Understanding the Mundane Nature of Self-care: Ethnographic Accounts of People Living with Parkinson's

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ABSTRACT

Self-care technologies have been influenced by medical values and models. One of the values that was acritically incorporated was that self-care was medicalised, and, as a result, technologies were designed to afford use with clinicians and fit structured medical processes. This paper seeks to broaden the understanding of self-care in HCI, to acknowledge the mundane ways in which self-care is achieved. Drawing on in-depth interviews with patients and carers, and online ethnography of an online community, we describe how the self-care of Parkinson's is mundane. The fieldwork contrasts with more medicalised perspectives on self-care, thus we discuss the properties of a self-care concept that would acknowledge its mundane nature. Our hope is to sensitise designers to identify the mundane ways in which self-care is performed and, consequently, design technologies that better fit the complexities of everyday life with a chronic condition.

ACM Classification Keywords

H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous;

Author Keywords

Self-care; self-management; chronic care; Parkinson's disease; self-care technology; health.

INTRODUCTION

In recent decades, western societies invested great sums into researching and developing technologies for people living with chronic conditions. Technology was seen as the key enabler of a healthcare reform that would move patients with incurable (or chronic) conditions from hospitals and clinics to the home, where they would self-care, or manage the condition by themselves. This reform promised to alleviate healthcare systems, pressured by fewer people in the job market, supporting more and more older people living with chronic conditions. In reality, however, the uptake of self-care technologies has been limited [3, 44] and the results very mixed [3, 84, 24].

We contend that the low uptake is partially due to the mismatch between everyday life with a chronic condition and self-care technologies. This hypothesis is backed up by examples from the literature in which patients[1] with chronic conditions felt that their identity, independence, or self-care was threatened by the way technologies operated [80, 76, 70]. Some authors postulated that when migrating technology from the hospital to the home, medical models or values were usually adopted without rethinking the circumstances in which care happens at home [26, 83]. We argue that the medicalisation[2] went beyond the migrated technologies, influencing self-care technologies in general. This would explain why these technologies are often focused on self-monitoring symptoms or performing treatment, affording use within structured medical interactions. However, our fieldwork with patients and carers living with Parkinson's provides a more mundane[3] picture of self-care.

People living with Parkinson's performed multiple activities, such as taking medication at specific times, but what was most interesting was the mundane ways by which they achieved these. For taking medication on time, people put it in specific places, used mobile phone alarms as medication reminders, and even delayed the intake time to ensure medication fitted their other activities. Managing the condition required constant negotiations and an on-going assessment of what was most important at each point. The daily life with Parkinson's posed multiple challenges to patients and carers, most of which were not purely clinical, but a result of adapting and integrating the condition into one's daily life, and interpreting and incorporating the necessary medical aspects into this.

This paper seeks to expand the concept of self-care that designers use to conceptualise self-care technologies. Similar to Akrich [2], we believe that preferences, values, and prejudices of designers influence the courses of action they include in the artefacts they create, or the characteristics of the users they devise for the technology. By discussing the mundane nature of self-care, our expectation is that designers will be better equipped to support daily life with a chronic condition.

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[1]We use the word patient to identify the people who have a chronic condition, and the word carer to name those involved in the care of a patient outside formal care institutions. Our aim is not to restrict people to this one role they play, but to achieve brevity.
[2]The term medicalised is used here to refer to the view on self-care, which restricts it to its medical aspects, or in other words, the activities or areas that afford interactions with clinicians.
[3]The adjective mundane is used here to refer to the practical, routine, or banal aspects that characterise daily life with a chronic condition.

The contribution of this paper is twofold. On one hand, it presents an ethnographic description of how patients and carers engage in self-care in a mundane way, drawing on in-depth interviews with patients and carers living with Parkinson's, as well as online ethnography of an online community where (other) patients and carers with Parkinson's discuss. On the other, it discusses the properties of a mundane concept of self-care for the Human-Computer Interaction (HCI) audience.

The paper begins by introducing self-care and self-care technologies. Following is a description of the methods used in this study. Then, we detail how patients and carers living with Parkinson's engage in self-care. The fourth section discusses the findings of the fieldwork, characterises a concept of self-care that considers the the mundane nature of self-care work, presents implications for design, and comments on transferability of the findings. The last section concludes the paper.

BACKGROUND

Self-care, a disputed concept
Self-care is defined here as the activities that people living with a chronic condition[4] (patients and carers) undertake to manage the condition as part of their everyday life. Engaging in self-care may occur in complement to the medical care undertaken by healthcare professionals, but is necessarily different from it [74, 26]. Among other activities, engaging in self-care often includes observing changes in the body, acting on symptoms, managing treatment, and dealing with the psychological, physical, and practical consequences of living with a chronic condition [7]. While these general activities are likely to exist, people with different diseases have distinct symptoms, ways of monitoring their status, judging what to do, and even ways of acting. People with diabetes, for example, need to balance exercise, diet, and insulin [80]. In contrast, people with Chronic Obstructive Pulmonary Disease (COPD), worry most about managing physical effort, prioritising tasks, and exercising [14]. Since self-care is intimately related with the disease being cared for, people with different diseases care for themselves in distinct ways.

The goal of self-care: medicalised vs mundane
While the community agrees that people living with chronic conditions engage in self-care, what authors mean with the term can be quite different. In particular, two conflicting perspectives exist in regards to the goal of self-care.

For some researchers, the goal of self-care is to extend the reach of medical care from the clinic to the home. Even though patients proceed with their lives outside formal settings, doctors are expected to coordinate or oversee their health through regular checkpoints, close scrutiny, and detailed guidance [15, 88]. Self-care is sometimes even described as a treatment, the goal of which is to maximise the regulation of the condition through different processes [61]. We argue this perspective is medicalised because self-care stays under the medical sphere.

