The Everyday Life with Parkinson's and Self-care Technologies

PhD THESIS

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I hereby declare that I have written this Doctoral Thesis independently, that I have completely specified the utilized sources and resources and that I have definitely marked all parts of the work - including tables, maps and figures - which belong to other works or to the internet, literally or extracted, by referencing the source as borrowed.

Vienna, 26th May, 2017

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Francisco Nunes

I dedicate this thesis to my wife, Ana Cristina, who sacrificed beyond her strengths to create the conditions for me to finish. We did it baby!

Acknowledgements

Abstract

Self-care technologies are often framed as key to the healthcare reform that is moving chronic patients from hospitals and clinics to the home. The basic idea is that instead of being admitted to medical institutions, patients stay at home and engage in self-care with the support of technologies. However, despite considerable investment and political will, the uptake of self-care technologies has remained low and the results, mixed.

The low uptake of self-care technologies is well documented, but its origins relatively unexplained. Previous work points to diverse causes, including lack of incentives, limited evidence, and contrasts between the self-care of patients and carers and the ways of self-care enabled by technologies. The last issue is particularly relevant for the HCI/CSCW audience, because technology designs that do not fit everyday life may restrict people from using technologies that could benefit them. With this work, I studied the contrasts between self-care and self-care technologies in the context of a common chronic condition, Parkinson's disease.

This thesis investigates how patients and carers live with Parkinson's as a way to understand how self-care technologies align with their everyday life. To understand the daily life with Parkinson's, I interviewed patients and carers, observed neurology consultations at the hospital, and performed online ethnography in two online communities for people with the condition. The investigation of self-care technologies was performed using a critical review of self-care technologies for Parkinson's published on several scientific venues and the iTunes store.

The main contribution of this work is in the identification of four misalignments between self-care technologies and the self-care of people living with Parkinson's. These misalignments help explain the low uptake of self-care technologies for that condition, and, at the same time, point to values worth considering during the design of self-care technologies. Contributing to the design of future self-care technologies are also the thick description of the self-care of Parkinson's, the review of self-care technologies, and the design considerations put forward in this monograph.

Together, the different contributions call for the design of self-care technologies that fit appropriately with the everyday activities, values, and concerns of patients and carers.

Kurzfassung

Technologien für die Selbstfürsorge (Englisch: self-care technologies) werden oft als entscheidende Faktoren bei der Umsetzung von Gesundheitsreformen beschrieben, die dafür sorgen, dass chronisch kranke Menschen weniger Zeit in Krankenhäusern und Kliniken verbringen müssen. Mit Hilfe dieser Technologien soll es den Patient*innen ermöglicht werden länger zuhause zu bleiben und sich eigenständig zu versorgen. Derartige Lösungen werden jedoch selten angenommen, trotz beträchtlicher Investitionen und eines starken politischen Willens.

Dieser Sachverhalt wurde bisher vielfach dokumentiert; die Gründe dafür bisher aber nicht ausreichend geklärt. Forschungsarbeiten zeigen unterschiedliche Ursachen, unter anderem fehlende Anreize, mangelnde Evidenz sowie Unterschiede zwischen der benötigten Selbstfürsorge der Patient*innen oder Pfleger*innen und der Selbstfürsorge wie sie von der Technologie ermöglicht wird. Letzteres Problem ist insbesondere für die HCI/CSCW Gemeinschaft relevant, denn auch sehr nützliche Technologien finden oft keine Verwendung, nämlich dann wenn sie nicht in den Alltag der Menschen passen. In der vorliegenden Arbeit untersuche ich Unterschiede zwischen tatsächlicher Selbstfürsorge und dem Angebot welches durch Technologien für Selbstfürsorge bereitgestellt wird im Rahmen der geläufigen chronischen Erkrankung Parkinson.

Diese Doktorarbeit untersucht wie Patient*innen und Pfleger*innen mit Parkinson leben, um zu verstehen, wie Technologien für Selbstfürsorge mit dem alltäglichen Leben in Einklang zu bringen sind. Dazu habe ich Patient*innen und Pfleger*innen befragt, neurologische Sprechstunden im Krankenhaus observiert und Ethnographien in zwei online Communities zu Parkinson durchgeführt. Zudem habe ich unterschiedliche wissenschaftliche Publikationen und den iTunes Store in Hinblick auf Technologien für Selbstfürsorge kritisch beleuchtet.

Der maßgebliche Beitrag dieser Arbeit liegt in der Identifizierung von vier Abweichungen zwischen Technologien für Selbstfürsorge und der tatsächlichen Selbstfürsorge derer, die mit Parkinson leben. Diese Abweichungen sind dabei hilfreich zu erklären, warum Technologien für die Selbstfürsorge bei Parkinson selten angenommen werden und zeigen gleichzeitig vielversprechende Ansätze für das Design künftiger solcher Technologien auf. Diese Ansätze werden zudem durch die reichhaltige Beschreibung von Selbstfürsorge in Parkinson, den Überblick über schon existierende Technologien, sowie weitere Design Überlegungen in dieser Dissertation untermauert.

Insgesamt legen die unterschiedlichen Erkenntnisse ein Design von Technologien für Selbstfürsorge nahe, welches angemessen auf die alltäglichen Aktivitäten, Werte und

Anliegen von den Patient*innen und Pfleger*innen eingeht.

Resumo

As tecnologias de autocuidado são apresentadas frequentemente como a chave para a reforma dos cuidados de saúde, que está a mover os doentes crónicos dos hospitais e clínicas para as suas casas. A ideia base é que, em vez de serem internados em instituições, os pacientes fiquem em casa praticando o autocuidado com a ajuda de tecnologias. Contudo, e apesar de investimento considerável e vontade política, a adoção das tecnologias de autocuidado é baixa e os resultados do seu uso, mistos.

A baixa adoção das tecnologias de autocuidado está bem documentada, mas as suas causas parcialmente por explicar. Estudos anteriores apontam para vários problemas, incluindo falta de incentivos, evidência limitada, e contrastes entre o autocuidado dos pacientes e cuidadores e as maneiras de autocuidado suportadas pela tecnologia. O último problema é particularmente relevante para a audiência de HCI/CSCW, porque tecnologias que não se ajustam ao dia-a-dia podem restringir o acesso das pessoas a ferramentas que podiam beneficiá-las. Com este trabalho, eu estudei os contrastes entre o autocuidado e as tecnologias de autocuidado disponíveis para uma doença crónica comum, a doença de Parkinson.

Esta tese investiga como pacientes e cuidadores vivem com Parkinson de maneira a compreender como as tecnologias de autocuidado alinham com o seu dia-a-dia. Para entender o dia-a-dia com Parkinson, entrevistei pacientes e cuidadores, observei consultas de neurologia no hospital, e conduzi etnografia virtual em duas comunidades da Web para pessoas com a doença. A investigação das tecnologias de autocuidado foi conduzida usando uma revisão crítica de tecnologias apresentadas em publicações científicas e na loja do iTunes.

A maior contribuição deste trabalho está na identificação de quatro desalinhamentos entre as tecnologias de autocuidado e o autocuidado das pessoas que vivem com Parkinson. Os desalinhamentos ajudam a explicar a baixa adoção de tecnologias para aquela doença, e, ao mesmo tempo, sugerem valores a considerar aquando do desenho de tecnologias de autocuidado. A contribuir para o desenho de futuras tecnologias de autocuidado estão também as descrições densas do autocuidado de Parkinson, a revisão de tecnologias de autocuidado, e as considerações de desenho apresentadas nesta monografia.

Em conjunto, as diferentes contribuições reclamam por um desenho de tecnologias de autocuidado que se ajusta apropriadamente às atividades do dia-a-dia, aos valores, e às preocupações de pacientes e cuidadores.

Published Work

Elements of my PhD research have been published in journals articles, conferences papers, and extended abstracts over the past four years.

Journal articles

P.1 F. Nunes, N. Verdezoto, G. Fitzpatrick, M. Kyng, E. Grönvall, and C. Storni (2015) "Self-care Technologies in HCI: Trends, Tensions, and Opportunities", *ACM Transactions on Computer Human Interaction*, 22(6), article 33.

P.2 F. Nunes, and G. Fitzpatrick (2015) "Self-care Technologies and Collaboration", *International Journal of Human Computer Interaction*, 31(12).

P.3 F. Nunes, P. A. Silva, J. Cevada, A. C. Barros, and L. Teixeira (2015) "User Interface Design Guidelines for Smartphone Applications for People With Parkinson's Disease", *Universal Access in the Information Society*, 16(2).

P.4 F. Nunes, T. Andersen, and G. Fitzpatrick (2017) "The agency of patients and carers in medical care and self-care technologies for interacting with clinicians", *Health Informatics Journal* (in press).

Conference papers

P.5 F. Güldenpfennig, F. Nunes, and G. Fitzpatrick (2015) "ProxyCare: Integrating Informal Care into Formal Settings" in *Proc. of PervasiveHealth 2015*, 141–144.

Extended abstracts

P.6 F. Nunes (2015) "Designing Self-care Technologies for Everyday Life: A Practice Approach", in *Proc. of CHI EA 2015*, 215-218.

P.7 F. Nunes (2013) "Improving the Self-care of Parkinson's Through Ubiquitous Computing", in *Proc. of Ubicomp Adjunct 2013*.

Parts of the papers mentioned above were reworked into chapters, sections, or merged with other texts in this manuscript. In particular, the following connections are worth mentioning:

- The 'Literature review' chapter was for some sections informed by P.2, and P.3.

- The 'Methodology' chapter adopted minor parts of a section from P.1.

- The chapter on 'The collaborations between patients and carers in the self-care of Parkinson's' was in part taken from P.2.

- The chapter on 'The active agency of patients and carers in their medical care' draws partially on P.4.

- The chapter on 'Review of self-care technologies' was in parts taken from P.2 and P.4

Contents

List of Figures

List of Abbreviations

COPD	Chronic Obstructive Pulmonary Disease
CSCW	Computer-Supported Cooperative Work
DA	Dopamine Agonist
F1Mx	Member number x who posted in the first online community – the community for patients and carers
HCI	Human-Computer Interaction
IPx	Patient number x who participated in the interviews
IPx_Cy	Carer number y who participated in the interviews (related with patient number x)
OPx	Patient number x who participated in the observations at the hospital
OPx_Cy	Carer number y who participated in the observations at the hospital (related with patient number x)
PD	Parkinson's Disease
PWP	People with Parkinson's
STS	Science and Technology Studies

Introduction

This thesis explores how patients and carers live with Parkinson's as a way to investigate the alignment between self-care technologies and the everyday life with Parkinson's. The work is motivated by the low uptake of self-care technologies, despite their potential to support the life of patients and (informal) carers. Drawing on qualitative ethnographic informed methods, the thesis characterises the concept of self-care of Parkinson's, and using a review of self-care technologies, it documents the opportunities promoted by self-care technologies. Comparing the ethnographic fieldwork with the reviewed self-care technologies points to currently existing misalignments, and leads the discussion to design considerations for designing self-care technologies for Parkinson's that are well aligned with the everyday life with the condition.

1.1   Background and motivation

Nowadays, numerous papers in Human-Computer Interaction (HCI) and Computer-Supported Cooperative Work (CSCW) start by saying that the population is getting older and having more chronic conditions (e.g., McNaney et al. (2011), de la Guía et al. (2013), Xu et al. (2016)). In times of low birth rates and high longevity, it has become common to design and study technologies to support the lives of older people with incurable (or chronic) conditions at home and in everyday life. There were good reasons for engaging in work in this area. After all, older adults are expected to make up 25% of the population in Europe and North America by 2030 (United Nations, 2015), and there is strong evidence that living longer increases the chances of developing chronic conditions (Ben-Shlomo and Kuh, 2002).

Besides the humanistic motivations of improving the lives of people with chronic conditions, there were strong economic incentives leveraging the research on technologies for this audience. Austere budgets and growing healthcare expenditures from treating more chronic patients (European Commission, 2012; OECD, 2015) motivated Western

Countries to invest in technologies to cut on healthcare costs[1]. In Europe, the European Union was pivotal in driving this investment by making available research and innovation funds to develop and study technologies for patients with chronic conditions to use at home and in everyday life. For example, in 2016 alone there were multiple lines of funding from the European Union to support projects in this area, including: AAL Programme[2], Health Programme[3], HORIZON 2020[4], and Investment Plan for Europe[5].

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 (Fitzpatrick, 2011). The basic idea was that instead of being in formal care institutions, people would stay at home and engage in self-care with the support of technology, thus alleviating healthcare professionals to focus on more urgent situations (see Figure 1.1). The technologies for supporting people living with chronic conditions are named self-care technologies in this thesis, but the literature also suggests other terms, including Telehealth, Telehealthcare, or Telecare. The definition of self-care technologies will be discussed in the Literature review chapter, but for now, it is enough to say that self-care technologies support patients and (informal) carers in engaging in self-care, away from doctors or other formal healthcare personnel.

