). We replaced an icon for the user-provided URL with the text 'Learn more' (see Fig. 3, B). This text link is blue and underscored to make it distinguishable from regular text. As short-term memory loss is commonly accentuated with PD (Nunes et al., 2016), we made non-visited and visited links distinguishable from each other by changing the color of the visited links (Nurgalieva et al., 2021).

The baseline interface showcased the goodness-of-fit of the search as the numerical euclidean distance (0-100) between the search and the participant ratings. To be more informative, we used a more visual indicator (see Fig. 3, C) of a traffic light (red, yellow, or green) and accompanying text (poor, moderate, or close). The interface element next to the criteria name shows the numerical value of the slider position. To highlight the functionality of sliders, we replaced '-' indicating inactive slider with a label 'Move slider to apply' (see Fig. 2, A).

5.2. Recruitment

After completing the first phase of the study, the participants had an option to leave their emails to get invitations to the second phase. We utilized this email list in recruiting for the second phase. In addition, we re-contacted those PD organizations that had participated in recruitment in the data collection phase.

The European Parkinson's Disease Association added our study in a monthly news roundup of surveys and research opportunities. We created a post into the Parkinson's UK discussion forum to section Research opportunities. The Finnish Parkinson Association added the announcement to their web page's news section. Parkinson's Society of Newfoundland and Labrador shared the announcement for their members. A video introducing the study and the tool interface was presented in a Parkinson's Resource Organization's support group meeting. We shared the link to the PDCareBox in ParkinsonsDisease.net Facebook page.

5.3. Participant profiles

Thus far, more than 120 people have tried discovering self-care ideas with PDCareBox. 23 persons of those who tried PDCareBox, replied to the provided questionnaire and hence participated in our study. See the overview of participant demographics in Table 7.

5.4. Self-care information

We asked the participants how they typically search for information about self-care, *e.g.* what information sources they rely on, and do they search for information on a specific topic, or browse for new ideas in general.

Table 7: Participant details. Note, in case of caregivers the disease specific data refers to the person for which they act as caregiver. PADLS refers to the Parkinson's Disease Activities of Daily Living Scale (Hobson et al., 2001)

Metrics	**Value**
Number of participants	23
Mean age (range min-max)	66 (43-80)
Mean years since PD diagnosis	5.2 (1-13)
Women/Men/Non-binary/Prefer not to disclosure	56.5%/43.5%/0%/0%
PADLS: None/Mild/Moderate/High/Extreme	21.7%/69.6%/8.7%/0%/0%

Parkinson's organisations' websites were the most popular self-care information source, 39% of the participants mentioned the organisations in general or specified which organisation's websites they use. 26% mentioned internet or internet search, including YouTube. One participant specified that when searching information on the internet, you have to evaluate the trustfulness of the information source. 22% said that they rely on information provided by peers. Also, articles, news, and research related to PD were mentioned as information sources by 17% of the participants. 34% told they search for information on a specific topic, 13% said they usually browse in general. One participant mentioned the continuous need for new information due to the disease progression: "*I search for specific answers to specific topics. As my Parkinson's progresses I have new issues to find coping strategies for!*"

We asked how the information provided by peers differs from the information provided by professionals. The participants described information provided by professionals to be research-based, more theoretical, and focused on drugs: "*The information from peers usually is easy to accept and take on board because of their own experiences and empathy. . . .professionals are more matter of fact, instructive, impersonal.*"

The information provided by peers was experienced as practical, and to be relevant in everyday context: "*It has more insight into everyday problems that the professionals don't even think about.*"

Peers also understand your situation, as they have experience of living with the condition: "*It is often more specific; you have to have the condition in order to really understand what works/doesn't work; it shows that not all techniques suit all people; it shows that people with Parkinson's are positively engaged in finding a cure or the easement of symptoms and are willing to share their experiences with others.*"

However, few participants brought up the reliability of the peer data. These participants stressed that the observed information might be biased, or even dangerous: "*I don't always trust peer advice, it can range from useful to dangerous.*"

5.5. Experiences with PDCareBox

5.5.1. Search statistics

Participants completed between 1–6 searches, with an average of 2.2 searches per participant. Participants could specify the level for 1–4 criteria for each search. On average, participants used 3.1 criteria per search. All four criteria were utilized in the majority of the searches (64.4%), and in

22.2% of the searches only one criterion was specified. Three criteria were used in 11.1% of the searches and two criteria only in 2.2% of the searches. Effectiveness was considered the most important criterion in our study sample, as it was used in 91.1% of searches. Affordability was used in 77.8%, sociality in 75.6%, and community familiarity in 73.3% of the searches. Figure 4 shows the spread of values of each criterion used in searches.