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[4]Self-care can also denote activities "healthy" people engage in for healthier living [15]. However, this broader view on self-care undermines the work patients and carers do to live with their condition. Thus, our use of the term self-care excludes preventive scenarios.
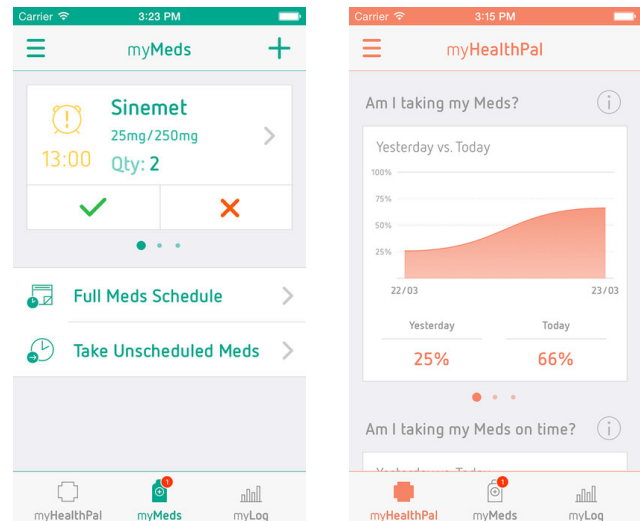

Figure 1. myHealthPal showing a medication reminder and a compliance plot (Credits: http://www.myhealthpal.com/).

The activities of patients and carers are limited to a compliance with treatment, with the clinician being responsible for all analysis and decision-making, as described by Parsons [68].

In contrast, other researchers defend a more mundane concept of self-care, in recognition of the complexity of living with a chronic condition in practice [87]. Rather than only pursuing clinical activities, people are juggling multiple goals, priorities, and issues because the condition is not something separate from their lives [19, 28]. Cicutto et al. [14] gives an interesting example of people living with COPD, where self-care is not restricted to performing exercise, the medical recommendation, but includes as well all the balancing of effort pursued to avoid damaging tissues. Moreover, according to this view, self-care is not a well-defined task people carry out, but a process of "persistent tinkering" [59] in which people negotiate and compromise among options and issues.

Medicalised self-care technologies
Self-care technologies are tools that support the self-care activities of people living with chronic conditions. This includes medical devices, such as the blood glucose monitor, and tools for exchanging data remotely with the medical care team, often under the umbrella of Telehealth [76, 37, 71, 36], Telehealthcare [55], and Telecare [6, 53]. In principle, self-care technologies would embody a mundane perspective, recognising the complexities of living with a chronic condition. In practice though, we find numerous characteristics in existing self-care technologies that suggest they are medicalised[5]. To explain this point, we describe three self-care technologies for Parkinson's: myHealthPal, Kinesia™, and SCRUMP. These examples represent different types of self-care technologies, and include both prototypes and products. Our aim is not to say that all technologies are similar, but to point how self-care technologies can be medicalised.

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[5]Researchers have not investigate the rejection of self-care technologies for Parkinson's, but evidence from other chronic conditions suggests it is partly related with their medicalised nature [80, 76, 70].

myHealthPal [60] is a mobile medication reminder specifically designed for Parkinson's. The app exhibits several features that remind one about how medication is handled in clinical settings. For example, it uses a single medication schedule that triggers reminders always at the same time, be it on weekdays or weekends, work periods or holidays. The general absence of an option to snooze gives evidence that designers expected patients to take medication exactly when the alarm was triggered. In addition, the app records missed intakes, displaying them in a compliance plot, which implies that skipping medication is always a sign of non-compliance (see Figure 1). These medicalised features also appear in other medication reminders (see [22, 47, 41]).

Kinesia™ (Cleveland Medical Devices Inc., USA) is a technology for assessing symptoms of Parkinson's at home and remotely sending the data to clinicians. For performing an assessment, patients place a wearable sensor on their finger, and perform specific movements in front of a tablet computer. Patients cannot reflect or analyse their symptoms as only clinicians can visualise the data about the assessment. In addition, the technology is designed to monitor a subset of clinically-useful motor symptoms, missing, for example, non-motor symptoms that might be relevant for practical everyday decisions. The medicalisation of Kinesia™ becomes even clearer when authors frame the tool as a way to "maximize therapeutic benefit" [58]. Kinesia™ is a good example of medicalised self-tracking technologies, but there are others [22, 77, 51].

SCRUMP [29] is an exergame for training movements of the arms and legs. The user is asked to pick apples without hitting certain elements. The game itself is displayed on screen and movements are tracked by a Microsoft Kinect. SCRUMP makes therapeutic exercises more engaging, but movements are well structured and not much different to what patients would perform in a physiotherapy session. Even though the technology could run at home, it is basically an extension of medical care to the home. Other therapeutic technologies present similar characteristics (see [43, 4, 42]).

While self-care technologies for Parkinson's have been often medicalised, some technologies embody a more mundane concept of self-care. Examples include a wearable bracelet for reminding patients to swallow saliva every couple of minutes [56], and a technology that warns users when their voice volume cannot be perceived by others [57]. However, these mundane examples seem the exception in HCI [31, 81, 64], as many technologies are focused on affording use with clinicians, within structured medical scenarios.

METHODS

In-depth interviews
To gain an understanding of the daily life with the condition, we conducted interviews with patients and carers [46]. The interviews were intense, qualitative, and loosely structured. We chose to involve patients and carers related with each other to gain an in-depth understanding of each specific self-care case. The interview guide touched on issues such as diagnosis, dealing with the disease, treatment, and everyday life with the condition. There were also multiple "world tour"

questions (e.g., describe a typical day) to open the conversation and capture different issues. Furthermore, participants were interviewed multiple times, allowing the analysis to guide the themes of subsequent interviews.