However, despite significant investment and political will, self-care technologies achieved a limited uptake (Paré et al., 2007; Hardisty et al., 2011; May et al., 2011; Gorst et al., 2014; Lau et al., 2015). While the low uptake is documented in numerous articles, its causes are not well explained. Some studies mention that projects in the area did not put enough attention on the regulatory aspects of the service (Hardisty et al., 2011), while others mention that the right incentives for clinicians to employ self-care technologies as part of their practice are not in place yet (May et al., 2011). In any case, two issues appear most commonly in the literature. First, the evidence around self-care technologies is limited and inconsistent. While there have been experiments showing improved clinical outcomes (Bensink et al., 2006; Paré et al., 2007, 2010; Chandak and

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[1]Chronic conditions can manifest at any life stage, from early childhood to older age. Nevertheless, the investments to cut on the costs of healthcare mostly targeted chronic conditions of older age, and so they appear foregrounded here.

[2]The AAL Programme in 2016 is themed "Living well with dementia" and is exclusively focused on funding projects that can leverage technology to improve informal care at home. The funding available was 30 million and the work programme is available at: http://www.aal-europe.eu/wp-content/uploads/2016/03/AAL-Call-Text-2016-07-Mar-2016.pdf.

[3]The Health Programme, awarding 36.3 million euros in 2016, has actions such as "Health Innovation and Health Technology Assessment" (50 million: 2016-2019), or "Health innovation and e-Health" that support, at least in part, the development of self-care technologies. The work programme is available at: https://ec.europa.eu/health/sites/health/files/programme/docs/wp2016_annex_en.pdf.

[4]The HORIZON 2020 has a societal challenge named "Health Demographic Change and Wellbeing", awarding up to 353 million euros in 2016, with multiple mentions to self-care technologies. The work programme is available at: http://ec.europa.eu/research/participants/data/ref/h2020/wp/2016_2017/main/h2020-wp1617-health_en.pdf.

[5]The Investment Plan for Europe is expecting to mobilise investments up to 315 billion euros between 2015 and 2017. One area the plan supports is the development of innovative health technology for active and healthy ageing which, at least in part, could suit the development of self-care technologies. See: http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing&pg=calls.
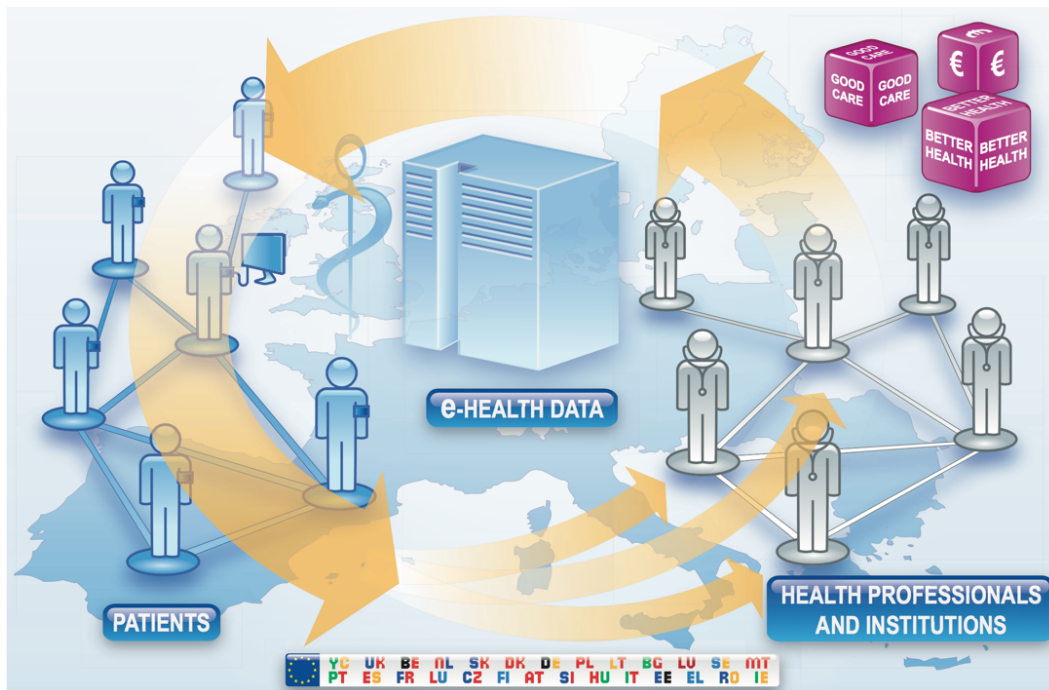
Figure 1.1: This figure accompanies the report of the EU Task Force on "eHealth: Redesigning health in Europe for 2020". e-Health and its generated data appear on the centre of the figure, connecting patients to healthcare professionals and institutions, and symbolising the key role of technology in enabling a healthcare reform that would reduce costs and improve care (see top right). (Credits: http://ec.europa.eu/newsroom/dae/document.cfm?doc_id=2650).

Joshi, 2015), many systematic reviews argue that using self-care technologies do not have clear and unequivocal clinical improvements over usual care (Barlow et al., 2007; DelliFraine and Dansky, 2008; Polisena et al., 2010; Archer et al., 2011; Ekeland et al., 2011; Hardisty et al., 2011; Cruz et al., 2014; Huang et al., 2014; Lundell et al., 2015). The mixed outcomes, together with the majority of the trials being conducted with a very small sample of participants (Paré et al., 2010), leads clinicians to doubt about the efficacy of self-care technologies and continue with their usual care approaches (May et al., 2011). The second issue is related with misalignments between self-care technologies and the self-care of patients and carers. Using self-care technologies often means adapting one's self-care to the way the machines operate, sometimes considerably, and despite the long experience or success of the self-care arrangements of patients and carers. Facing these forced adjustments, some people try to use self-care technologies in ways that better fit their self-care or reject the self-care technologies altogether (Storni, 2010; Grönvall and Verdezoto, 2013; Piras and Zanutto, 2014; Lau et al., 2015). Moreover, some people even reject self-care technologies before using them, because the explanation offered by researchers or technicians setting up the trial makes patients and carers feel that they

would have to change their self-care substantially in ways they did not appreciate (Mort et al., 2013; Sanders et al., 2012).

This thesis investigates how self-care technologies align with the self-care of patients and carers as a way to inform the design of the next generation of self-care technologies. Instead of developing a particular technology and then studying whether it fits the self-care of patients and carers, I studied how people live with Parkinson's and compared this understanding with the opportunities that are promoted with existing self-care technologies. This way, misalignments could be identified before starting the design process, saving time and understanding values that might have been taken for granted in the existing self-care technologies.

1.2   Parkinson's disease as an example

To investigate how self-care technologies align with the everyday self-care experience of patients and carers, I focused on a specific chronic condition: Parkinson's disease. I chose to investigate a single condition because I could directly compare the experience of patients and carers with the self-care technologies available to them.

Parkinson's is a neurological condition that impacts different areas of the body. The characteristic features are four motor symptoms: slowness of movement, rest tremor, rigidity, and postural instability; yet, non-motor symptoms, such as pain, depression, or cognitive impairments, are also likely to appear. Parkinson's has a progressive outlook, so symptoms are expected not only to persist but to get worse with time. Symptoms can also fluctuate for a number of reasons, such as the weather or emotions. To make matters even more complex, Parkinson's medication can only address symptoms and has a transient effect that runs out after some hours.

This quick description of Parkinson's is not enough for grasping its complexity[6], but it outlines some issues that make Parkinson's an interesting case study for this thesis. First, the varied symptoms that impact multiple parts of the body, indicate that the condition has a strong influence in daily life. Second, the progressive nature of the condition, suggests that self-care may change every couple of years. Third, the fluctuations of the condition, lead to believing that people may often need to adjust and adapt their plans. Moreover, fourth, the transient nature of medication suggests that medication will represent important work.

1.3   Research questions and approach

This work was guided by five research questions:

- RQ1: How do people living with Parkinson's engage in self-care in everyday life?

- RQ2: How do people living with Parkinson's learn to perform self-care?

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[6]Refer to Section 2.3 for a thorough description of the characteristics of Parkinson's.

- RQ3: How do people living with Parkinson's interact with their doctors?

- RQ4: How do self-care technologies support everyday self-care, the ways in which people learn to live with the condition, or the ways in which people interact with their doctors?

- RQ5: How do self-care technologies align with the ways in which patients engage in self-care, learn to perform it, and interact with their doctors? And what are the critical everyday issues to consider when designing self-care technology based on how people living with Parkinson's self-care?

The investigation of the daily life with Parkinson's was based on in-depth interviews with patients and carers, online ethnography of two online communities, one where patients interact with other patients and carers, and another one where patients and carers interact with doctors, as well as observations at an outpatient neurology clinic. I also performed a critical review of studies describing self-care technologies, and compared the opportunities promoted by these technologies with the findings from the ethnographic study. This comparison yielded important contrasts between the everyday life with Parkinson's and the lives that were promoted by self-care technologies. This comparison was possible because technologies define a course of action and characteristics of the users, based on the preferences, values, aspirations, and prejudices, that designers put into their development (Akrich, 1992). By contrasting the daily life with Parkinson's with the expected users and course of action of technologies, it was possible to uncover opportunities for self-care technology to better fit everyday life.

1.4 Contributions

The main contribution of this thesis is in the identification of misalignments between the everyday self-care and self-care technologies. The thesis not only identifies the misalignments, but also investigates their origin, and proposes design considerations to potentially overcome them. Besides the main contribution, this work offers three supplementary contributions:

- A thick description of the self-care activities of people living with Parkinson's;

- A characterization of the concept of self-care of Parkinson's, in comparison with self-care literature concerned with other chronic conditions;

- A review of self-care technologies for Parkinson's, published in different venues, as well as self-care technologies in general as published in HCI and CSCW conferences and journals;

These four contributions should help designers working with self-care technologies in different ways. The more direct one is to inspire designers to work on areas or issues in which self-care technologies are misaligned with the everyday life with Parkinson's, so

that self-care technologies can better fit the lives of patients and carers. The second way is to give designers a better understanding of the concept of self-care from a perspective of daily life, enabling them also to empathise with the issues patients and carers go through. Moreover, the third way is to give designers an overview of the variety of self-care technologies that have been developed for people living with Parkinson's, enabling them to identify areas where most work has occurred.

1.5   Overview of the chapters

This thesis is structured as follows:

- Chapter 2 overviews the various literatures that inform this PhD research. Self-care, self-care technologies, and Parkinson's disease, are the broad themes covered in the chapter that introduces the reader to the multidisciplinary area of research where this thesis fits in.

- Chapter 3 turns to the methodological framework orienting this thesis. The chapter starts by introducing the constructivist lens used in this research, together with the epistemological and ontological principles it adheres to, as well as evaluation criteria proposed by researchers working in this paradigm. Then, I introduce the Grounded Theory methodology, an important *compagnon de route*, which influenced strongly the inquiry and analysis of this research. This is followed up by a description of the data collection methods used in this thesis, which include in-depth interviews, observation, and online ethnography. At the end of the chapter, I offer some notes on the specific perspective I bring to this work.

- Chapters 4, 5, 6, 7 correspond to the ethnographic fieldwork conducted with people living with Parkinson's. They describe how people engage in self-care (RQ1), how they learn to live with the condition (RQ2), and how people interact with their doctors (RQ3). Moreover, the chapters characterise the concept of self-care for people living with Parkinson's. For a more granular explanation of the contribution of each fieldwork chapter, refer to Table 1.1.

- Chapter 8, the last empirical chapter, critically reviews self-care technologies for Parkinson's, and other chronic conditions, to understand the ways of self-care that they have promoted (RQ4). See also Table 1.1.

- Chapter 9 pulls the preceding five empirical chapters together, comparing the everyday self-care observed in the ethnographic fieldwork and the ways of self-care promoted by self-care technologies (RQ5). First, misalignments between self-care technologies and everyday life are identified. Then, the chapter reflects on the theoretical perspectives that could originate the misalignments. Moreover, I propose design considerations that can help reducing or addressing those misalignments.

Chapter	RQ	Methods	Conceptual contribution
4. The mundane self-care of Parkinson's	1	In-depth interviews with patients and carers, and online ethnography of a community for patients and carers	Self-care as entailing important mundane work, rather than only medicalized activities
5. The collaborations between patients and carers in the self-care of Parkinson's	1	In-depth interviews with patients and carers, and online ethnography of a community for patients and carers	Self-care as collaborative, not strictly individual endeavour
6. Learning to live with Parkinson's	2	Online ethnography of a community for patients and carers, and in-depth interviews with patients and carers	Learning as led by patients and carers, instead of doctors
7. The active agency of patients and carers in their medical care	3	Observations at hospital, online ethnography of a community for interacting with doctors, and in-depth interviews with patients and carers	Patients and carers as very active, rather than passive agents in consultations
8. Review of self-care technologies	4	Critical review of self-care technologies	Most self-care technologies are individual and medicalized. Potential to support learning and interactions with doctors, despite obstacles
9. Discussion	5	Comparison of all mentioned above	Multiple misalignments between everyday self-care and self-care technologies, probably due to incorporating medicalized values. Design considerations for better aligning self-care technologies

Table 1.1: Overview of the thesis: research questions, methods, and contributions of each of the main content chapters.