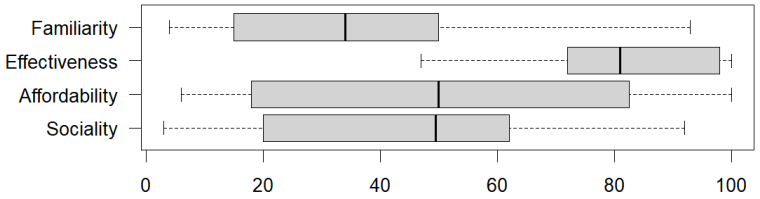

Figure 4: The spread of values participants used in configuring their search criteria.

5.5.2. Adoption of the new search approach

34.7% of the participants described PDCareBox positively, for example, using words interesting, helpful, useful, or novel. A slightly smaller share, 30.4% gave negative feedback. They experienced the tool as not useful, confusing, or bewildering. The same amount of participants (30.4%) gave a neutral response (*e.g.* do not know or do not have an opinion).

Participants described how identifying a suitable self-care technique with PDCareBox differs from their typical approach. Compared to informal information exchange in *e.g.* a peer meeting, information search with our tool starts with setting the criteria "*I was starting from a set of criteria rather than just hearing spontaneous suggestions from others* ". On the other hand, many participants compared the tool to an internet search: "*I have always searched for specific topics before*". The new search approach using four criteria was adapted well by some users: "*It is a new way to choose what might be interesting. Makes it easier to narrow the research*", and "*Interesting. At first wasn't sure what to do, but soon got the idea. Useful to hear about other people's experiences and match them with my own.*". Users described the PDCareBox as quick, patient-specific, and accessible. One user specified that the sliders help in choosing the suitable technique, while another user experienced the sliders as subjective, not knowing *e.g.* what in practice highly affordable would mean. As a downside, a participant pointed out that finding something specific using the criteria would take a while to locate. As

a practical design implication, three participants suggested enhancing the search by filtering the search results by categories: "*I would find it useful to have a kind of index of subjects that I could click on, then go to the 4 criteria. Eg: Diet, Muscle stiffness, Swallowing etc*"". Few participants felt that better instructions would make understanding the tool easier.

5.5.3. The search criteria

The participants also evaluated the usefulness of each criterion on a five-point scale ('Not at all useful' to 'Extremely useful'), see Fig. 5. This is aligned with the actual search statistics. As stated before, effectiveness was used in 91.1%, affordability in 77.8%, sociality in 75.6%, and community familiarity in 73.3% of the searches.

In addition, we asked if they would like to add some criteria. We got a suggestion of frequency of participation, degree of side effects, the level of required training of the technique, degree of difficulty, and alignment with science. In addition to no responses, a participant specifically stated more criteria would not benefit: "*No, the more you have the more complicated it gets*".

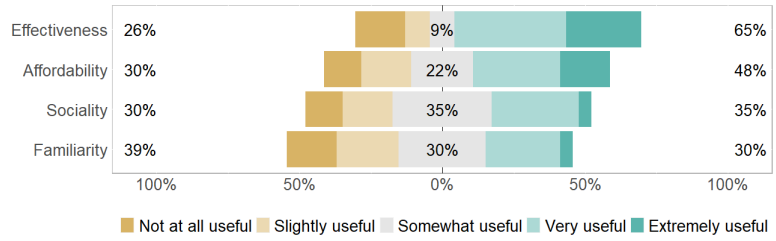

Figure 5: The perceived usefulness of each search criteria.

5.5.4. Evaluation of the search results

Participants evaluated the self-care techniques provided by PDCareBox on different attributes on a four-point scale from 'Strongly disagree' to 'Strongly agree', see Fig. 6. The results highlight the positive aspects of the data. We asked with an open-ended field how well the search result matched the required level of criteria. 65% responded positively, 22% gave a negative answer and 13% said they did not know.