In total, 10 patients and 10 carers were involved, resulting in around 20 hours of audio-recordings. The participants were recruited through a local chapter of the Portuguese association of patients with Parkinson's. They had diverse professional backgrounds and level of education. All patients were older than 60 and retired, either because of the disease or shortly before it was diagnosed. Eight carers were retired, one worked, and one was a college student; all carers held an active role in the care of their relative.

We obtained informed consent from all interviewed participants, after presenting the interviewing researcher, the project, and the reasons for the interview. The names of participants reported in the paper are fictional.

Ethnography of an online community
To complement the interviews, we used online ethnography [30]. The chosen community was English-speaking and associated with a national Parkinson's association of another European country. This particular forum was chosen because it had a large database of posts >40K (excluding archives), multiple daily posts, moderation performed by patients and carers, and a policy of having posts publicly available. Moreover, choosing a community from a country other than where the interviews were held was a deliberate choice to maximise the differences between groups in the data collection.

The analysis was based on the extant texts [46] produced by the members and documented in forum posts in five folders of the forum, namely: i) Treatments and therapies, ii) Symptoms, iii) Wellbeing, iv) Daily life, and v) Carers friends and family. These folders were selected as being most closely related with the self-management of the condition. This judgement was based on the folder's description and on exploration across all folders. Excluded from the analysis were folders such as those relating with introduction of new members, diagnosis, research, questions about the forum, the creative corner, and events. In total, 5224 posts were screened, belonging to 500 threads equally distributed among the five folders.

We did not obtain informed consent from members, as posts were publicly available. However, to prevent exposure to members' lives, pseudonyms were replaced by fictional names, posts were edited to prevent search engines from linking to the original content, and the community remains anonymous.

Analysis
Our analysis followed the constructivist version of grounded theory methodology [12]. We performed iterative coding, on interview transcripts and excerpts from the online community, using the Scrivener writing software. Data analysis drove the data collection, so the interview guide kept being adapted to focus on emerging themes. Participants were also interviewed multiple times, to explore new themes with them. Constant comparison was carried out at different levels, including comparisons between excerpts, participants, and settings

(i.e., online vs offline). The overall focus was on developing theory grounded on the collected data.

We reviewed literature from beginning to the end of the study, to ensure we were sensitive to the setting and informed about questions previously explored [12]. In writing up the study, we pursued yet another level of comparison, this time between the literature and our findings, and between our findings and the opportunities promoted by self-care technologies.

The findings from this paper have been partly scrutinised by participants. In particular, some interviewed patients and carers were given the chance to read an early draft of the analysis and comment on it. This draft evolved through analysing subsequent interviews and the online community data, and through the writing of this paper; however, the reported findings still resemble the initial draft read by participants.

THE MUNDANE SELF-CARE OF PARKINSON'S

Parkinson's disease is a progressive neurological disorder that is responsible for numerous motor and non-motor symptoms [52]. The symptoms of Parkinson's vary from patient to patient, however, there is a group of symptoms that is very common. The cardinal features, as usually referenced in the literature, are muscle rigidity, slowness of movement, postural instability, and, the most well known, rest tremor. Non-motor symptoms are also common and include depression, pain, and sleep disturbances. Parkinson's does not have a cure yet, but some medications can attenuate it.

The fieldwork presented here describes how people self-manage Parkinson's in daily life. In particular, we focus on the four main self-care activities: taking medication, exercising, adapting lifestyle, and accepting the consequences of the disease. These activities are presented together with excerpts from the interviews and the online community.

Taking medication

Even though Parkinson's cannot be cured, there are numerous drugs available that can address its symptoms. Different medications have an effect on different symptoms, so patients usually take a cocktail of pills[6]. Getting to the right medication plan is a complex and delicate activity. Too little medication will not soften the symptoms enough, and too much of it will have negative side-effects – such as uncontrollable involuntary movements. Nevertheless, the medication for Parkinson's has a strong effect on symptoms and, in the best case, can even hide the condition.

> Peter: *This is a complicated disease, of course, because we only walk if we take the medication. So, it [taking the medication] has to be [done] daily.* – patient, interviews

Medication played an important role in the lives of many patients. For people like Peter, medication was essential for enabling any movement. As he explained in the interviews, the day only started after taking the morning pills because

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[6]When referring to medication for Parkinson's we consider mostly patients under pill therapy. Some patients undergo deep brain stimulation or duo dopamine pump implants, and thus do not need to worry about taking medication. Still, a large percentage of patients undergo pill therapy and face challenges in managing it.

Figure 2. Medication list/schedule of Aaron.

before that moment he simply could not walk out of the bed. To complicate matters even more, medication has a transient effect that wears off after 2-6 hours. As a result, patients need to take the medication throughout the day to keep the effect going and symptoms softened. In the excerpt, Peter said that the medication had to be taken "daily", but that is an oversimplification considering how many times patients need to take their pills. Figure 2 shows the medication schedule of patient Aaron. For Parkinson's alone he took one Stalevo® pill five times a day (7:00, 11:00, 15:00, 19:00, and 23:00), one Azilect® pill, and one Requip® pill. Aaron also took medication for other conditions, which increased the burden of medication even more.

Memory issues[7] caused by Parkinson's and (normal) ageing do not help patients in remembering their medication, so if there is a sudden change in routines or a distraction, a pill can easily be missed[8]. Missing medication makes the symptoms return, so people living with Parkinson's used a diversity of approaches for reminding themselves about medication.