- Chapter 10 concludes this work. It starts by outlining the contributions made in this thesis. Then, it discusses similarities and differences between Parkinson's and other common chronic conditions. The chapter continues with a discussion of the findings in relation to the constructivist evaluation criteria outlined in Chapter 3. Following is a discussion of the limitations of this work. At the end of the chapter, I advance possible directions for future research.

- Enclosed as appendices are: notes on the technology probes, analysis process, ethics information sheets and consent forms given to participants, and a list describing the self-care technologies mentioned in the thesis.

CHAPTER 2

Literature review

This chapter introduces the scientific context that gives rise to this work. In particular, I review[1] previous work around the topics of self-care, self-care technologies, and Parkinson's, the broad areas in which this thesis is built upon. To cover the complexity of these topics, the literature reviewed is not restricted to publications in HCI or CSCW venues, but encompasses work coming from the social sciences, including Science and Technology Studies (STS), Sociology of Ageing, or Sociology of Health, as well as from the medical sciences, including areas such as Neurology, Health Informatics, or Medical Informatics (see Figure 2.1). This chapter shows that a large body of work exists around self-care and self-care technologies and that distinct perspectives coexist. Moreover, the chapter demonstrates that the literature has failed to provide an in-depth analysis of the self-care of Parkinson's or of the self-care technologies for people living with that condition.

The chapter is structured in three sections: an introduction to self-care, a contextualization of self-care technologies, and a section about Parkinson's.

2.1 Self-care

The literature on the self-care of Parkinson's is rare. While previous work has investigated some of the self-care activities involved in Parkinson's, the research does not use the label of self-care (see Section 2.3.4). Consequently, this section will refer to the general

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[1]One proponent of Grounded Theory, i.e., Glaser (1992), claims that the literature review should only occur after direction has been gained with the analysis. He aimed to prevent concepts of the literature from influencing the analysis of the field data, and could imply that the literature review chapter would appear towards the end of the thesis. I have a less restrictive perspective on this issue. Similar to Charmaz (2006), I believe that not reviewing related work before starting the research may render researchers unproductive, because they investigate issues that others have reported, or naïve, because they do not have sensibility for important issues documented before. Thus, in this work, I have reviewed literature from beginning to the end. Moreover, this chapter appears at the beginning of the thesis to contextualise the reader on previous work, but should not be seen as material gathered before starting the work. The Literature Review was actually one of the last chapters to be completed.
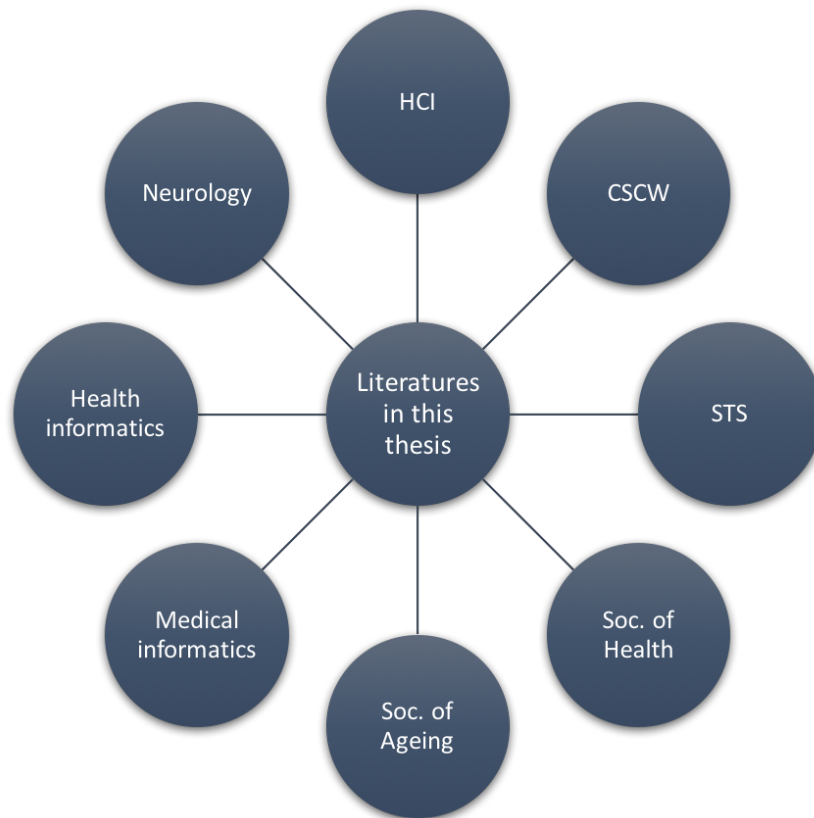
Figure 2.1: Broad scientific areas surveyed in the literature review.

literature on self-care and, in some cases, refer to studies concerning other chronic conditions, such as diabetes or Chronic Obstructive Pulmonary Disease (COPD). Doing so will provide an overview of the work that has been conducted around self-care, enabling the reader to understand the intellectual tradition on which this work is built upon.

2.1.1 Introduction to the self-care of chronic conditions

To introduce self-care, it is useful to take a look at the concept of chronic conditions[2]. As previously noted, chronic conditions are medical conditions that have no cure or definitive treatment. Care, although able to contribute to better living circumstances, does not lead to health, so its goal is not to cure, but to create a good quality of life for as long as possible (Mol, 2008). This is easier said than done because, as Wagner

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[2]The expressions "chronic condition", "chronic illness", and "chronic disease" are used interchangeably in this thesis. Some authors use "chronic disease" when talking about medical diagnosis or symptoms, and "chronic illness" to refer to the experience of patients (Eisenberg, 1977); however, applying this dualist perspective is not very productive, because medical and experiential aspects of a chronic condition are deeply intertwined. Using the expressions interchangeably enables me to refer to the condition in all of its dimensions, from the medical or biological definition to the lived and social experience.

et al. (2001) explain, people living with chronic conditions[3] have to deal with symptoms, face disabilities, understand and cope with complex medication schemes, and find ways to obtain useful medical advice. A given chronic condition may also have an emotional impact and force radical lifestyle changes (Bodenheimer et al., 2002). These challenges encourage patients and carers to self-care, that is, to manage the disease by themselves.

Self-care is defined here as the activities that people living with a chronic condition[4] (patients and carers[5]) 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 (Randell et al., 2010; Fitzpatrick, 2011). 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 (Barlow et al., 2002). 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 living with diabetes, for example, need to balance exercise, diet and insulin (Storni, 2010). In contrast, people living with COPD, worry most about managing effort, prioritising tasks and exercising (Cicutto et al., 2004). Since self-care is intimately related with the disease being cared for, people living with different diseases care for themselves in distinct ways. Furthermore, it is important to stress that self-care is not a well-defined role people play, but a process of "persistent tinkering" (Mol et al., 2010) in which people negotiate and compromise among different options and multiple issues.

2.1.2 The goal of self-care

While researchers agree 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 and everyday life of the patient. Even though patients proceed with their everyday lives outside formal settings, doctors are expected to coordinate or oversee their health through regular checkpoints, close scrutiny, and detailed guidance (Clark et al., 1991; Worth, 1997). Self-care is sometimes even described as a treatment, the

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[3]When referring to people living with chronic conditions I refer to both patients and (informal) carers. While carers do not experience the condition in their body, they are also affected by it. Thus it makes sense to say that they live with the condition.

[4]The term self-care is sometimes used to denote the preventive activities healthy people engage in to live a long and comfortable life (Clark et al., 1991). This broad definition undermines the work of people living with chronic conditions by putting it on the same bag as that of healthy people. Thus, in this thesis the term self-care refers only to people living with chronic conditions.

[5]In this thesis, I use the word patient to identify people who have at least one chronic condition, and the word carer for those involved in caring for and with patients outside of an institutionalised setting. Being a patient or a carer are not the only roles in which people engage, however, I use these terms for clarity and brevity.

goal of which is to maximise the regulation of the condition through different processes (Nakagawa-Kogan et al., 1988).

In contrast, other researchers defend that the purpose of self-care is to deal with the practical issues of living with a chronic condition. Cicutto et al. (2004) 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. Rather than only pursuing medical activities, people are juggling multiple goals, priorities, and issues because the condition is not something separate from their lives (Corbin and Strauss, 1988; Funnell and Anderson, 2000). This perspective recognises that living with a chronic condition in practical terms is quite complex (Wagner et al., 2001).

2.1.3 The actors involved in self-care

Another point of discussion in the self-care literature relates to the people who perform self-care. In this case, there are three different interpretations.

The first discourse frames care as exclusively or largely undertaken by *patients*. Patients 'self-care' or 'self-manage', meaning that they care for their condition by themselves. This narrative is exemplified by definitions in the medical literature as the following:

> *"Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life"* (Barlow et al., 2002).

Patients are individually managing their conditions. They are the ones observing the condition, addressing symptoms, managing their behaviour, and adjusting their emotional responses. Carers are absent from the definition. Sometimes researchers argue that self-care is not an individual activity, in recognition of the influence of other patients (Pols, 2014), doctors (Unruh and Pratt, 2008), or technologies (Pols, 2012), but carers are not usually mentioned. Carers are thought to provide only support. This discourse emerged in the United States for good reasons, as part of a trend to question established authority (Shoor and Lorig, 2002); in this specific case, the authority of the doctor in the doctor-patient relationship. Doctors and researchers defended a shift of power from the doctor to the patient in the context of medical care. The overall idea was that, with adequate education and tools, active patients would be able to manage their conditions by themselves. Other studies displaying this narrative include Clark et al. (1991), Worth (1997), Anderson and Funnell (2000), and Wagner et al. (2001).

The second perspective considers self-care to be exclusively or largely performed by *carers*. Carers "informally care", meaning that they provide care to the patients in need, usually those who are unable to, or need help to, perform their own care. This discourse appears in definitions such as the following:

> *"Informal care refers to all unregulated, mostly unpaid, activities on behalf of children, elderly relatives, or others. (…) In principle, these provisions are targeted either to persons who need care (care receivers) or to persons who provide care (care providers or carers)"* (Bettio and Plantenga, 2004).

Care is provided *pro bono* to relatives, in this case, with a chronic condition. The roles seem to be very well-defined. One gives and the other receives. Underlying such a definition is also a supposition that patients are not part of their own care. They have lost, or never had the ability to care for themselves, for example, through age or disability, and so are under the carer's responsibility. Sometimes, authors mention that care is dependent on the condition or the functional status, but no further mention is made about how much patients participate or collaborate in their care. This discourse on care[6] also emerged for good reasons, as a contribution of feminist academics who tried to make unpaid work by women[7] become more visible and understood (Fine and Glendinning, 2005). Their agenda had not only research aims but also activist aspirations to influence political decision making. This narrative can be found in other studies including (Brouwer et al., 2004; Given et al., 2001; Fine and Glendinning, 2005).

The third narrative frames self-care as a collaborative endeavour between patients and carers. They see collaborations as happening at multiple levels, from medical consultations to the more mundane work at home (Corbin and Strauss, 1984, 1988; Strauss et al., 1985). Some authors even argue that the word 'self' in 'self-care' undermines its dependence on the actions of a collective of multiple actors (Danholt and Langstrup, 2012). Collaboration in this context "refers to the manner in which couples [or patients and carers] work together – the work pattern that they have established between them" (Corbin and Strauss, 1984). This division of self-care activities is flexible, changing in the face of progression of their condition or the emergence of unexpected life events. Moreover, the collaboration is based on the acceptance of the chronic condition, and a mutual commitment to its management.

2.1.4   The learning involved in self-care

The research community acknowledges that people living with chronic diseases can learn. In fact, living with a complex condition is expected to motivate people to learn how better to deal with it. However, the learning processes and the intermediaries involved vary according to two different perspectives.

For some researchers, learning happens mostly in consultations or other medical encounters and is coordinated by the doctors involved. While patients are the ones learning, doctors are expected to lecture them on all aspects of the condition that they should learn about (Clark et al., 1995). This perspective essentially sees patients as

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[6]Care in this part of the literature is, many times, defined broadly encompassing health-related tasks, as well as household chores.

[7]In their pursuit of making the work of women more visible, feminist scholars and activists often emphasised the work of women in caring for their sick relatives. However, it is important to mention that not all carers are women.

naïve and doctors as the guardians and owners of expert knowledge about the condition. As Lawn and Schoo (2010) argue, patients "do not immediately feel the consequences of poor lifestyle choices on their health and wellbeing" (p. 205), so it is up to doctors and patient education programmes to persuade and inform patients, so that they reach recognised standards of behaviour[8]. The information people can learn also tends to restrict to medical insights about the condition.

On the contrary, other researchers see learning as linked with the experience with the condition and focused on improving the quality of life. Patient knowledge[9], as commonly referred in this literature, is used by patients and carers to "interpret, appreciate, and shape their daily lives with the disease in a good way" (Pols, 2014, p. 75). Learning activities are not dependent on doctors, but are based on the personal experience with a specific phenomenon: living with a chronic condition (Borkman, 1976). The purpose of learning is not, so to say, academic. In general, people are not trying to gather biomedical knowledge about their condition (Mol and Law, 2004), or become familiar with the causes of their disease and symptoms (Storni, 2015a) for its own sake. The point is intervening to address one's current issues, in the pursuit of creating a life with quality[10].