One participant described he would be more comfortable if PDCareBox would offer data provided by professionals. However, the variable content with

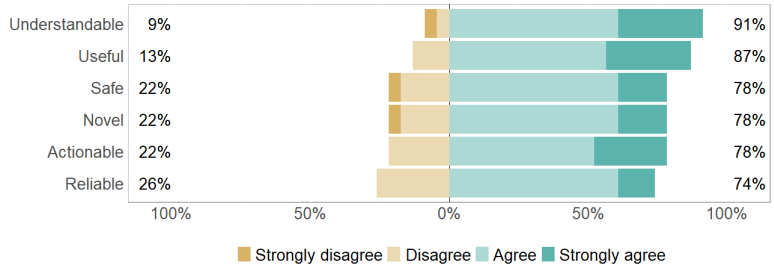

Figure 6: The evaluation of features of the self-care techniques provided by the PDCareBox.

shared experiences was seen also as a benefit: "*Wide variety of information provided, easy to understand/ read, comments valuable may discover and learn about new techniques,etc*" and "*There may be a wide range of options shown than would usually be suggested. For example, Reiki*". The experience of the disease itself is subjective, and even though the tool would give the techniques matching to the criteria, the user has to evaluate the suitability of the proposed techniques personally: "*Parkinsons is highly Individual. Must judge whether suggestion can be effective for me.*" The idea of more data providing better search results was understood: "*By continuously adding peoples experience will enrich the data and lead to more options and accurate searches.*"

5.5.5. Use of PDCareBox for different self-care functions

According to the Middle-Range Theory of Self-Care of Chronic Illness (Riegel et al., 2012) self-care can be divided into three sections, self-care maintenance, self-care monitoring, and/or self-care management. Referring to this, we asked which of these self-care areas the participants would make use of PDCareBox: 1) Maintaining physical and emotional state, 2) Monitoring and detecting changes in the physical and emotional state, including symptoms, 3) Making conclusions of the physical and emotional state, making decisions on self-care, or 4) none of these. A large majority of 73.9% of the respondents would use it for self-care maintenance (option 1), 26.1% for self-care monitoring (option 2), 39.1% for self-care management (option 3). The remaining 17.4% would not use this tool for any of these purposes (option 4).

6. Discussion

Parkinson's Disease is a condition with an exceptionally broad range of symptoms that can progress from barely noticeable to extremely severe. In any case, its effect on perceived QoL can be detrimental, and there are no single solutions that work universally for everyone. As such, different self-care techniques are important for PD just as they are important for various other chronic diseases and conditions. To this end, in our work, we contribute a public online repository of PD self-care techniques, PDCareBox, with a continuously growing database of structured content that is provided and evaluated by people with PD. While we attempted to tailor the UI to be suitable for use by people with PD, we acknowledge that it was still found somewhat confusing by many. Based on this and other feedback from our study participants, we also identify opportunities for future work – both in the development of PDCareBox, as well as in the design of future patient-driven knowledge repositories (see Section 6.4). We publicly release the source code of PDCareBox for use by the (research) community. The longitudinal deployment was not one of the easiest studies to conduct, and we also wish to reflect on our experiences on reaching the vulnerable group of participants and end-users in Section 6.3.

6.1. Self-care techniques providing actions towards coping

Self-care is an essential part of living with a chronic disease, including both daily mundane actions of dealing with the symptoms, as well as dealing with the disease emotionally (Nunes and Fitzpatrick, 2018). We identified nine categories for the collected PD self-care techniques: 'Physical activity and exercise', 'Well-being', 'Equipment, aids and re-organizing', 'Leisure and hobbies', 'Medication and treatment', 'Diet and nutrition', 'Social interaction', 'Knowledge', and 'Monitoring' (see Table 6 for descriptions and frequencies of the categories).According to the user feedback, techniques provide actionable, understandable, and useful information.

Some of the provided self-care techniques were similar to the practical methods identified in (Miertová et al., 2014). They collected the activities through Activities in Daily Life scale. The techniques in PDCareBox are collected as open-ended text, hence, the topics of techniques in PDCareBox were more various, spreading to all aspects of daily life. We found similarities also with the categorisation of (Nunes and Fitzpatrick, 2018), with the taking of medication included in 'Medication and treatment', exercising in 'Physical

activity and exercise', 'Well-being', and 'Leisure and hobbies', and adapting lifestyle in 'Equipment, aids and re-organizing'. The category accepting the disease consequences is more related psychological coping, and as such does not directly match to our categories, but the reflections of some techniques describe they may help in adapting to a more accepting attitude towards PD. Our approach differs from these earlier papers. In prior work participants were interviewed and observed, whereas in our study, the participants provided the practices related to self-care as a self-care contribution to the PD community.