> Jack: *I setup alarms on my mobile! 7:30, 10:00, 12:00, 14:00, 16:00, 18:00, 20:00, 21:30. (...)* – patient, online community

Some strategies for reminding themselves were related with controlling the time. Most people constantly looked at their watches to make sure they took medication at the right time. Others, like Jack, used the alarm function of their mobile phone to remind themselves at the right time. Besides strategies for controlling time, people also used the physical placement of medication as a reminder. For example, they kept medication on the kitchen table or on top of the TV to take it before meals (see Figure 3), or on the bedside table to take it

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[7]Parkinson's can bring mild cognitive decline and with it difficulties in remembering events at a specific time (prospective memory). Remembering to take medication can thus become harder for patients.
[8]Missing medication does not happen solely at home. Buetow et al. [9] report that formal carers often miss giving medication to Parkinson's patients at the right time in formal care settings.

Figure 3. Peter stored his medication over the TV so that he remembered to take it before meals.

before going to sleep[9]. Putting medication in specific places, as Danholt and Langstrup [21] explain, helps weaving medication into daily life and, thus, patients and carers used these strategies to manage medication.

Taking medication at the right time helped in keeping symptoms softened throughout the day. However, sometimes patients delayed their medication on purpose. For example, Louis delayed her medication when she had physiotherapy sessions, or when she visited her neurologist. Delaying medication meant that she endured stronger symptoms for a period of time, yet she felt it was inevitable to attend some events. As Parkinson's progresses, medication starts wearing off faster and patients start experiencing intervals when the medication effect is weaker, also known as the Off phase. During these periods, symptoms are stronger and patients cannot pursue their activities in the way they would like. Patients learn to live with these moments and endure symptoms for some time before taking the next pill. However, some activities are not compatible with having less control of the body. This was the case for consultations, when Louis needed to walk from the car to the clinic, or for physiotherapy sessions, when she needed her body fit to be able to perform the exercises. Delaying was thus a strategy that enabled patients to adjust their medication effect window to better fit their daily life activities[10].

Despite the advantages of delaying medication, the activity was not free from consequences. In fact, when patients delayed, they also had to adjust the following medication intakes.

> Arthur: *So if you were supposed to take it at 4 and 8. If you take it at 5, then you will take at it at 9.* – carer, interviews

As Arthur explains, the remaining medication schedule needs to be adjusted to keep the same temporal distance, be it three or

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[9]Some strategies for remembering medication uncovered in this study find a parallel in [66, 20].

[10]Besides delaying, patients also took larger doses than prescribed, for example, for driving [69, 33]. However, that practice was rare among our participants.

four hours. Otherwise, the patient might have too much medication in the body and start experiencing dyskinesia episodes. Moreover, in case one pill is not taken before the time of the next one, it should be skipped for the same reason. While these adjustments may appear as simple changes, it is important to remember the complexity of the medication for Parkinson's, with multiple intakes, at different times, and with different doses, which challenge patients and carers even when they follow the same daily medication plan.

Delaying practices were commonly mentioned during interviews, but rarely in the online community. In the second dataset, posts mentioning delays related mostly to long-haul flights – in which people needed to adjust their medication to a different time zone.

Exercising

Exercise is another important self-care activity. It is not referred to as a treatment in the literature, but exercise can have a significant role in improving patients' control of movements and mental wellbeing.

The interviewed patients and online community members exercised very often. We commonly heard (or read) people saying that they engaged in exercise activities more than three times a week. Most patients with Parkinson's were exercising for hours and performing effortful aerobic activities. They seemed more like athletes than what one would expect from people who have a 'movement disorder'. Besides the formal forms of exercise, people engaged in multiple informal exercise activities, such as going for walks, doing housework (e.g., doing the laundry, washing the dishes, or vacuum cleaning), walking the dog, or even dancing. It is, thus, surprising to read van Nimwegen et al. [86] reporting that patients with Parkinson's are 30% more sedentary than people without the condition. Quite on the contrary, the patients in this study were extremely active. For them, exercising was an essential part of living with the condition.

> Jo: *Exercise is essential. Whatever form you can do it, exercise will make you stronger and keep your body fit for a longer period.* – patient, online community

People living with Parkinson's saw performing exercise as an important proactive role they could take in setting the trajectory of their condition. They knew that controlling Parkinson's was not possible, but performing exercise might help them prepare their bodies to deal better with the condition. After all, exercise trained balance, developed muscles, and made joints work better, so they had reasons to think that they would be better off in the future with a fitter body. The literature concurs with their experience and even argues that exercise can reduce the overall disability caused by the condition [35, 79].

Exercise came at a high cost, though. Due to the disease, patients experienced fatigue, stiffness, and difficulties in moving precisely, which made exercising more tiring for them compared to people who do not have the condition.

> Joseph: *I make a terrible effort. I make an effort. I walk slowly, but every day I go for a walk.* – patient, interviews

When we interviewed Joseph, he had only lived with Parkinson's for two years, yet his symptoms were quite strong. Walking was very hard for him, and yet he went out every day holding hands with his wife. He also used a stationary bicycle at home every day. Ten minutes cycling were enough for leaving him exhausted and feeling that he could barely move. However, he felt that exercising was good for him and thus kept pursuing it every day. The effort to exercise demonstrated by Joseph was common among participants in this study. Even though exercising could be extremely hard, it did not stop patients from exercising, and could sometimes even motivate them to regain control over Parkinson's.

When feeling nervous, worried, or depressed, symptoms became even worse. Thus, patients occupied themselves as much as they could. In some cases, carers also provided ideas of useful activities that they could do to keep their heads occupied.