2.1.5   The interactions with doctors

As mentioned before, self-care occurs mostly while people are at home and in everyday life, away from doctors and medical institutions. This is interestingly displayed by Figure 2.2, in which the interactions with clinicians are only the tip of the iceberg of the overall self-care engagement that people living with the condition go through. Nevertheless, patients and carers do visit the doctor at regular intervals to re-evaluate the state of the condition state and, if necessary, adjust treatment. The interactions with doctors are usually seen as collaborative and framed under a narrative of patient-centred care; however, the level of participation expected of patients and carers is not always the same.

Some researchers see the participation of patients and carers as a way to help doctors make the best medical decisions. Patients and carers are expected to bring issues and complaints to consultations, for doctors to be able to make an informed diagnosis and advise them on the best treatment (Clark et al., 1995). Even though people may track symptoms and other aspects of their health, in practice, the analysis and decisions are

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[8]The Expert Patients programme from the United Kingdom is an example of an educational programme where healthcare professionals are the guardians of knowledge (Wilson et al., 2007). Even though patients lead the training sessions, the themes, content, and the structure of the educational programmes are modelled to focus on medical aspects and promote medically-recommend standards of behaviour.

[9]The expression "patient knowledge" hints that patients would be the ones learning, however, carers can also recognise subtle changes in abilities, interests and behaviour (Prior, 2003; Mol and Law, 2004), and thus are capable of developing knowledge themselves. The perspective of carers is necessarily different because they do not live with the condition through their body, but one can also say that they experience the condition.

[10]Some patients and carers become experts in their condition also in the biomedical sense in the pursuit of contributing, influencing, or challenging research. Examples have been documented in, for instance, Arksey (1994) or Epstein (1995). However, these contributions fall out of the scope of this chapter because the production of biomedical knowledge is not the focus here.

Figure 2.2: With the message "You are already your own doctor", this figure aims to encourage an active role of patients, who are performing "the predominant form of healthcare" (Credits: http://e-patients.net/u/2014/12/iceberg-spm-2000x2000.png by Hugo Campos, licensed under CC A).

made by their doctors (Ong et al., 1995; Godolphin, 2009). This perspective on the interactions with doctors bears some resemblances with the traditional model of care as described by Parsons[11], because while people might engage in some preparatory work at home, doctors are still at the centre of the medical decisions.

Other researchers argue that patients and carers assume a crucial role in consultations, contributing to discussions and decisions made. Rather than mere informants, patients and carers are seen as experts in their own lives, who have important insights to bring to the consultation (Anderson and Funnell, 2000; Glasgow and Anderson, 1999). Understanding their lived experience, their objectives, and their expectations is seen as the only way to provide appropriate medical care (Epstein et al., 2004). Instead of behaving as coordinators of care, doctors take on the role of advisors, helping people achieve the objectives that are important to them in ways that are appropriate for them (Bodenheimer et al., 2002; Berwick, 2009). They will inform and advise patients and carers, but it is up to patients and carers to reflect and choose what is most important to them (Mol, 2008).

This section has shown that the concept of self-care is very disputed in the literature, with authors advancing very distinct perspectives on what self-care is or entails. The existence of such disparate perspectives indicates the complexity of the context where self-care is performed and the multiple facets it includes. Inspired by this work, this thesis was set out to investigate different aspects of self-care, from daily life to medical consultations, to understand the perspectives of patients and carers living with Parkinson's on what self-care is.

2.2 Self-care technologies

To help people deal with the complexity of self-care, multiple self-care technologies were developed. Chapter 8 will make a thorough review of self-care technologies for patients and carers living with Parkinson's and other chronic conditions, however, it is relevant to introduce the topic of self-care technologies here. This section starts by defining self-care technologies. Then, I describe the most common approaches to studying self-care technologies. Moreover, this section concludes with an explanation of what misalignments between self-care technologies and self-care of patients and carers are.

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[11]The traditional model of care was initially described by Parsons (1951). In his book, Parsons detailed the characteristics of the 'sick role', a circumstance in which patients were exempt from performing their activities and obligations, but were expected to visit their doctor in search of a cure for their ailments. The role of doctors was to carefully analyse the patients' cases and decide on the treatment. Patients were expected to cooperate with their doctors and comply with their orders. In this relationship, the patient was framed as largely ignorant and thus in great need of the (expert) doctor's guidance and advice. The patient was also supposedly frustrated or emotionally unbalanced and, for that reason, thought to behave irrationally. The traditional model of care has been extensively criticised for being inappropriate for dealing with chronic diseases, because it contributes to uninvolved patients, or unneeded hospitalisations, and thus low quality of care (Holman and Lorig, 2000). Still, many if not most care medical encounters still operate under a framing that reminds the description of Parsons (Pinder, 1990; Ong et al., 1995; Godolphin, 2009).
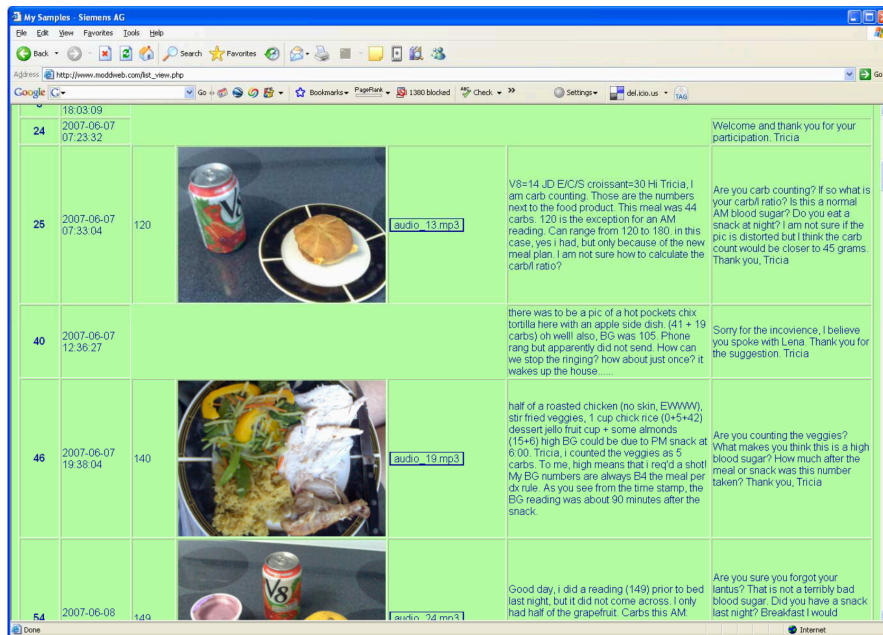
Figure 2.3: MAHI by Mamykina et al. (2008) was one of the first self-care technologies published in HCI. Participants with diabetes were given a special glucose meter that uploaded measurements to a web application where they could be accessed by them and a diabetes educator. The idea was that people would discuss measurements and any other doubts with the diabetes educator, employing text, pictures, or audio-recordings. The figure shows a screenshot of MAHI web application displaying multiple message exchanges (Credits: Mamykina et al. (2008) © ACM).

2.2.1 Introducing self-care technologies

Self-care technologies are tools that support the self-care activities of people living with chronic conditions (see Figure 2.3 and 2.4 for examples[12]). 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, Telehealthcare, and Telecare[13,14] (see Figure 2.5 for definitions). The goal of self-care technologies is not restricted to enabling interactions with the care team, but includes the support of more mundane issues of patients and carers. Smartphone medication reminders, for example, help people dealing with the practical issue of remembering about medication.

Having said this, it is important not to confuse self-care technologies with tools for

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[12]The self-care technologies mentioned in this thesis are quickly described in Appendix D.

[13]Besides connecting patients with their medical care team, Telecare can connect with social services, for monitoring emergencies at home. These aspects are not included in the concept of self-care technologies.

[14]The term Telemedicine is also used at times to name self-care technologies (e.g., Samii et al. (2006), and Dorsey et al. (2010)). However, Telemedicine refers more commonly to tools for enabling the communication or collaboration between clinicians, which are distinct from self-care technologies.

Figure 2.4: The self-care technology by McNaney et al. (2011), here named **Cueing Swallowing**, is a wearable device that produces a vibration cue every minute. Its goal was to alert patients of the need to swallow the saliva excess. The figure shows a picture of the device (Credits: http://openlab.ncl.ac.uk/v2/wp-content/uploads/2010/08/PDQ.jpg by Open Lab).

personal health, such as those for losing weight or increasing one's daily amount of exercise. While there might be some similarities in the interfaces and ways of operating, the motivation for using personal health tools is rarely comparable with the need to self-manage a chronic condition, so people will use them in a fairly different way. For example, if someone without a chronic condition does not exercise for some days, the impact on their health will probably not be very noticeable, but if patients with Parkinson's do not exercise for a few days, they will have issues in performing movements the way they did some days before. The impact of using a self-care technology is thus quite different from that of using a personal health tool.

Moreover, it is relevant to distinguish self-care technologies from tools for clinicians, such as those presented in Ni et al. (2011) and Febretti et al. (2014). While self-care technologies might be used by both patients, carers, and their clinicians, tools for clinicians are developed to specifically support the work of these professionals, which often means that they are the only users.

The concept of self-care technology is particularly appropriate here because it places the emphasis on self-care, as performed by patients and carers, and not on the care provided at a distance by the medical care team, as is the case with the terms Telehealth or Telecare. In this way, self-care technologies aggregate different tools for patients and carers that enable or support particular parts of their life with a chronic condition.

"In the present paper, **telecare** is defined as the use of communications technology to provide health and social care directly to the user (patient)." (Barlow et al., 2007)

"**Telehealth** interventions allow remote exchange of data (e.g. blood glucose and blood pressure readings) and additional information between a patient and health care professional(s) to assist in the diagnosis and management of a health care condition(s)." (Sanders et al., 2012)

"Since the beginning of the 1990s, **telecare** systems – information and communications technologies that link people (usually at home) to health and social care services – have been promoted as a technological solution for problems of equity and access to care, and as a means of support for self-care in the community." (May et al., 2011)

"The term '**telehealth**' (for which a more detailed definition might be technology-supported medical or nursing tasks undertaken in a person's home or other remote site, especially sending biometric data from the patient to the healthcare system and/or sending advice, instructions or reminders from the healthcare system to the patient)" (Greenhalgh et al., 2012)

"**Telehealthcare** is the provision of personalised healthcare over a distance.[1] It has the three following essential components[2 w1]:
- The patient provides data such as a voice recording, video, electrocardiography, or oxygen saturation that gives information about the illness.
- Information is transferred electronically to a healthcare professional at a second location.
- The healthcare professional uses clinical skills and judgment to provide personalised feedback tailored to the individual."
(McLean et al., 2001)

"**Home telehealth** can be categorized as home telemonitoring (HTM) or telephone support (TS). Home telemonitoring is remote care delivery or monitoring that occurs between the patients in their place of residence and the health-care provider located somewhere else. Telephone support is patient or caregiver support by a health-care provider through telephone contact." (Polisena et al., 2010)

"**Telehealth** is a comprehensive concept that encompasses the transfer and exchange of health information through electronic devices. The focus of the present review is home telehealth, which involves the remote delivery of health-related services via information and communication technologies between a patient and healthcare professionals (…)" (Gorst et al., 2014)

Figure 2.5: Definitions of the concepts of Telehealth, Telecare, and Telehealthcare as they appear in the literature. The concepts overlap with the definition of self-care technology I put forward, for example, in regards to the central role of the patient, the focus of the technology on self-care aspects or activities, and the usage setting of the home.

2.2.2 Approaches to the study of self-care technologies

The research on self-care technologies is extensive and diverse in terms of approach. The diversity of approaches was expected as multiple research communities, with different traditions, interests, and methodological commitments, engaged in the study of self-care technologies. This section describes the four main approaches appearing in the literature. These four categories do not exhaust all existing approaches but describe the most commonly used ones.

The first approach is the technological feasibility study. This category consists of studies that document the design and initial testing of technologies. The typical technological feasibility study starts with qualitative preparatory research, with interviews, observation, or workshops with potential users; literature reviews also appear at times. The goal of the preparatory research phase is to understand the setting where technology will be used and, consequently, inform the design process. Following the preparatory research phase, is usually a design phase, which often involves user-centred methodologies and multiple iterations. The final pilot lasts few days to few weeks and engages a small number of participants. This study approach is common in HCI and CSCW, and was used, for example, in Mamykina et al. (2008), Aarhus et al. (2009), Glasemann et al. (2010), Jordan et al. (2013), and Güldenpfennig and Fitzpatrick (2013).

The second approach is the structured trial. This approach is characterised by an evaluation of the technology with participants using a well-defined study design, such as the randomised controlled trial. The typical study is performed with a small number of participants for few weeks or months. Unlike the technological feasibility study, the structured trial does not usually present details about the design of the technology. The focus of studies in this category is showing the efficacy of a particular technology. The analysis in this approach is often quantitative to determine the effect of the technological intervention. This study type is common in Medical Informatics and, was implemented, for example, in Samii et al. (2006), Marzinzik et al. (2012), Pompeu et al. (2012), Dorsey et al. (2013), and Killane et al. (2015).