There are several positive outcomes related to self-care, such as maintaining quality of life (Riegel et al., 2012), and our participants described the outcomes for the self-care techniques in the open-ended fields during assessment as reflections. Tuijt et al. (2020) investigated PD self-management themes through a literature review, and Haahr et al. (2021) similarly studied categories of PD coping strategies via a metasynthesis. These studies focused on *how* people with Parkinson's manage in daily life. In our study, the categories of the self-care techniques have similarities with these studies, but produced more actionable data, highlighting *what* it is in practice the people living with Parkinson's do. For example, Tuijt et al. (2020) and Haahr et al. (2021) both defined maintaining independence as a category of coping strategies or self-management. In our study, the independence was an outcome described in the reflections for many practical techniques, such as utilizing assisting equipment, as described in Section 4.5.2. Inside the theme of maintaining independence, Tuijt et al. (2020) describe the contradiction in receiving help and feeling independent. Similar feelings were described in the reflections by our participants (see Section 4.5.2), on the other hand, they valued techniques supporting independence, and at the same time appreciated the support and help by their families and friends. The psychological strategies category by Tuijt et al. (2020) had similarities to focus to the present from Haahr et al. (2021). We categorized these in techniques for wellbeing. In this category, maintaining normalcy/(pre-Parkinson's) self was mentioned as a sub-item of focusing on the present strategy by (Haahr et al., 2021). Again, in our study, feeling 'normal' or having a break from PD was mentioned as an outcome of various techniques in the reflections (see Section 4.5.2).

The Middle-Range Theory of Self-Care of Chronic Illness divides self-care into the categories of self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2012). A majority of the submitted techniques fall into self-care maintenance, and similarly, most of our participants (73.9%) also indicated that they could imagine using our tool for this purpose. A good

quarter (26.1%) would use it for self-care monitoring, and approximately 40% for self-care management.

Participants in our study submitted only a few techniques for monitoring health and symptom status. For us, this was perhaps slightly surprising, as modern mHealth and eHealth solutions are increasingly being used and offered for monitoring various symptoms and body functions (Espay et al., 2016, 2019). We hypothesise that the low number of monitoring techniques submitted is a direct result of the perceived lack of benefit of such tools among the majority of people living with PD, possibly based on prior negative experiences. According to the prior research, less than 40% prepare a list of changes in symptoms for doctor's appointment (Bloem and Stocchi, 2015). A slightly larger share of the techniques were related to obtaining knowledge and information about PD, which would support decision-making in self-care management. This type of self-care technique is likely to be perceived as more relevant for other types of knowledge gathering – as for example typically found through general search engines.

6.2. Validity of community-contributed techniques

As the sample of our study was recruited through online PD communities, it comes as no surprise that the participants were used to utilising the internet in obtaining PD-related information. The starting point in using general online search tools, such as Google or Bing, is to identify a theme or a problem area on which the user wishes to obtain more information. The logic behind PDCareBox is different, as the starting point for any search is the selection and weighting of criteria. In online PD communities, peer information is usually exchanged via discussion forums. While often containing rich information, prior work has identified the challenges that arise when trying to find information in this largely unstructured data source (Hartzler and Pratt, 2011). Interestingly, most of our participants did not compare our tool to discussion forums, but rather to internet search.

Aligned with prior research (Hartzler and Pratt, 2011), our participants described the information provided by peers differs from information by professionals in terms of context (daily life vs. medical issues) and form (actionable vs. theoretical/informative), highlighting the practicality of peer provided data. This underlines the importance of sharing (self-care) information as gained through experience with living with PD, to complement the information by professionals. However, the correctness or accuracy of patient-provided health information sometimes raises concerns. In our study,

few of our participants described the peer information might be biased, and you have to consider if the techniques provided would be suitable for you, effective, or even safe. The crowd consensus is an important factor when assessing experience-based information (Lederman et al., 2014), and in online health forums, the common understanding is found via discussion (Huh and Ackerman, 2012). In some platforms, for example, Patient Innovation (Innovation, 2021), the submitted solutions from the users are evaluated by a medical team. While this is suitable in the solution-oriented approach of the Patient Innovation platform, the content of discussion forums might be affected by the presence of professionals (Visser et al., 2016). We will discuss more how these factors shall be taken into account in the future in Section 6.4.