> Anna: *It is also part of the therapy. What they do in the physiotherapy is moving their legs and arms, right? That is why I ask him to do the dishes, right? He takes the sponge, washes, and rubs, and whatsoever. And [while doing so] he is there with his head occupied thinking about what he is doing.* – carer, interviews

Exercise can distract patients from worrying about their condition or from drifting into depression. For this reason, Anna often motivated her husband to do housework. As he was not the type of person who goes to a Cafe, she felt that he needed to occupy himself during the time that he spent at home. In this situation, exercise was not meant to train the muscles or keep the body fit. Instead, exercise was a way of avoiding depressive or worrying thoughts and keeping the mind busy[11].

Adapting Lifestyle

Medication limits the symptoms of Parkinson's to a certain extent, but as the condition progresses, the medication addresses the symptoms less and less effectively. As a result, patients often needed to make adaptations [89] that included stopping or slowing down activities or getting used to living with fluctuations of the disease state.

Stopping or slowing activities down
At some point during their lives, patients faced the need to quit activities. This seems like the logical thing to do when activities are too hard or risky to perform, however, quitting some activities could be emotionally straining.

> Jane: *The decreasing ability to do what used to be boring yet necessary chores, and the need to ask for assistance (and pay for it!) is both embarrassing and humiliating (also costly). As for the requirement of leaving work - do I need to say more?* – patient, online community

This patient talked about the difficulties of quitting activities and the need of having others performing them. Leaving work was very hard for Jane, but she missed even ordinary activities, the repetitive and boring work. Being unable to carry out these necessary activities made the patient feel humiliated and

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[11]Experimental studies were not able to prove the benefit of exercise in alleviating depression and improve mood [35], but patients did not seem to have any doubt of its beneficial role.

embarrassed. It was as if these routine activities played an important role in the life of the patient that was now missed because performing these activities was no longer possible. Gibson [32] presents a similar example when describing a "handyman" who no longer can take care of his garden and thus has to hire the service. Hiring someone was practical and effective, but it brought frustration because it reminded the patient of his limitations.

Indeed, patients may be required to quit numerous activities. The simple loss of dexterity in the hands, for example, required some patients to quit hobbies like hunting, work that involved control of machinery, or even cooking because they could not safely manipulate knives. Activities might also become exhausting due to the symptoms. The same loss of dexterity hindered some of the patients from working with their hands, eating by themselves, or maintaining bodily hygiene, all of which were greatly important for a self-determined lifestyle.

The example of hand dexterity was only one of the symptoms people living with Parkinson's needed to adapt to, however, others are also likely to force changes. The main point is that because Parkinson's is a progressive condition, patients have to adapt to their constantly evolving situation, which may require changing hobbies, habits, the dynamics of the family, stopping work, or not doing their personal activities by themselves. In being forced to quit these activities, patients sometimes felt that they lost a part of their identity.

> Rose: *I have a driver's license since 30 something years ago and he never let me drive. (...) And now, do you think he feels good? Being driven by me, after he never wanted me to drive?* – carer, interviews

Rose's husband was the family's driver for the past 30 years. However, due to Parkinson's, he had to pass the wheel to Rose. After more than three decades without sitting on the wheel, Rose experienced difficulties and was not able to drive in highways. As a consequence, the couple depended on others to go to numerous places. Being the family's driver was an important part of the patient's identity, that he could no longer perform. What seemed to be a straightforward change to implement, just passing the driving responsibility from one driver to the other, ended up being a complex adaptation.

Enduring fluctuations
The symptoms of Parkinson's do not always behave in a predictable way. In some situations, symptoms become stronger and more noticeable than in others. People living with Parkinson's have attributed these fluctuations to medication effect losses, cold weather conditions, and some emotions. Experiencing fluctuations was common, so people living with the condition often planned their days in great detail, to ensure they could attend their activities. However, plans were not guaranteed to work, thus they needed to reconcile themselves with not knowing how their bodies will act, and consequently, what they will be able to do at each moment.

Earlier, we mentioned that the medication for Parkinson's has a limited effect that wears off after a few hours. This is not necessarily a problem when the body responds well to medication. A pill can be added at a later time to overcome the

loss of effect. However, as the condition progresses, symptoms become stronger just before the intake time. This phenomenon is called wearing off.

Marion: *Do others also suffer from pain in the feet? When meds are wearing off (Sinemet, Mirapexin, Entacapone) I get foot cramps and shooting pains, which are really painful.* – patient, interviews

When medication starts wearing off, symptoms slowly return. For Marion, entering the Off phase meant feeling cramps and pain in the feet. For other patients, the experience might be slightly different as they may have other symptoms. During consultations, neurologists tried to reduce the duration of Off phases by making adjustments to medication. Unfortunately though, it was not always possible to completely remove these phases. As a result, patients learned to plan meetings for On periods or to delay medication, as previously mentioned. In any case, their plans were not guaranteed to succeed, because the effect of medication might not be the expected one.

The weather was also likely to have an influence on how patients moved and felt. Interviewed participants frequently complained that the cold rainy weather – characteristic in their winter – made them move with more difficulties and overall feel worse. In contrast, with warm weather, they felt their bodies were "lighter".

Elisabeth: *The summer is another life for him.(...) It is another freedom, there is no doubt. (...) The cold is very. It is a great enemy of this disease.* – carer, interviews

People living with the condition attributed fluctuations to the weather itself, and also to the fact that in the rainy winters they did not go out as often, and wore more clothes, both of which made movements harder to perform. This example shows the complex interplay of factors influencing how patients feel. Someone without Parkinson's could also claim it is harder to move in the winter, but for people with Parkinson's, the effect is more pronounced. Moreover, not being able to exercise as much in winter means that the body of patients will move less effectively, resulting in even stronger symptoms.

Emotions were also responsible for fluctuations in the state of the disease. When patients felt worried, nervous, or upset, symptoms became stronger. If they were able to calm themselves, though, activities would become easier to perform.