The third approach is the ethnographic study. This study type entails employing ethnographic methods to investigate the use of self-care technologies in everyday life. Similar to the structured trial, this approach is not concerned with documenting the design process, but rather in understanding how people use the self-care technology in practice. The engagement with people varies, from few in-depth interviews with participants, to years of participatory observation. The contribution of this study type is usually in understanding the multiple dimensions of the life with the self-care technology. This approach appears in STS, HCI, and CSCW. Examples of studies using this approach include Aarhus and Ballegaard (2010), Kilbourn (2010), Storni (2010), Toscos et al. (2012), and Grönvall and Verdezoto (2013).

The fourth approach is the systematic review. Unlike the previous three approaches, the review does not analyse the use of a single technology, but rather focuses on comparing multiple technologies published previously. In most cases the technologies analysed are found through searching scientific databases for certain keywords but there are also studies that use other indexes, such as mobile application stores. The analysis is often

quantitative to assess the accumulated effects of technology. Qualitative reviews also exist and focus on themes that are common to different technologies or studies. Reviews mostly appear in Medical Informatics. Examples of studies using this approach include DelliFraine and Dansky (2008), Polisena et al. (2010), Huang et al. (2014), Cruz et al. (2014), and Lundell et al. (2015).

This section has shown that there are a variety of approaches to study self-care technologies. All four approaches are valid and can potentially deliver relevant contributions to the design and understanding of self-care technologies. However, this thesis required a combination of two approaches, as no single approach could contrast the everyday self-care with available self-care technologies. From the technological feasibility study, I borrowed the primary concern of informing the design of technology and the tradition of investigating everyday life with the condition before introducing self-care technology. Even though this PhD research does not lead to the specific design of a self-care technology, the commitment to understand the context where self-care technologies would be incorporated is the same. From the review approach, I borrowed the qualitative systematic analysis of multiple technologies to understand common themes or issues in a group of existing self-care technologies. This combination of approaches enabled the contrast between the opportunities promoted by self-care technologies and the ways in which patients and carers engaged in self-care.

2.2.3 Misalignments between self-care technologies and the everyday self-care

Self-care technologies have potential to support self-care, however, as the previous chapter has shown, they enjoy a relatively low uptake. One issue that contributes to the low uptake is the misalignment between self-care technologies and the everyday life of patients and carers. A misalignment is defined here as a relevant difference between the self-care of patients and carers and the ways of self-care supported or enabled by a particular self-care technology. Misalignments are not usage or adaptation issues that can be easily solved through training; instead, they are significant differences in perspective or ways of doing things that can make the use of the technology incompatible with daily life and thus lead to the rejection of self-care technology.

To better explain what misalignments are, I present four examples from the literature around self-care technologies[15], divided between differences in perspective and distinct ways of engaging in self-care.

The misalignments related with differences in perspective arise when the self-care technology contrasts with fundamental views on self-care from patients and carers. For example, in Lau et al. (2015), the contrast referred to opposite views on the usefulness of having a paper-based self-management action plan. The self-care technology to learn about asthma incorporated the idea that creating a paper-based self-management action plan was essential. However, most participants rejected that view, either because they

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[15]The authors of these studies did not name the issues as misalignments, yet they can be named as such according to the definition offered here.

already knew how to manage their condition, or because they could memorise plans instead of having them printed. As a result of this difference in perspective, patients used the application only once or not at all.

Another example showing different points of view appears in Piras and Zanutto (2014). In this particular case, the conflicting views related to the expected privacy of the collected glucose values. The self-care technology for children with diabetes and their parents incorporated the idea that all glucose values should be shared with clinicians. The parents, however, felt that the clinicians could not understand some exceptional values, and thus this data should not be shared automatically. Parents argued that interpreting values required knowing the context in which they happened, and that was not always accessible to the clinicians. The paper does not say whether people ended up rejecting the technology, but the issues mentioned generated relevant conflicts.

Self-care technologies can also contrast with the ways in which patients and carers engage in self-care. For example, in Storni (2014), the contrast appeared in the measurement practices of people living with diabetes. While participants from the study often made notes about their meals each time they performed a measurement, their blood glucose meters did not store these auxiliary notes. Instead of supporting the measurement practices of patients, the blood glucose meter adhered to a reductionist perspective on measurements, which led to the frustration of patients.

Another example showing different ways of engaging in self-care appeared in Pols (2012), concerning the self-care activities for addressing fluid retention. Each time the patient with heart failure sensed fluid retention in the swallowing of her ankles, she would lay down and take medication. However, the self-care technology – which included a blood pressure monitor and a scaled used daily – incorporated a more alarming perspective on the liquid retention. A difference of 100g from the weight range (62-63kg), triggered a call from the nurses for advice. For the patient, this was "over the top", as she knew how to act on the situation and the retention would usually be gone the following day.

This section has shown multiple examples in which self-care technologies were in contrast with the self-care of patients and carers. The self-care technologies used by people in the mentioned examples might have had important qualities to offer, however, since misalignments existed, they were responsible for frustration and, in some cases, the rejection of the self-care technology. These misalignments inspired me to investigate how self-care technologies for Parkinson's support the ways in which patients and carers live with the condition. While the low uptake of self-care technologies could be studied in different dimensions, in this work, I investigated how self-care technologies align or misalign with the ways in which people engage in self-care to identify potential sources of frustration and disengagement caused by the way in which self-care technologies were designed.

2.3   Parkinson's disease

Having introduced self-care and self-care technologies, this section focuses on familiarising the reader with Parkinson's. In particular, the following sub-sections will introduce the

condition, describe its symptoms, give detail about the diagnosis and treatment, self-care, and offer some examples of self-care technologies for people with the condition.

2.3.1 Introducing Parkinson's

Parkinson's disease is a progressive neurological disorder that is responsible for numerous motor and non-motor symptoms. The condition was named after James Parkinson's, the doctor who in 1817 described the symptoms of the condition for the first time. Parkinson's is one of the most common neurological diseases, only surpassed by Alzheimer's. It affects around 0.3% of the total population, and 1% of people above the age of 60 (de Lau and Breteler, 2006; Gago et al., 2014).

The condition itself is caused by the death of dopamine-producing neurones in the midbrain, in an area that is called *substantia nigra*. The reason for the degeneration, or the death of these cells, is not fully understood at this point though, despite considerable research (de Lau and Breteler, 2006). As a result, there is currently no cure for the condition available, only some medication that can address its symptoms.

Patients with Parkinson's can live for many years as life expectancy is only slightly reduced by the condition (Ishihara et al., 2007). Parkinson's does not directly contribute to an earlier death, but it can increase the chances of falling or choking, especially if people are left untreated.

Parkinson's is often considered a condition of old age as it is more likely to appear after the age of 50, with the average age of diagnosis being 70 (Van Den Eeden et al., 2003). There are some cases in which Parkinson's appears before 40, referred as young-onset, or even before 21, the juvenile-onset, however, these are rare cases (0.5% of all cases). It is also relevant to mention that Parkinson's is twice as likely to appear in men than in women (Van Den Eeden et al., 2003).

2.3.2 Symptoms

The symptoms of Parkinson's are very diverse. As Parkinson's affects the brain, symptoms appear in different parts of the body in ways that may seem unconnected. This section documents some of the motor symptoms of the condition, including its cardinal features, and examples of non-motor symptoms that can appear. The list presented here does not exhaust the symptoms of Parkinson's, but it gives an idea of the complexity and diversity of the challenges that patients can encounter.

Motor symptoms

The parkinsonian symptoms vary from patient to patient, however, there is a group of symptoms that is very common. The cardinal features, as usually referred in the literature, are bradykinesia, rest tremor, rigidity, and postural instability (Jankovic, 2008). These motor symptoms are quickly described here. I also describe the freezing of gait phenomenon.

Bradykinesia, also known as slowness of movement, consists of a reduction of movement speed and amplitude while performing sequential and simultaneous tasks (Berardelli et al., 2001; Jankovic, 2008; Massano and Bhatia, 2012). According to the same authors, buttoning a shirt, eating, or handwriting, are examples of activities of everyday life that are slowed down by bradykinesia. Under bradykinesia, movements also become less wide. While handwriting, for instance, people will often start with a normal font size and, as they proceed, slowly decrease the size of each character, to the point that the text becomes difficult to read. Bradykinesia also affects unconscious movements such as eye blinking, swallowing, or the arm swing while walking.

Rest tremor is an involuntary oscillating movement that occurs when the muscles are relaxed or supported by a surface (Edwards et al., 2008). Tremor usually appears in the hands, but as the condition advances can reach the legs, chin, or the head (Stoessl and Rivest, 1999). Contrary to common belief, tremor does not necessarily affect the execution of fine motor activities as it disappears or is attenuated when an action is started. However, tremor can cause pain, stress, fatigue, and thus it can become a considerable burden (Jankovic, 2008). Furthermore, tremor is probably the most well known symptom of the condition, yet 30% of patients do not have it (Marsden, 1994).

Rigidity, also known as stiffness, is identified by an increased resistance to perform passive movement of a limb (Jankovic, 2008). It can occur in different locations of the body, such as the neck, the arm, or the hand. When someone has rigidity in the hand, for example, flexing, extending, or rotating their hand passively becomes much harder, and the movement can resemble that of a cogwheel. The presence of rigidity can be responsible for various issues, from pain, to difficulties in performing fine motor movements, or the inability to perform facial expressions as easily (EPDA, 2011). Turning around or getting up from a chair may also become harder.

Postural instability appears towards more advanced phases of the condition (Jankovic, 2008). As Parkinson's advances, patients tend to adopt a stooped posture, with head and shoulders hanging forward, as a way to compensate for the loss of stability and postural reflexes. During a neurological examination, doctors pull the patient back or forward to assess whether they struggle to keep balance. If patients take more than two steps back or forward, the symptom is present.

Freezing of gait consists of a sudden loss of movement that can occur while walking or when trying to initiate gait (Schaafsma et al., 2003). It is more common in situations that require more attention while walking, such as passing narrow spaces, making turns, initiating gait, or while multi-tasking, but it can occur in open spaces as well. When freezing occurs, patients are conscious that they are stuck, but they are unable to perform any voluntary movements. They feel like their feet are glued to the floor. While freezing of gait goes away in less than a minute, it reduces the confidence and independence of patients as it can happen anywhere anytime and lead to dangerous situations.

Non-motor symptoms

Parkinson's is often presented as a movement disorder in reference to the numerous motor symptoms that characterise it, but the condition is responsible for several non-motor

symptoms as well. The non-motor symptoms tend to be under-recognised due to the absence of complaints by patients during their medical appointments (Bonnet et al., 2012). Yet, these issues are diverse and can be detrimental to the patient's lives. In this section, I outline the most common non-motor symptoms.

Pain is quite prevalent and can have multiple origins in Parkinson's (Bonnet et al., 2012). Foot pain can be the result of twisting movements and muscle contractions caused by dystonia. Shoulder aches can result from muscular rigidity (Poewe, 2008). A constant burning sensation, known as central pain, can be caused by issues in the nervous system.

Depression is characterised by sadness, discouragement, or hopelessness (Bonnet et al., 2012). Patients with Parkinson's may experience a lack of energy, an overall slowing down, and sleep disorders. Yet, unlike other people with depression, they do not develop guilt. The depression in Parkinson's is generally attributed to the degeneration of the brain, but it can become worse if people struggle to accept the condition or have a conflicting relationship with their partner (Seiler et al., 1992). This symptom can appear in all phases of the condition and is usually assessed as mild or moderate (Schrag, 2004).

Olfactory dysfunction often appears as a result of Parkinson's and many times even precedes the diagnosis of the condition (Haehner et al., 2011). Hyposmia, the most common issue, reduces the ability to smell or detect odours and, consequently, to distinguish between different tastes. In rare cases, patients might detect smells that do not exist in the environment, a phenomenon that is called phantosmia.

Mild cognitive impairment is common in Parkinson's and can appear in all phases of the condition (Bonnet et al., 2012). The cognitive decline of Parkinson's affects the frontal execution function (Poewe, 2008). Learning new things, planning activities, or finding words, for example, becomes harder for patients (Tröster, 2011). Patients also find it more complicated to remember to perform things at some point in the future, such as taking medication at a specific time. The overall thinking becomes slower and dividing attention between multiple activities is made more difficult.

Dementia can appear in older patients towards the more advanced phases of the condition (Zesiewicz et al., 2006). It can affect learning, planning, attention, problem-solving, but also personality and behaviour. Unlike the mild cognitive decline described before, the loss of intellectual abilities related with dementia can hinder social interaction and the performance of multiple activities of daily life.

Psychotic symptoms can also be a result of Parkinson's (Zahodne and Fernandez, 2008). There are three main types of psychotic episodes. First, patients with delusions often have an altered perception of what happens in their environment. Thinking that their partner is unfaithful to them is a common theme. Second, "sense of presence" hallucinations lead patients to believe that someone is close to them when looking at a plant or animal. Third, visual hallucinations can consist of seeing passing lights, or animals at the periphery of the visual field (Bonnet et al., 2012). In earlier phases of the condition, patients can identify these phenomena as unreal; however, as the condition advances they may lose this ability (Zahodne and Fernandez, 2008). The cause of psychotic episodes is thought to be related with the condition, yet medication for Parkinson's can trigger or exacerbate episodes in some cases. Dementia can also be

related with the appearance of these episodes.