Mamykina et al. (2015) point out the difference in traditional discussion forums and platforms focusing on collective sensemaking, such as Stack Overflow. Traditional discussion forums allow a diversity of perspectives, and in sites like Stack Overflow the users vote for the 'best answer', across one simple criterion of "goodness". In PDCareBox, the users assess the submitted techniques according to various related criteria, highlighting the different aspects of each technique in a more nuanced, multidimensional fashion. And as evident based on the data log, people also used this functionality when discovering techniques: various combinations of the criteria were used. This approach allows users to search not only for the 'best' solution but rather find suggestions that fulfil simultaneously a set of wanted criteria. The reflections provide additional information on the effects of the technique. PDCareBox does not replace discussion forums, which are also a source of empathy and social contacts but act as a novel way for discovering peer-provided information. It also differs from traditional Internet search, as all the data is community contributed and in a structured form.

6.3. Involving the people with PD in online research

6.3.1. Comparing our sample to the general PD population

Prior work has highlighted that internet usage is dependent on age, but there is an indication that having PD does not affect internet use (Marxreiter et al., 2020). Prior work has studied PD burden (Pohar and Jones, 2009) as well as general prevalence of PD in Canada (Wong et al., 2014), allowing us to compare the characteristics of participants in Phase 1 to their respective samples (see Table 8). The mean age of our participants with PD was 67.3 years, slightly lower than in the study by Pohar and Jones (2009), 68.7 years, which reflects also the mean years since diagnosis. We find a clear difference

in the education level of the participants with PD, with our sample having a much higher educational attainment as compared to a prior PD sample (Pohar and Jones, 2009). In general, higher education is connected to larger access to the internet and to higher levels of internet use, which may explain the difference (Saboor et al., 2015; Berner et al., 2012). In an online study in Sweden with 346 participants with PD, more than half of the participants with university education (Riggare et al., 2019).

Table 8: Participant characteristics in our study Phase 1 as compared to Pohar and Jones (2009) and Wong et al. (2014).
* Information is based on 274 responses by people with PD.

Participants with PD	**Our study**	**Pohar and Jones (2009)**
Number of participants	288	261
Mean age	67.3	68.7
Mean years since PD diagnosis	5.7	7.3
Women/Men	57%/43%	44%/55%
Education: Prim./Sec./Post-sec./Univ.	1%/27%/21%/51%	43%/18%/24%/15%
Caregivers	**Our study**	**Wong et al. (2014)**
Number of participants	31	274*
Mean age	65.7	69
Women/Men	74%/26%	62%/38%
Work: Full time/part time/not working	23%/13%/64%	23%/14%/63%

PD is slightly more common with men than with women (Wong et al., 2014; Pohar and Jones, 2009), and men are also more likely to use the internet as compared to women (Morris et al., 2007). In contrast, women are more likely to search for health-related information from the internet (Fox and Fallows, 2003; Riggare et al., 2019). Aligned, the participants with PD in our sample contained more women by a large offset. Similarly, among caregivers, our sample contained more women than reported by Wong et al. (2014) (see Table 8). We hypothesise that women are more likely to share their experiences with PD; in our sample, women were more likely to submit techniques and to provide reflections. This is supported by literature too, Seale et al. (2006) studied internet support groups and interviews of people with cancer by comparing the language of men and women. They noticed that compared to men, women seek and provide emotional support more, and express their feelings and emotions more.

Finally, we find that the caregivers in our sample reported more advanced

stages of PD with the Modified Hoehn & Yarn scale (Table 3) and higher level of difficulties with the Parkinson's Disease Activities of Daily Living Scale (Table 4). In addition, on average caregivers reported more symptoms per participant. This is aligned with the fact that the need for support is bigger in the later stages of PD, perhaps enticing participants to contribute to and make use of, the self-care techniques available in our knowledge base.