Mary: *If I do things relaxed, without getting nervous, I can do everything. At my speed, I do. But if I get nervous, then [I don't].* – patient, interviews

Patients may try to avoid some of the complications of fluctuations, but they cannot control them completely. Martin [50] labels this phenomenon as "chronic uncertainty" in the recognition of the impossibility to know how bodies will behave.

Accepting the consequences of the disease
Some of the adaptations people living with Parkinson's need to do can be quite hard to accept. The previous section already mentioned how difficult it can be when a patient faces the inevitability of leaving work, stopping driving, and ceasing to perform routine activities of daily life. Being unable to

pursue these activities forced people to abdicate from roles they played (e.g., family driver), thus challenging their identity. In this section, we reflect on the implications of adapting to Parkinson's, detailing how people accept the condition and the changes in their self-image.

Accepting current and future disease situations
Most participants showed great resilience. They lost important things to Parkinson's and yet were able to accept the condition and face it with hope. Accepting the condition was not the result of a single event that changed everything, but of regular episodes in which people confirmed their willingness to live with the condition. During the interviews, for example, people living with Parkinson's mentioned patients they knew who had worse cases of the disease, reminding themselves how lucky they were to live with a milder case of Parkinson's. They also compared Parkinson's with conditions such as Alzheimers or cancer, concluding that their disease was the more benevolent. In making these comparisons, people were creating the conditions to accept their situation. Using what Forsyth et al. [27] calls comparative optimising, people compared their situation with more complicated cases, as a way to put their disease case in perspective and to focus on the numerous things that they could still do. This state of acceptance was not stable though. People endured moments in which they feared getting worse and questioned the purpose of their lives when they could not control their bodies. However, in most cases, patients and carers did not excessively think about their condition.

Nataly: *In most days, I am solid as a rock and strong as a lion. I would even feel proud if I listened to myself. But, oh dear! Sometimes are awful. Everything is so bleak. Nothing seems to matter anymore (...) where is the hope I had last week?* – patient, online community

Some days can be tough. During the time spent at the association we witnessed episodes in which patients were feeling really down. However, when it happened, they were not left alone. Other patients and carers mentioned others living in worst situations, they mentioned more severe conditions, and they reminded them of the things they could still do. The online community played a similar role when patients and carers were feeling down. Members reminded each other of the benefit of "venting" frustrations and offered each other an understanding and supportive community[12].

Besides accepting their current situation, people living with Parkinson's have to prepare themselves for the future disease state. Patients are likely to experience stronger symptoms in the future and, if medication stops having an adequate effect, be forced to abdicate from further activities they value.

Peter: *This is something that has no cure mate. And adapting to it is even harder. You have to keep going, put it behind you and try to forget it.* – patient, interviews

Like Peter, many patients tried to put the condition behind them. They could not escape Parkinson's symptoms, but thinking about them all the time did not help make things better

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[12]Numerous studies have discussed the role of online communities in offering social support. See for example [73, 75, 62].

either. The solution was often to "forget" that they had the condition, to pursue their lives in the best way possible as if they did not have Parkinson's. Only then could they better accept the condition and adapt to it.

Interestingly, when speaking about the future, patients often talked about hope.

> Emory: *We all progress at different rates, take different drugs, and experience a variety of reactions. However, one thing we all have in common is the confidence that a cure will one day be found.* – patient, online community

Patients and carers frequently said that the cure for Parkinson's was close. This wish is detached from today's scientific research expectations and outputs[13], but people hold on to the possibility of a breakthrough at any time. Believing that a cure was close gave people the motivation to bear the symptoms and consequences of the condition every day. It gave them the strength to "fight" a condition that they cannot avoid[14].

Accepting changes to their self-image
As Parkinson's progressed, it challenged the self-image of patients. Some of the problems were triggered by the display of the symptoms. For example, being seen trembling in public often triggered looks of pity from others, and having difficulties walking was easily confused with being drunk. As a result, patients often tried to hide their symptoms from others. To hide tremor, people would put their hands in the pocket, inside a newspaper or bag, or sit on their hands. While walking, they would concentrate their thoughts on the next steps to avoid making gait issues noticeable. When asked why they tried to hide symptoms, patients explained that they did not want others to feel pity or have preconceived ideas about them. Patients felt what Goffman [34] calls stigma. Their bodies displayed characteristics that led others to see them and treat them negatively. Some patients felt socially obliged to hide their symptoms for avoiding embarrassment and standing out.

Besides stigmatisation, people also needed to accept changes to the image that they had about themselves. This was introduced before with the example of Rose's husband, the man who could no longer be the family's driver. Here we provide another example, this time concerned with quitting work.

> Elisabeth: *He would say: does this make any sense? The woman goes to work and the man stays at home? And when you went to work and I stayed at home? It was the same thing, right? But in his head it did not work like that.* – carer, interviews

After some years with the condition, Elisabeth's husband was no longer able to work in the restaurant he owned with his wife, and, thus, had to retire. Before that, he was a tireless worker. He went to work before everyone, rarely took breaks, and was always concentrated on the needs of the clients. Working was

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[13]A lay explanation about the challenges of finding a cure for Parkinson's can be found at: `www.pdf.org/en/chasing_parkinsons_cure`.
[14]The hope in a cure could be related with our recruitment, as less hopeful people would not participate in the interviews. However, many posts in the online community suggest that the hope might be a common feeling. Moreover, prior work argues that patients often hold on to the possibility of a cure [11].

an important part of his identity, which he found difficult to abandon. He knew he could not work, but it was very hard to be at home, see his partner going to work, and realise that he would never be able to go back again. Suddenly life restricted the role he played in his family from a tireless worker to a person that just stayed at home. In his mind, he was no longer able to contribute to the family and was now a dependant. Eventually, he was able to adapt his role and find realisation in doing other activities. Other patients might not have to quit their work as early, but they are likely to have to withdraw from roles they play and, as a consequence, adapt the image they have of themselves. This process will not be straightforward, but it is essential to continue living with quality.