Impulsive control disorders consists of a varied set of issues that are compulsive, repetitive, or excessive in their nature (Wu et al., 2009; Bonnet et al., 2012). Three examples are especially common and, thus, worth mentioning here. Pathological gambling is the inability to resist the urge to place bets, play with slot machines, or other types of games or activities where chance is involved. Hyper-sexuality is related with an increase in sexual thoughts potentially resulting in a greater urge for sex and use of pornography. Compulsive shopping represents an increased urge to shop regardless of need or financial means. The occurrence of these disorders is related with the use of antiparkinsonian medication, especially dopamine agonists, and can usually be solved by adjustments in medication (Weintraub et al., 2013).

On/Off phenomenon

Besides motor and non-motor symptoms, there is an important characteristic of Parkinson's that appears in intermediate to advanced phases of the disease: the On/Off phenomenon. Patients are said to be in an On phase when the medication is acting with great strength, and thus the patient shows fewer symptoms. During Off phases, however, the medication stops being as effective and patients might experience a severe impact on their autonomy.

As the disease progresses, Levodopa, the most common medication for Parkinson's, is likely to be less effectively absorbed by the brain. This means that in the intermediate to advanced stages of the disease, patients can fluctuate between On and Off phases. The long-term intake of Levodopa is also likely to produce 'dyskinesias' (spasmodic movements, repetitive motions or lack of coordination), during the On phase. This is considered to be a side effect of having too much medication in the organism, which can occur in later phases of the condition (Massano and Bhatia, 2012).

2.3.3 Diagnosis and treatment

The diagnosis of Parkinson's is performed by a neurologist, taking into consideration the history of the patient and the results of a neurological examination (Stoessl and Rivest, 1999). The decision is mainly based on the presence of bradykinesia and at least one of the other cardinal features of the condition – tremor, rigidity, and postural instability (Massano and Bhatia, 2012). Diagnosis is said to be clinical as it depends on the ability of the doctor to identify the condition, and not on a definitive test that can determine the presence of the condition. Having multiple symptoms of Parkinson's helps gaining confidence in the diagnosis. In some cases though, the diagnosis is provisional for some years because the symptoms of the condition are not clearly visible. In these circumstances, it is common to give Levodopa to patients, because exhibiting a strong unequivocal response to the substance is evidence of having Parkinson's (Stoessl and Rivest, 1999).

Patients with Parkinson's are not hospitalised because of the condition, so they usually go home after receiving the diagnosis and an initial medication plan. A small

number of people undergo surgery to implement deep brain stimulation, a system that electrically stimulates the brain using small implanted electrodes. Others go through surgery for inserting a thin tube in the intestine to support the infusion of medication with a pump. Nevertheless, these cases are exceptions due to financial reasons and multiple contraindications, such as age, years with the condition, presence of psychiatric issues, and others. As a result, most people take numerous pills every day. There are three main types of medication for Parkinson's (PDF, 2014):

- Levodopa, the strongest substance, is transformed into dopamine in the brain. Benserazide/Levodopa (Madopar®), Carbidopa/Levodopa (Sinemet®), Carbidopa/Levodopa/Entacapone (Stalevo®), are some of the medications that include this substance;

- Dopamine agonists are a group of substances that mimic the effect of dopamine in some parts of the brain. Pramipexole (Mirapex®) and Ropinirole (Requip®), are two common examples;

- COMT and MAO-B inhibitors are used to prolong the effect of Levodopa, by inhibiting enzymes that transform it. Entacapone (Comtan®), Rasagiline (Azilect®), and Selegiline (Zelapar®) are examples of this type of medication.

The medication for Parkinson's is symptomatic, meaning that it only addresses the symptoms of the condition. Once the symptoms interfere with the activities of the patients, doctors recommend medication regimens to reduce their impact[16]. The medication has a strong effect on the body, being able, in the best cases, to completely mask the symptoms of the condition. However, the effect is transient, wearing off after a few hours. Medication will also have to be adjusted every couple of months to deal with the progression of the condition.

2.3.4 The self-care of Parkinson's

Facing such complex symptoms and treatment, patients and carers living with Parkinson's engage in self-care. Sara Riggare, a patient with Parkinson's, represented her self-care engagement with an interesting infographic (Figure 2.6) that displays the time she spends on medical care (1h/year), versus the time she spends in self-care (8765h/year). By looking at the infographic, it becomes clear how much time people engage in self-care and how little they spend in interactions with their doctors.

Unlike other chronic conditions, the self-care of Parkinson's has not been thoroughly described in the literature. In fact, while researchers described several activities that people living with Parkinson's engage in, they did not use the word self-care. This section summarises previous work that investigated the activities that are part of the self-care of Parkinson's.

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[16]In an ideal world, patients would always start taking medication once the symptoms disturb or hinder them from performing their activities. However, I discovered in the fieldwork that that is not always the case due to difficulties in diagnosis.
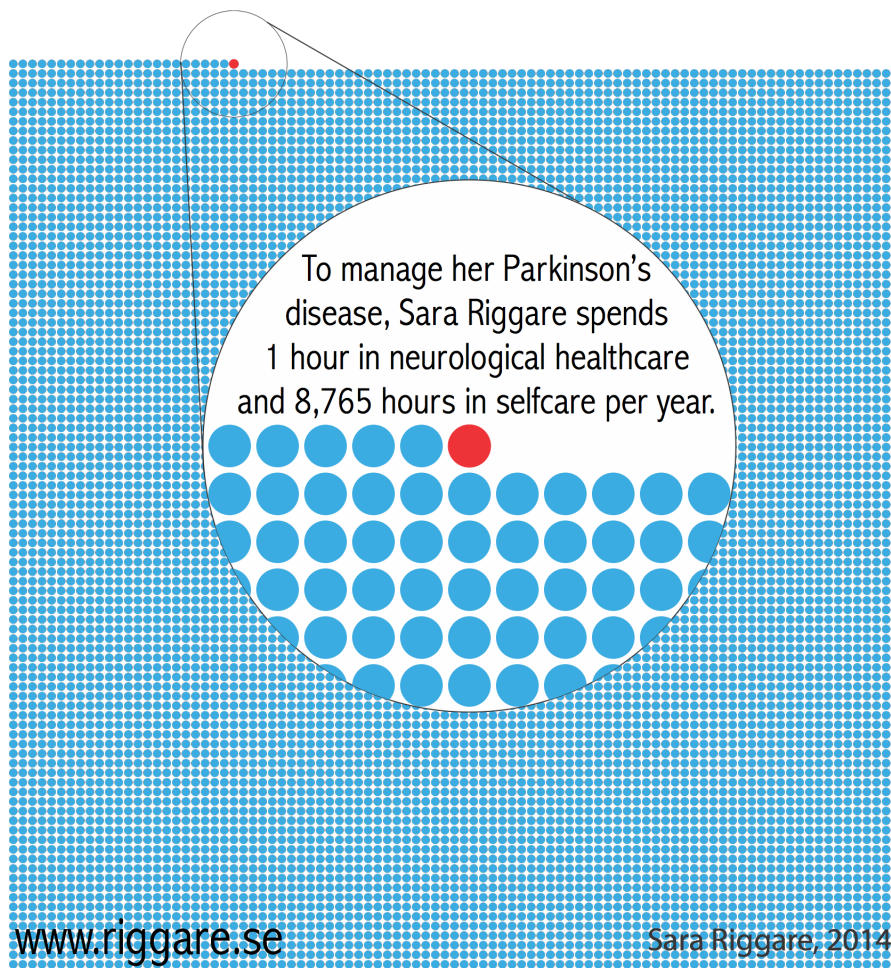
Figure 2.6: People living with Parkinson's Disease spend 8765 hours of their year in self-care and only one in clinical care (Credits: www.riggare.se/wp-content/uploads/2014/04/Selfcare-infographic-English.jpg by Sara Riggare).

Taking medication is the self-care activity performed by people living with Parkinson's that appears the most in the literature. The activity has been described as extremely complex because patients need to take a variety of pills, multiple times a day, and with different doses (Gibson, 2016). To help them take medication at the right time, people have used various strategies, including setting up alarms on their mobile phones (Gibson, 2013). Despite the willingness to take medication at the right time, authors agree that patients do not always follow their medication schedule. Some researchers attribute these "deviations" from the medication plan to non-compliant or non-adherent behaviours (Leopold et al., 2004; Grosset et al., 2005; Drey et al., 2012). Other authors argue that adjusting the medication schedule is a practical way to take the most from the hours in the day when medication works at its best (Pinder, 1990).

Previous work has also focused on exercise activities. In particular, multiple studies have assessed the potential of exercise interventions in improving the condition state (Ahlskog, 2011; Speelman et al., 2011). Exercise is known to reduce the disability caused by the condition, and there are expectations that it might contribute to a slower progression as well (Goodwin et al., 2008; Speelman et al., 2011). A study by van Nimwegen et al. (2011) suggests that patients are more sedentary than people without the condition, but there is little understanding of how patients engage in exercise outside formal interventions.

Researchers also investigated the adaptations that people living with Parkinson's did because of the condition. Some adaptations were required because the symptoms did not enable the performance of certain activities (Wressle et al., 2007; Chiong-Rivero et al., 2011; Marr, 1991). Fluctuations in the symptoms also forced last minute changes in the planning as activities might suddenly become impossible to perform (Bramley and Eatough, 2005; Haahr et al., 2011; Martin, 2012; Thordardottir et al., 2014). In both cases, adaptations might trigger stopping activities or shifting them to carers, consequently making people reassess their roles in the process (Charlton and Barrow, 2002; Chiong-Rivero et al., 2011).

Finally, there has been some work studying how people accept Parkinson's. When confronted with the multiple losses caused by the condition, people engaged in a variety of coping attitudes (Charlton and Barrow, 2002), including: pursuing an active lifestyle, avoiding thoughts about the condition, increasing social interactions, and keeping a fighting spirit. Patients and carers also tended to compare their case with worst Parkinson's cases or even to other conditions that they considered to be worse than theirs (Chiong-Rivero et al., 2011; Charlton and Barrow, 2002). While studies have described these attitudes towards accepting the condition, little is known about how these practices integrate the self-care of patients and carers.

This thesis will complement previous work by investigating in-depth the self-care of people living with Parkinson's. The above-mentioned studies show that people engage in different activities and that there are some points of discussion. These insights will be useful in studying different aspects of self-care. Furthermore, this study will complement previous ethnographies of the everyday life with Parkinson's, focusing on the self-care engagements.

2.3.5 Self-care technologies for Parkinson's

There are numerous self-care technologies for people living with Parkinson's. As the condition presents multiple impacts, technologies have been developed to address a variety of aspects. Available technologies include: mobile apps to remind about medication (e.g., **myHealthPal**), tools for tracking symptoms (e.g., **Parkinson's Diary**), technologies for supporting therapeutic activities (e.g., **SCRUMP**), or tools for interacting with doctors remotely (e.g., **Video Consultations**).

However, while self-care technologies for Parkinson's exist, no study has previously reviewed these. There are two related studies though. Achey et al. (2014) published a review of Telemedicine technologies that includes some examples of tools that can be

considered as self-care technologies. The study presented a historical analysis of existing work as well as an analysis of clinical outcomes, however, it did not analyse in-depth the characteristics of the technologies reviewed. Another related review was conducted by Godinho et al. (2016), who looked at remote monitoring technologies for neurologists working with Parkinson's. The study focused on the clinical outcomes of technologies and offered recommendations about whether and how to use them in clinical practice. While this review could in principle include self-care technologies, apart from one example, the reviewed technologies offered an extremely passive role to patients, which does not fit with the concept of self-care technologies.

This thesis will complement previous work by reviewing self-care technologies for people living with Parkinson's. Unlike the above-mentioned reviews, the study will not focus on the clinical outcomes of technologies, but rather on the ways of self-care that they enabled to support a direct comparison with the self-care of patients and carers.

2.4   Summary

This chapter has provided an overview of the research area where this work is built upon. It became clear that there is a *large body of work on self-care*, and that there are several *conflicting perspectives* currently co-existing. Multiple *self-care technologies have been developed*, but studies also documented *misalignments* between self-care technologies and everyday self-care practices. The chapter demonstrated that Parkinson's is a *complex condition*, with several symptoms, progressive nature, and fluctuations in severity. Moreover, the chapter has shown there is a *limited understanding* of the self-care of Parkinson's and the self-care technologies currently available for the condition.

CHAPTER 3

Methodology

This chapter describes the methodology followed in this PhD research. I start by situating this work within a constructivist research tradition. Views on epistemology and ontology are outlined, and towards the end of the subsection, criteria for evaluating the quality of this work are advanced. Next, the chapter describes grounded theory, an approach that has deeply influenced the data collection and analysis of this study. The third section describes the qualitative ethnographic informed methods that I used to understand the lives of people living with Parkinson's. In particular, I describe the in-depth interviews with patients and carers, the observations of consultations, and the online ethnography in two online communities. The fourth section describes the critical review of studies describing self-care technologies, for Parkinson's and other chronic conditions, conducted to get an understanding of the opportunities being promoted by these technologies. Finally, the chapter concludes by detailing the specific perspective I bring to this work.