6.3.2. Experiences with recruiting

Even though our tool was clearly branded as a collaboration between several academic institutions, we note that some users felt unsure about our motives. This is not surprising though, as typical internet safety advice is to be cautious. For example, *Age UK* instructs people not to click things online without thinking (UK, 2021), and European Parkinson's Disease association advises to always carefully evaluate the reliability of an online information provider, *e.g.* is it a commercial website (the European Parkinson's Disease Association, 2021)? Indeed, we got a few emails from our participants related to security and if there are commercial purposes behind the PDCare-Box. When describing self-care information search, our participants indicated that they frequently evaluate the reliability of their online search results. We got one feedback item from a participant that our introduction of the tool seemed like 'a sales pitch'. This obviously was not our intention, but different people perceive calls to action in a different light.

The various emails in relation to data collection and the deployment of PDCareBox from our participants highlight the high levels of engagement of the PD community members. From these emails, we confirm the need for technological solutions to support those dealing with PD in their lives, which has been previously described in the literature (Wang et al., 2011, 2019; Roupa et al., 2010). Based on our experience, some of our participants were looking for explicit confirmation regarding their eligibility to join, where we would expect more experienced internet users to just try the provided internet link and the functionalities. Clearly communicating the eligibility criteria is therefore critical in the deployment of similar studies.

We tried to get announcements about our study to various private Facebook groups related to PD. Many of these groups had rules denying all kinds of advertising, including research recruiting. In addition, the concept of crowdsourcing was not familiar to most page administrators, few times confused with 'crowdfunding', and were not willing to discuss more. This highlights the importance of avoiding jargon when communicating outside of

the wider HCI community.

According to our earlier experience on research with people with PD, having a trusted partner, *e.g.* a well-known PD organisation, helps in this effort due to the (implicit) vetting of the study's reliability. We approached several organisations and succeeded in finding a number of interested partners. Yet, many of the organisations never replied to any of our inquiries. Also, some organisations had decided to only cooperate with medical studies and hence excluded Computer Science-related research. Some of the organisations are staffed by a very small group of possibly unpaid volunteers, and thus we suggest reserving plenty of time for any cooperation in recruitment efforts.

The technical abilities of some organisations were limited. In small organisations there might be one person responsible for updating the web pages and social media, likely in their free time. Technical problems may occur also when working with large organisations. We created a profile to a PD platform provided by a large organisation (according to them reaching more than 90 000 individuals). After submitting the required information for the profile, putting those on the web page took a full month. They also did add their own data collection, yet it was mandatory to give contact details for the organisation before entering the study, see Fig. 7. This was removed after our query, as we pointed out it was not clear for the user who was collecting data and for what purpose. For promoting the second phase of the study, we got an opportunity to promote in a monthly newsletter of the organisation. When we wanted to update our profile in Phase 2, and add the link to the PDCareBox, and we sent the new text and link three weeks before the newsletter sending date. Unfortunately, the organisation was not able to add the link to the PDCareBox into our profile before the newsletter got out, and only links to the profile pages were allowed in the newsletter. In addition, after we pointed out the problematic collection of contact details, they removed the query and simultaneously disabled the link to Phase 1 from our profile.

6.4. Design implications and future work

The experiences with the tool, PDCareBox, itself and the longitudinal engagement with the different stakeholders yield the following three key design implications:

- **Provide relatable communications;** Crowdsourcing-based systems that collect, organize and transfer information among the community

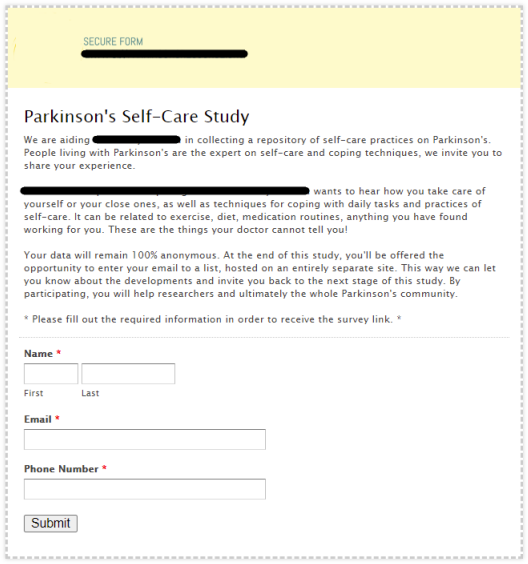

Figure 7: The mandatory collection of contact details before entering our study, by a PD organisation. The user has to find out who is collecting data from the yellow top banner, with a logo on top left (removed from this figure) and organisation name (black strikethrough), with no description of usage of the collected data. 'We' in text refers first to the organisation, and later to our research team. The text highlights 'your data will remain 100%' anonymous, with the mandatory personal data collected below.

itself have an excellent opportunity to talk to the beneficiaries in their own, relatable style.