DISCUSSION
The findings presented above show that living with Parkinson's is complex and full of mundane challenges, aligning with previous work [8, 78, 33]. Taking medication does not simply happen as a matter of routine, as is implied in some studies (e.g., [17]); instead, it is the result of placing medication on the right places, controlling time constantly – with or without alarms [32, 33] – and carefully assessing the advantages and inconveniences of taking medication on schedule or a bit later. Exercising is not restricted to formal activities such as physiotherapy, but entails a very diverse set of informal activities to train the body and keep the head occupied. The functional restrictions imposed by the condition [89, 13, 49] force patients to abandon activities that were once important and, with them, the roles they played. Patients need to get used to living with uncertainty due to fluctuations [85, 40]. They need to be flexible as well for dealing with last-minute adjustments. Facing such challenges, people put effort into accepting the condition. They compare themselves with worst cases [10, 13], try to put things into perspective, and find hope by holding on to the possibility of a cure.

The different activities described in the fieldwork are part of the everyday life with Parkinson's, but hardly fit into a medicalised frame of self-care. Even though doctors prescribe medication, recommend exercise, and advise people to get distracted and enjoy life as much as possible, how patients interpret and implement these activities into their daily lives depends only on them (and their carers [63]). Patients and carers are the ones who need to make things work with the options they have at their disposal.

The findings from this study converge with literature from the social sciences around the mundane nature of self-care. The three types of work described by Corbin and Strauss [18], for example, appear in this study. Taking medication could be categorised as illness work, accepting the consequences of the disease partially as biographical work, and adapting lifestyle and exercise as a mix of illness and everyday life work. Nevertheless, this paper questions the division into types of work, when some self-care activities, such as exercise, pursue multiple objectives. The "persistent tinkering" [59] of patients and carers could also be observed in this study, as fluctuations and progression continuously challenged people to often adjust their self-care. Moreover, the practices of managing medication described in this paper confirm previous work, showing

that temporal [54] and spatial [20] arrangements play a significant role in remembering medication, and that people may delay medication to address practical issues [16].

Towards a mundane concept of self-care

The everyday experience of living with Parkinson's calls attention to very mundane aspects of self-care. With this in mind, we now proceed to characterise the concept of self-care taking into consideration the practical dimensions that were outlined in the fieldwork.

Performing self-care entails great work

Living with Parkinson's requires people to engage in numerous activities that can amount to significant time and effort. For taking medication on time, for example, people used placement, clocks, and phone alarms. The practical effort of patients and carers is not usually recognised as multiple studies in the medical literature talk about non-compliance or non-adherence to say that patients fail to take all their pills according to schedule [38]. On the contrary, it should actually come as a surprise that people are able to deal with most of their pills, while going through cognitive decline and depression. Moreover, the consequences of occasionally skipping or delaying a pill are not serious. Apart from stronger symptoms and potential difficulties assessing symptoms in consultations[15], there are no consequences to digressing from the medication schedule. In essence, taking medication at the right time, as other self-care activities, takes great work.

Activities are intertwined and ingrained in daily life

Living with Parkinson's entails performing different self-care activities, but these are not independent from each other, nor are they separated from other aspects of daily life. For Anna doing the dishes was a form of exercise, a way of keeping the head occupied, and a source of fulfilment by being useful to the family. However, it is hard to imagine that a medicalised perspective on self-care would consider washing the dishes as relevant when there are other exercise activities that are more structured and deliver stronger outcomes (e.g., [1])[16]. Nevertheless, in doing so, this perspective would disregard an activity with multiple benefits, interconnected with different practices, and well ingrained in daily life. Understanding self-care in practice entails recognising that self-care activities are not separated from other daily activities, but rather repurposed and integrated into the fabric of everyday life.

People negotiate and compromise

When living with Parkinson's, not everything is possible all the time, so people need to negotiate and compromise. For example, when delaying medication, people accept stronger symptoms during a given period, for the possibility of being

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[15]If patients delay their medication and visit their doctor hours later, it may be harder to assess the symptoms because symptom increase can be explained by progression or missing a pill.

[16]Doing the dishes would not even be considered exercise according to some definitions. For example, Speelman et al. [79] restrict exercise to the "physical activity undertaken specifically to maintain or improve physical fitness and functional capacity". Even though training the body was part of the goal of doing the dishes, the activity was not targeted specifically at improving functional capacity, thus it would not be considered exercise by these authors.

fitter at some later time. It is a sign of practical adaptation to the condition because people can adjust their self-care to pursue the activities they want. Yet delaying is often framed as a sign of non-compliance or non-adherence to the medication plan [45, 38, 23]. By using the terms non-compliance or non-adherence to describe delaying, authors imply that patients deviated from the medication plan they agreed to. They acted erratically, or with the wrong information in hand, so education plans, such as the one proposed in Grosset et al. [39], are put in place to "educate" patients and eliminate that practice. However, it is not fair to attribute delaying to a lack of information about the condition or the consequences of delaying. Quite the contrary, the people delaying their medication were highly educated and well aware of the consequences delaying had on their body, and it was the in-depth experience with the condition that motivated them to use that strategy. As a patient from the study of Pinder [69] explained, the day of a patient with Parkinson's has six to eight useful hours, so people make sure they use these slots to their fullest, doing the activities they most value. Understanding the everyday experience of self-care requires one to overcome a medicalised perspective of isolated activities on fixed schedules, and accept the complex negotiations and compromises that are part of the daily life of people living with a chronic condition. At each point, people will need to judge what is most important and act accordingly. Sometimes, the decision will be to pursue what is recommended medically, while others, people might decide to re-interpret and adapt this, going for an alternative solution that enables them to attend other priorities.