3.1 A constructivist lens to inquiry

This thesis investigates how people live with Parkinson's disease as a way to understand how self-care technologies align with the everyday self-care of patients and carers. This approach aligns with a tradition within HCI and CSCW of using qualitative ethnographic informed methods to understand contexts that are of interest to design[1]. Gaining an in-depth understanding of the lives of patients and carers calls for an active interpretation of practices and meanings that are often taken for granted. The researcher participates

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[1]The tradition of using ethnography in design dates back to the seminal work of Suchman (1987), Heath and Luff (1991), and Hughes et al. (1992). Ethnography has many times been used to capture design requirements and produce implications for the design of a particular technology (Dourish, 2006). At the same time, a broader approach has also coexisted, which studied scenarios that are relevant to design (Dourish, 2007). This approach is not directly related with the design of a specific technology, but can have equally important consequences, in making one rethink the ideas and assumptions that underline the development of technologies. My approach aligns with the latter.

in the construction of the investigation, in close interaction with participants, previous literature, and other entities; thus, this inquiry used a constructivist lens.

Constructivism is a school of thought in philosophy of science that, through different approaches (Riegler, 2005), argues that the knower/researcher is involved in the creation of knowledge. My constructivist background draws on the work of Humberto Maturana[2], a Chilean biologist who established constructivism after reflecting on his practice as a biology scientist. I will refrain from providing a detailed account of Maturana's constructivism as it is out of the scope of this thesis, but I will discuss the ontological and epistemological characteristics of the approach and propose quality criteria to evaluate this type of research.

Maturana explains that there is knowledge when there is appropriate behaviour in the domain that we implicitly define with a question. For example, we say someone knows how to do usability testing, by observing that individual performing appropriate activities in the course of a usability test. For Maturana, developing knowledge is not an ability restricted to humans, but common to all living beings. When living systems regenerate themselves they develop knowledge, because through their actions they adapt to their environment, and thus have appropriate behaviour[3].

Living systems cannot be understood outside of their setting. They are always in interaction with other entities and with the environment. The interactions between living systems and the environment make the structure of the living system change, not in a way determined by the external agent, but by the structure[4] of the living system. For example, when reading a political piece in the newspaper I might change my opinion. The content is responsible for making me think, but the author cannot control whether and how my opinion changes, that is determined by my own structure.

3.1.1 Epistemological and ontological position

The ideas presented above have relevant consequences for understanding the perspective researchers bring to their research. As part of their living, researchers have undergone numerous interactions with their family, friends, political groups, university lecturers, other researchers, the literature, and other entities that have helped shaped their unique perspective. At each moment, their structure is the result of the history of changes that occurred until then. In other words, their perspective is shaped by everything they experienced to date.

However, even if a researcher wanted to, it is not possible to separate herself from the observation. Maturana gives the example of a visual experiment (see Figure 3.1). On

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[2]Maturana never called his work constructivism, because he did not think that other constructivism theorists argued the same perspective (Maturana and Pörksen, 1985). His work usually appears under the label of cultural biology, acknowledging the implications of the biology of living systems in knowing.

[3]According to Maturana and Varela (1992), the knowledge is embodied in the structure of living systems, so even if plants develop knowledge about how to live they are not conscious of it. Humans have another cognitive level, language. Through language, humans become observers, reflecting on their actions, and speaking with another observer, who can also be themselves.

[4]Maturana (1988) defines structure as the set of components and relationships that constitute a specific unity and realise its organisation.

Red light

White light

(a)

Object

(a) pink
(b) red
(c) green/blue

(b)

(c)

Shadow of light
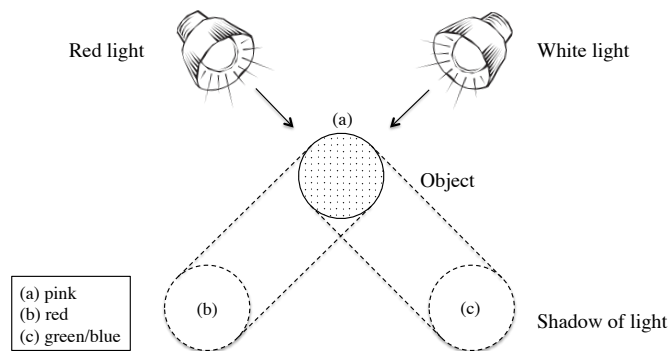
Figure 3.1: Experiment showing that perception cannot be distinguished from "illusion" in experience. Adapted from Maturana (1990).

one side, there is a white light, on the other a red one, and in the middle, an object that intercepts both lights. In the experiment, the observer sees that one of the shadows is pink, another red, and another green or blue. Seeing green or blue is not an expected result to the observer. Positivist researchers would reduce the observation to an "illusion" or a "hallucination" because green or blue lights cannot be justified in perception. While making the experiment however, it is not possible to distinguish between the "illusion" and the "real". The process of perceiving an image and reflecting about it is part of the same brain process. This example shows the impossibility to achieve a reality independent of the observer, because perception cannot be distinguished from reflection.

The inability to separate the observer from the observation makes it impossible to talk about a *universum* – an external reality independent from the observer. In fact, there is a *multiversa* constituted by multiple legitimate realities, as many as the number of explanatory domains (see Maturana (1988, 1990)). Each of the branches of the *versum* is equally plausible, valid, and comfortable to sit on. This does not mean that every opinion is valid. Realities are made explicit through explanations that require validation. By saying that all realities are valid, I mean that as long as there is a group or community validating an explanation, there is a *versum*.

Even things and entities are made distinguished from their environment by the observer (Maturana and Varela, 1992; Maturana, 1988). By naming a unity, for example, the observer makes the distinction criterion implicit. To give an example, the class of chairs is the set of relations that have to exist for something to be named a chair. Entities are not simply there but are identified as such by the observer who by choosing the distinction criterion sets the unity apart of the background.

The absence of an external reality independent from the observer may concern some researchers, regarding their ability to attain 'truth' with their work. These researchers commonly, though mistakenly, assume that applying their methods rigorously will enable them to observe reality 'as it is', and therefore know the 'truth'. However, science is not validated by the existence of an external reality, but rather by the coherence of method. Maturana and von Foerster discussed this exact issue at a meeting in 1998 (Maturana

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and von Foerster, 1998). Von Foerster argued that the misunderstanding of truth in science could be attributed to the multiple origins of the word. The Latin root *veritas*, according to him, is always connected with a validation check. Saying that the sky is blue would require a listener to be able to check the argument, in this case, by looking at the sky. The English word, on the other hand, is related with another concept: trust. So the emphasis is not on the validation, but on trusting the claimer that confirms to have used a procedure to check the result. Maturana explained that science requires trust but not truth, because the scientific validation is related with "the procedure that we have to verify" (10:35), the "coherences in the doing and in the explanations" (14:15) and not on the correspondence to an external reality. In other words, validity is based on the trust in the method and not on the existence of an external independent reality.

3.1.2   Criteria for evaluating the quality of constructivist research

Traditionally, studies are evaluated regarding their validity, reliability, and objectivity, aligning with the positivist and post-positivist research traditions (Guba and Lincoln, 1989). However, these criteria do not fit constructivist research, as they are based on very different theoretical assumptions (Seale, 1999). Here I discuss five criteria[5] mentioned in the literature to evaluate constructivist research accounts.

- *Credibility* refers to whether an account can be trusted. Credibility judges the familiarity with the setting, demonstrated through prolonged and persistent engagement and the confrontation of participants with accounts about them (Guba and Lincoln, 1989, p. 236). Another side of credibility is related with the strength of the argument. It evaluates whether the connections between data and account are strong, and whether there is enough evidence to support the claims made (Charmaz, 2006, p. 182).

- *Rightness* judges whether the account fits into a particular context and background (Goodman and Elgin, 1988, p. 158). There might be multiple realities relating to the same observation, but the researcher constructs the account in a specific narrative and tradition. Judging the argument is then possible within the same context and background that was used by the author (Guba and Lincoln, 1989, p. 143).

- *Resonance* relates to whether the analysis portrays the fullness of the studied phenomena. This is analysed by judging whether the analysis revealed only liminal concepts or if it also uncovered new ways of interpreting meanings that were previously taken for granted (Charmaz, 2006, p. 182). Resonance also becomes apparent when participants feel they were offered deeper insights about their life and world (p. 183).

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[5]Maturana did not discuss criteria for evaluating the quality of research generated by constructivist researchers. However, previous work in the social sciences developed criteria that is compatible with the perspective he defended.

- *Usefulness* refers to the ability to use the account in a functional way. It judges whether the account or concepts generated can be used to solve a problem that concerns a group of people (von Glasersfeld, 1991). Usefulness also judges the contribution of the account to creating a better society (Charmaz, 2006, p. 183).

- *Transferability* refers to the ability to transfer insights or concepts from the presented account to other contexts. This criterion is not limited to the settings evaluators might know, but rather judges whether the detailed information provided about the study (i.e., time, context, culture) enables readers to judge the applicability of the account to settings they encounter (Guba and Lincoln, 1989);

3.2 A grounded theory approach

Within the constructivist tradition, I employed qualitative ethnographic informed methods. My approach to inquiry was deeply influenced by grounded theory, a systematic approach to inductively constructing theory from empirical data. The method was originally described by Glaser and Strauss (1967), in the seminal book "The discovery of grounded theory"; however, years later, the authors entered in disagreement and evolved the method in diverging ways[6]. The version of grounded theory used in this work resembles the constructivist grounded theory proposed by Charmaz (2006).

Grounded theory is a complex framework that recommends procedures, methodological orientations, and expects particular views on theory. However, as Charmaz (2006, p. 9) explains, these considerations should be interpreted as "set of principles and practices, not as prescriptions or packages". This section paints a "broad-brush" description of grounded theory as per Charmaz (2006), together with detail on made operationalisations.

3.2.1 Procedures

Grounded theory recommends a set of procedures to focus the analysis on the data collected. This includes coding and writing memos[7]. Coding[8] consists of assigning a label to a piece of data that describes what it is about. The idea is to summarise, describe, and provide an analytic handle to the collected data. The codes should be grounded on the data and not inspired by theoretical frameworks, as to keep the analysis close to the data. Coding is not a mechanical exercise, but a way to promote early theorising about data, and identifying which areas to investigate next. In this study, as in many grounded theory projects, coding started as soon as empirical material was available

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[6]Different versions of grounded theory appear, for example, in Glaser (1992), Strauss and Corbin (1998), and Charmaz (2006).

[7]The original version of grounded theory did not describe coding or writing memos in great detail; however, both Glaser (1992), Strauss and Corbin (1998), and Charmaz (2006) describe these procedures in more recent descriptions of the method.

[8]The coding and memo writing were done in digital form using the Scrivener[TM] writing software (www.literatureandlatte.com/scrivener.php). Figure B.1 in Appendix B shows an example of how the codes and memos appeared in my analysis.

and lasted until the end of the analysis. In the beginning, word-by-word, line-by-line, or incident coding were used to open multiple directions for analysis. As the analysis proceeded, focused coding enabled the categorization of larger amounts of data according to previously created codes. Some grounded theorists advise the additional use of axial coding (Strauss and Corbin, 1998) or coding families (Glaser, 1992), however, as these instruments steer (or force) analysis to fit specific theoretical directions (Charmaz, 2006), they were not used in this study.

Writing memos is another way of advancing analysis. Memos are informal notes that reflect on the collected data. I used them to describe codes, compare different incidents, and try connections between codes, ideas, and literature. Since memos make reflections about the data explicit, they help raise hypothesis or questions and thus guide the inquiry. They can also be useful to reflect on the analysis made at a previous time, as they keep a record of the line of thought from earlier phases.

3.2.2 Methodological orientations

Besides analysis procedures, grounded theory influences the methodology of projects. This comes as a result of adopting specific principles, such as letting analysis guide data collection, performing constant comparison, and using theoretical sampling.

In grounded theory projects, the analysis does not happen after data collection is complete; instead, *analysis is expected to co-occur with data collection* and even drive it. This might sound as a matter of ordering activities, however, it has deeper implications. As data collection is not done all at once, it is possible, for example, to adjust interviews to focus on the insights of the analysis, or to query previous participants on themes that just appeared in the last interviews. Letting analysis guide data collection requires data collection to be spaced along time to give time for analysis to take place.

Constant comparison is another principle that has important methodological implications. Grounded theory recommends making comparisons at different levels. This includes comparing incidents, observed events, data about various participants, and different groups, to better understand the collected data. Comparisons help test developing accounts against the data they are supposed to fit and describe. Besides influencing the analysis, constant comparison also shapes data collection. For example, it is advisable to draw on different groups of participants to enable comparison between them. I can point to the comparisons used when studying the interactions with doctors (see Figure 3.2). In this example, interviews documented the perspective of patients and carers of their encounters. The observations contrasted this perspective with what happened in consultations. The online ethnography in the "Ask The Doctor" section enabled the comparison between online and offline observations, and the comparison between patients from the United States of America and Portugal (observation/interviews). A similar procedure was adopted for the remaining parts of the study as is documented in each of the fieldwork chapters.