- **Design contextually appropriate data quality improvement methods**; The intuitive improvements in e.g. text-based communication (fixing grammar, style) are useful but not enough. In our case, it became quickly clear that PD, as a use case, has various other considerations to account for, and for instance the search-ability and different ways of assessing the data are critical.

- **Account for diverse users**; The traditional way of attempting to accommodate different types of users from an user experience perspective fall short when designing information search systems for people with complex medical conditions. Issues, such as people's felt comfort when giving advice should be considered in the user interface itself.

We will discuss each of these in detail next.

6.4.1. Crowdsourcing can produce understandable and actionable data

As mentioned earlier, online information is an important source of disease-specific knowledge for people with PD (Riggare et al., 2019). However, in order to turn this available information into something usable, the provided information should be understandable. Fitzsimmons et al. (2010) assessed 100 PD web pages, concluding that none of them complied with current readability guidelines. Understandable health information facilitates shared decision-making (Odisho and Gore, 2017). Riggare et al. (2019) suggested utilizing input from patients to complement the current health information on PD, and Hartzler and Pratt (2011) similarly suggest that tools designed to share patients' expertise with one another would benefit the users, which is exactly what we set out to do with PDCareBox. Similar to many chronic illnesses and ageing in general, PD may cause cognitive deterioration (Weintraub et al., 2008) and the understanding of complex sentences might be difficult (Goldman and Litvan, 2011). All information in PDCareBox is produced by people with PD and their caregivers, thereby written in the common language without medical jargon. In addition, the descriptions of techniques are short. An overwhelming majority of 88% of the study's participants considered the information provided by PDCareBox as understandable. We argue that utilizing community-contributed data in future systems produces understandable information.

Health information should be also actionable, in order to ensure that the reader is able to act on the provided information (for Disease Control and Prevention, 2021). Our participants highlighted the practical aspect and everyday context of peer-provided data, which is in line with earlier research on peer-provided data (Hartzler and Pratt, 2011). A total of 76% of our participants considered the information provided by PDCareBox as actionable and 88% as useful.

6.4.2. Improving the crowdsourced data: quality and search-ability

Even though some of our participants pointed out the possible non-reliability of peer-provided data, 78% of participants experienced the techniques provided by our tool as safe. As discussed before, some studies propose a professional moderator for peer-provided information-sharing platforms for ensuring the correctness of the data (Attard and Coulson, 2012). While having a medical professional reviewing the safety and accuracy of provided techniques might affect the user's behaviour (Visser et al., 2016), it would also require resources. In PDCareBox, all techniques are assessed via peer-

users, and we could consider adding an option for flagging a technique as a possible safety risk or incorrect information when a moderator could check that technique.

Peer-produced data resulted in inconsistencies in the way data is presented, including irregular capitalisation and punctuation, which potentially reduces end-user trust and overall UX of PDCareBox (Lederman et al., 2014). Using relatively straightforward string operations, such issues could be reduced in the future.

The sliders in the search were experienced as confusing by some participants, while some adopted the new search strategy well. We analyzed the usability and number of usages in search for each criterion and also asked for feedback about missing criteria. We got varying suggestions for new criteria, along with a statement of more criteria complicating the search. In the future, we shall work with the users to find out if some of the current criteria shall be replaced with new, more relevant ones.

Morahan-Martin (2004) studied how internet users search for online health information. People typically use search engines and enter short (frequently misspelled) phrases, with the authors recommending the promotion of more effective search and evaluation techniques (Morahan-Martin, 2004). Relevance and trustworthiness of results are the most important features of a search engine (Pletneva et al., 2012). Our participants described they often search for information on a specific topic and were hoping to see some of these search functionalities integrated into PDCareBox. Based on these suggestions, we will add an option to filter the search results according to the categories or different parameters (*e.g.*, can be practiced at home), along with a word search (*e.g.*, search techniques with the word 'tremor' in the title or description).