Self-care as dynamic

Living with Parkinson's is not the same every day. Due to fluctuations, people might have reduced symptoms at some point during the day, and very strong symptoms, just hours after, which inevitably forces them to adapt their plans and activities. The dynamic nature of the everyday life with Parkinson's contrasts with medicalised perspectives on self-care that assume it to be static. In fact, when researchers equate self-care to a treatment to be optimised, as in Nakagawa-Kogan et al. [61] in referring to hypertension, or as a routine to be guided by doctors, as in Clark [15] in referring to multiple conditions, they portray a picture where self-care can be stable and predictable. Therefore, it would be possible for an external actor, in this case the doctor, to supervise and drive the patient away from dangerous situations. However, the self-care of Parkinson's, with its unpredictable fluctuations does not fit into this frame. Indeed, even if patients and carers made plans in advance, for avoiding potential problems, it was not really possible to predict when fluctuations will arise [85, 40], and thus adapting on-the-go is inevitable. Symptom fluctuations are a characteristic of Parkinson's, but researchers have documented unpredictable situations in other conditions as well [82, 72]. Charmaz [11] made the point that chronic conditions in general are dynamic because people experience "good days" – when symptoms are controlled and regimen works efficiently, and "bad days" – when the condition intrudes in more activities, control is limited, and the regimen overwhelming, and thus the experience can greatly vary from time to time. Moreover, as the "bad days" cannot be predicted

[27], people have to live with some uncertainty and need to adapt as things progress. Understanding self-care in practice requires one to shift away from a concept of static self-care to embrace a changing condition state and self-management, where different issues can force people to adapt and plan ahead for different possibilities.

Implications for design

Besides conceptual implications, recognising the mundane nature of self-care entails the consideration of more practical/technical implications for design. The following three seem to be most immediate.

Focus on the practical work of patients and carers

Since self-care often amounts to relevant work, self-care technologies for people living with Parkinson's should be designed to support the practical activities of patients and carers. This requires a shift in design activities, from focusing on interactions with clinicians and clinical outcomes, to everyday life issues and the perspective of patients and carers. When applying this consideration to the design of the SCRUMP, designers could consider supporting informal ways of exercise, for example, by counting the activities of washing dishes or cycling as input for the game. Designers could also consider involving carers, given their active role in preparing and accompanying the exercise of the patient. Acknowledging the practical work of patients and carers recognises that daily life with Parkinson's is challenging, and that technology can have a role in helping people to live well in practical terms.

Support negotiations and compromises

Since Parkinson's involves negotiating and compromising, self-care technologies should support people in making informed decisions about their health. For example, the medication reminder myHealthPal could allow people to snooze an alarm, enabling patients to take their medication slightly later, or even to delay medication in advance, keeping the same time interval between pills. Rather than restricting self-care activities, self-care technologies should inform patients and carers about the advantages, consequences, and overall impacts of following a certain approach (e.g., delaying), so that users can interpret and act upon the situations in which they find themselves at. Acknowledging the mundane nature of self-care invites one to consider that people living with Parkinson's have multiple competing concerns, and that they need to negotiate what is most important at each moment.

Support dynamic changes in self-care

The experience of living with Parkinson's can dramatically change from day to day or from hour to hour, based on several circumstances. Thus, self-care technologies should be designed to adapt to variations in the condition state. For example, Kinesia™ could accept delayed self-reports of symptoms, to account for the times when people experience fluctuations and find it hard to report them. The same technology could also enable people living with Parkinson's to adjust the current or next self-reporting schedule, so that patients could plan ahead their day to fit well with their agenda and issues they expect. Acknowledging the mundane nature of self-care entails accepting that daily life is dynamic, and that self-care technologies need to adapt to variable condition states and engagements in self-care.

Transferability

The findings reported in this paper originate from research with people living with Parkinson's, so it is only possible to talk about mundane self-care for their specific cases. However, previous research seems to indicate that insights from this study apply as well to people living with other chronic conditions. For example, we see evidence that *self-care entails great work*, when people who have migraines carefully track their activities to identify triggers for their symptoms and the best strategies to address them [67], or when people with rare diseases keep their own medical records, for sharing information between their different doctors [48]. We understand that self-care activities are *intertwined and ingrained*, when people with COPD balance effort in activities during the day to avoid damaging tissues [14, 72], or when people with diabetes decide to conceal or reveal their condition to others, as part of a process of impression management [65]. The *negotiations and compromises* of living with a chronic condition are visible when people with diabetes pursue multiple goals, priorities, or family issues to live well [28], or when people who had traumatic brain injury negotiate their social participation, taking into consideration their symptoms, goals in participating, and their independence level [25]. The *dynamic* nature of self-care is evidenced when migraine symptoms flare up unpredictably [67], or when people have to adapt to the degenerative nature of a condition like multiple sclerosis [5]. In essence, and independent from the particular issues caused, chronic diseases are enmeshed in the fabric of everyday life, so they are likely to originate mundane issues.

CONCLUDING REMARKS

This paper presented the everyday practices of the self-care of Parkinson's. It was clear that numerous challenges of Parkinson's were mundane and related with the need to practically adapt to the condition. These findings question the common assumption that self-care equates with monitoring symptoms or performing treatment and thus point to the need of approaching self-care through a different lens. Recognising the mundane nature of self-care entails understanding that performing self-care requires *great work* in organising and conducting activities. The activities are not isolated, but rather *intertwined and deeply ingrained in the everyday life* of specific people. Also, as not everything is possible at the same time, self-care is the result of *negotiations and compromises* that are *dynamically* adjusted as needed to live a life with quality.

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