6.4.3. Taking into account different user types

Self-care is an integral part of daily life, and it might be difficult to identify the actions as techniques and remember all things when asked to provide self-care techniques. Some might feel uncomfortable taking a role advising others, as only 24% of our participants in Phase 1 submitted a self-care technique. However, describing what a provided technique is good for seemed to be easier, with 75% of our participants having submitted reflections. Prior work has highlighted the different social roles that people play in online health communities characterize, *e.g.* informational support providers often share information and advice, and informational support seekers ask questions and seek information from others (Yang et al., 2019). In discussion forums,

many of the discussion threads start with a question or problem statement (Mamykina et al., 2015). Future work may consider how different data sharing and seeking behaviours can be supported in one tool, and allow users to submit a specific question or a problem in addition to solutions (in our case, self-care techniques) – allowing for structured responses in the form of rated self-care techniques to problems raised by other users.

We acknowledge that many people with PD have difficulties in using technology, *e.g.* due to motor symptoms, such as tremor or rigidity, or cognitive impairment (Nunes et al., 2016). Caregivers often provide assistance in this issue, and Piper et al. (2016) suggested solutions that support co-operation and varying support needs in online presence due to symptom fluctuation, such as a 'family account'. Community-driven tools can offer an easy way for a person with PD and their respective caregiver to signup to (research) platforms with one account that shares relevant background information. Given these stark differences in the symptoms of people with PD, we may wish to offer users the possibility to filter and assess previously submitted and evaluated self-care techniques based on the profile of the people that have contributed to the self-care solutions.

Providing the best possible user experience for PD patients would require further end-user testing. Following general guidelines in order to enhance the accessibility of a web interface is helpful from the designer's point of view, but these guidelines can not take into consideration every variable that comes into play when designing and developing web interfaces. This non-comprehensiveness of the accessibility guidelines has been showcased by Rømen and Svanæs (2008), and by Power et al. (2012). Therefore, the more active involvement of people with PD in the design and development of future iterations of PDCareBox is likely to be highly valuable.

6.5. Limitations

We identify several limitations in our work that are critical to consider when interpreting the presented work. First, our participant sample differs from the whole population of people diagnosed with PD and their carers. Based on our sample demographics, we identify a difference in the education level and gender share as compared with the overall PD population (Pohar and Jones, 2009). Second, participant recruitment was carried out with the help of PD organisations. Therefore, our recruitment was biased towards people that are already (active) members of one or multiple PD communities - these individuals might be more intrinsically motivated to share their experiences.

Third, our participant sample consists solely of PD patients and carers who have the necessary cognitive and motor ability to participate in our study. Those who suffer from severe symptoms that obstruct internet or computer usage were unable to join without additional help. We identified a difference in the severity of PD when comparing the Modified Hoehn & Yarn scale (Goetz et al., 2004) (Table 3) and the Parkinson's Disease Activities of Daily Living Scale (Hobson et al., 2001) (Table 4). This suggests that in the later stages of PD, the carers are the ones seeking for information on self-care. Finally, one of the four criteria on which the collected self-care techniques are ranked is 'affordability'. However, the affordability criterion is heavily dependent on user location, as health care costs vary from country to country. For example, one of the submitted techniques suggested Deep Brain Stimulation – a surgery for alleviating symptoms. The cost for a patient to undergo Deep Brain Stimulation is likely to differ a lot depending on their respective country's level of social security.

7. Conclusion

Parkinson's Disease is a neurodegenerative chronic disease with a severe impact on daily life due to a wide possible range of symptoms. 'Patient knowledge', as gained through a lived experience of PD, provides actionable and practical information for daily life context that can be as useful in managing PD as suggestions from the medical staff. However, this important information is often available only in an unstructured form, in which actionable information is challenging to find. In this paper, we present a public, accessible, online repository of PD self-care techniques, as contributed and assessed by the global PD community. Through a real-world evaluation, we have identified practical design implications for our tool, as well as opportunities for future research opportunities for community-contributed data repositories. We furthermore identified the characteristics of people with PD who are able and willing to play an active role in the online sharing of PD knowledge, and share our experiences on reaching and interacting with this community. Through our collaboration with the PD community, we wish to further expand PDCareBox to support people in their self-care needs and practices.

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