The last principle with methodological influence is *theoretical sampling*. Instead of aiming for representative samples or specific numbers with data collection, grounded theory moves the focus to the development of the analysis. The data collection is in
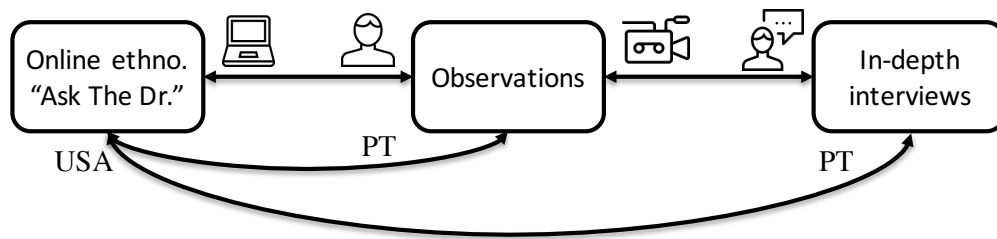
Figure 3.2: Using constant comparison to better understand the interactions with doctors. Arrows indicate comparisons between different methods. Bottom arrow, for example, relates to the comparison between what people wrote in the online community for interacting with doctors and what interviewees said about their interactions with doctors (Credits: https://www.iconfinder.com/iconsets/streamline-icon-set-free-pack (icons) by Webalys are licensed under CC BY 3.0).

progress until the categories being developed are saturated, which means that new data does not spark additional theoretical insights. This is not the same as not seeing something new, but rather that the new field data does not question, add, or change the pre-existing analysis.

3.2.3 Views on theory

The objective of grounded theory has always been to generate theory. However, epistemological and ontological concerns have inspired great discussions among different proponents of grounded theory. The original version of grounded theory included numerous positivist notes. For example, Glaser and Strauss (1967) talked about "predicting" phenomena (p. 8) and the term "discovery" in the title points to the existence of a factual reality that can be discovered instead of constructed. As the authors entered in disagreement, Glaser (1992) continued positioning the method in the positivist realm, while Strauss and Corbin (1998) ended up aligning with interpretivism. Charmaz (2006) followed the constructivist approach. I concur with Charmaz (2006) in my approach to theory (see Section 3.1). I see theorising as an exercise of gaining understanding that is constructed by the author in interaction with participants, where results contribute to a framing of a situated reality.

3.3 Data collection

This study used a varied set of methods to collect data (see Table 3.1): in-depth interviews, observations, and online ethnography in two online communities. These methods guided my investigations of the practices of people living with Parkinson's. Additionally, I performed a critical review of self-care technologies for Parkinson's and other chronic conditions to understand the opportunities promoted by technologies in this space. The choice of investigating different contexts and settings was motivated by the possibility

to compare field data and thus improve the depth of analysis. As Glaser and Strauss (1967) explain, maximising the differences between groups in the data collection can help uncover meanings or assumptions that might otherwise be taken for granted.

This section describes the application details of each of the methods, together with details on the participants and ethical issues where applicable.

Data sources	Numbers	Context
In-depth interviews	31	– 20 open interviews (13 individual, 7 with a group) – 7 informal interviews after participants read draft manuscript with preliminary analysis of the open interviews – 4 interactive interviews after using technology probes (1 individual, 3 with a group) – Participants involved: 10 patients and 10 carers – Audio-recordings: 20 hours
Observation	14	– Moderate participation in waiting room of neurology outpatient clinic – Passive participation in Parkinson's consultation – Participants involved: 14 patients and 12 carers – Audio-recordings: 6 hours
Online ethnography	2	– 5224 posts from online community where patients and carers interact with each other – 800 posts from the 'Ask The Doctor' section of an online community where patients and carers interact with doctors
Critical review	86	– 52 self-care technologies for people living with Parkinson's – 34 self-care technologies for people living with other chronic conditions

Table 3.1: Overview of data collection methods.

3.3.1 In-depth interviews

To gain an understanding of the daily life with Parkinson's, I conducted interviews with patients and carers (Lofland et al., 2005)[ch. 5]. The interviews were intense[9], qualitative, and loosely structured. I chose to involve multiple perspectives (of patients and carers) as a way to gain an in-depth understanding of each specific self-care case. Furthermore,

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[9]Lofland et al. (2005) catalogues interviews into: i) talk in action (in the flow of a specific activity); ii) informal interviewing (happening as part of an observation session); or iii) intense interviewing (a directed conversation). The latter corresponds to the interviews held with patients and carers.

participants were interviewed multiple times, allowing the analysis to guide the themes of the interviews.

The participants[10] were recruited through a local chapter of the Portuguese association of patients with Parkinson's in an urban town[11]. They had diverse professional backgrounds and levels of education. All patients except two (IP2, IP4) met every week for two physiotherapy sessions. Some carers also participated in the physiotherapy sessions, performing exercises and helping patients (IP5_C1, IP7_C1). All patients were older than 60 and retired, either because of the disease or shortly before it was diagnosed. All interviewed carers but two, were retired and held an active role in the care of their affected relatives.

Most interviews were conducted in the association's premises, while the others were conducted at the patients' homes. Conducting the interviews in the association had a number of advantages. I was able to attend physiotherapy sessions and observe some of the physical issues people described in the interviews. I was also able to witness interactions between patients and carers and learn from the advice they gave each other. The inspiration to study how people learned to self-care (see Chapter 6), for example, came from the advice I saw people exchanging in interactions at the association. Visiting the homes of the people was also useful. I was able to see how people fitted their environment to the life with the condition. For example, when visiting IP6, I was able to see the calendars marked with appointments, the medication lying in a special place over the TV, or the lack of rugs or mats to avoid falls.

Recruiting participants was a challenging task. Even though the secretary of the association called members who were not part of the physiotherapy sessions inviting them to participate, few responded positively to her request. Interviewees later explained that students and researchers often came to the association and that some people got tired of answering similar questions over and over again. Moreover, the secretary confided to me that many patients did not want to talk about their condition as it makes them sad. This insight was confirmed by the findings from this study. At the end of the third phase of interviews though, a carer offered me a handful of contacts of patients she knew from another physiotherapy session she and her husband attended at the hospital. I considered contacting these people, but as the findings of the everyday practices of people living with Parkinson's were saturating, I decided not to interview further participants.

The interviews were conducted in three phases, namely: a) Open interviews, b) Informal interviews after reading a draft of the analysis, and c) Interactive interview sessions following the use of technology probe(s). These are described in the next subsections. At the end of this section, I detail ethical considerations that guided all interviews.

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[10]Interviewed participants are named according to a specific template. IP1 refers to the interviewed patient 1, while IP1_C1 to their first carer.

[11]The city of the local chapter of the Parkinson's Association was left unnamed to protect the privacy of the participants.

Phase 1: Open interviews

The first phase of interviews was explorative and open to the themes participants might want to bring to the conversation. The interview guide[12] 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. While I had an interview guide, I engaged minimally to keep conversations according to the topic. Embarrassing or sensitive topics (e.g., things they lost because of the condition) were left towards the end of the interview to enable rapport and empathy to grow. As interviews evolved, questions became more analytical and aligned with the analysis.

Participants were interviewed alone and in a group, according to what was practical for them at the moment[13]. In total, 20 interviews were held: 13 with one participant, five with two (patient + carer), and two with three participants (patient + two carers). These interviews involved nine patients (see Table 3.2) and eight carers related with them (see Table 3.3)[14]. In most cases, participants were interviewed on the association's premises, but I also visited two in their homes (IP4, IP6_C1).

These interviews were audio recorded. During the interviews, I only made notes on themes to follow-up with questions later, and avoided writing more to give all attention to the participants and ensure steady eye contact. I transcribed the recordings of conversations (14 hours) verbatim and coded the transcriptions for themes.

Phase 2: Informal interviews after reading a draft of the analysis

After partially analysing the first phase of interviews, I had an initial understanding of the practices involved in living with Parkinson's. However, these were mostly my interpretations of the participants' lives. To give interviewees the opportunity to criticise my perspective, I produced an initial draft of my analysis[15] and made it available to them, as suggested by Guba and Lincoln (1989).

I printed 15 copies of the draft and asked the secretary of the association to give it to the people who previously participated in the interviews. I also added extra copies for people who might be potentially interested in reading the draft, but that did not participate in Phase 1 of the interviews. After two weeks, I returned to the association's premises and held informal interviews with the people who read the draft. I did not bring an interview guide to these interviews. The idea was solely to collect the feedback patients and carers could offer to my analysis.

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[12]The interview guide can be found in Section B.1 of Appendix B.

[13]Similarly to Solimeo (2009), in this study, patients and carers seemed to prefer being interviewed together rather than individually. On hindsight, this tendency appears to be a symbol of the collaborations between patients and carers in self-care. As it was not possible to understand the condition with one of the perspectives, patients and carers presented themselves together. Moreover, interviewing patients and carers together enabled me to grasp a holistic picture of how their lives were like.

[14]I interviewed a carer recently widowed (IP8_C1). The remaining carers were related with patients who were also interviewed.

[15]The initial draft provided to patients was at the onset of Chapter 4.

Participant	Age	Sex	First signs[a]	Diagnose[a]	Phase 1	Phase 2	Phase 3
IP1	67	F	11	10	x	.	.
IP2	75	M	13	12	x	x	x
IP3	62	F	23	22	x	.	x
IP4	86	M	2	2	x	.	.
IP5	80	M	17	15	x	x	x
IP6	65	M	11	9	x	x	x
IP7	65	M	10	10	x	.	.
IP8	79	M	22	21	.	.	.
IP9	?	F	3	3	x	.	.
IP10	67	F	10	7	x	x	.
IP11	?	F	?	?	.	x	.

[a] - number of years since.

Table 3.2: Patients involved in interviews.

Participant	Age	Sex	Patient connection	Phase 1	Phase 2	Phase 3
IP3_C1	65	M	Husband	x	.	x
IP5_C1	?	F	Wife	x	x	x
IP5_C2	?	M	Son	.	.	x
IP6_C1	?	F	Wife	x	.	x
IP6_C2	?	M	Son	.	.	x
IP7_C1	60	F	Wife	x	.	.
IP8_C1	?	F	Wife	x	.	.
IP9_C1	?	M	Husband	x	.	.
IP9_C2	?	F	Hired carer	x	.	.
IP10_C1	74	M	Husband	x	x	.

Table 3.3: Carers involved in interviews.

In total, five patients and two carers were interviewed. Apart from one, all had participated in the initial phase of the interviews (see Table 3.2 and 3.3). The responses were captured in field notes, registered after I left the association premises. I also received three copies of the draft with comments, underlines, and even suggested edits (see an example in Figure B.2 in Appendix B). The field notes and the commented drafts enabled me to iterate my analysis.

Phase 3: Interactive interviews following the use of technology probe(s)

The third phase of interviews focused on the issues of living with Parkinson's. To inspire discussions, I brought up issues I identified during the analysis, read quotes from previous interviews, and invited patients and carers to switch roles. Moreover, I provided

participants with technology probes before the interviews (Hutchinson et al., 2003).

One week before meeting patients and carers, I gave them technology probes[16] that could potentially address issues in their self-care. I developed three different technology probes using quick prototyping tools and physical prototyping materials (see Figure 3.3). These were:

- **"Remind me when it is..."** – a medication reminder that can be easily configured by inserting dongles on times to receive alarms;

- **"I cannot forget..."** – a box (size of a ring case) that records a 10-second voice message to be heard at a later time;

- **"I was shaking like this..."** – a device that captures movement acceleration and prints it to a receipt paper to enable the visualisation of tremor.

The goal of the technology probes was not to assess the efficacy or feasibility of the prototypes, but to learn more about issues of the condition.

- "Remind me when it is..." was designed to inquire about the challenge of taking medication at the right time. By providing participants with a medication reminder, my expectation was that they would talk more easily about issues in remembering to take medication at the right time.

- "I cannot forget..." aimed to investigate the acceptance of the condition and the role of remembering certain messages in this endeavour. The expectation was that by providing participants with boxes to record messages to remember, they would discuss more about how they accepted the condition.

- "I was shaking like this..." was designed to probe conversations about investigating tremor and other symptoms of the condition. By offering a technology probe that could track tremor in a visual form, I was hoping people would use the tool to learn about their health and discuss how they tracked symptoms and other issues of the condition.

In other words, rather than prototypes to study in use, the technology probes were instruments of inquiry to open conversations about the issues of the condition and potential solutions people found for them. Consequently, the fieldwork discussions focus on self-care issues and strategies, rather than on the specific use of the probes. For further details about the technology probes and their use refer to Appendix A.

Following the use of the technology probes, I interviewed four patients and five carers (see Table 3.2 and 3.3) in four separate sessions. Two interviews were held at the patients' home, one in a cafe, and another in an office of a company that used to be run by the patient interviewed. Unlike previous interviews, these interactions were interactive and provocative. As mentioned above, I brought quotes from previous interviews to trigger

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[16]Besides the technology probe, each package included a flyer with instructions on how to use it, as well as a space for making notes and asking questions.

Figure 3.3: Developed technology probes. From left: i) "Remind me when it is...", ii) "I cannot forget...", iii and iv) "I was shaking like this...".

discussion around issues I identified in the fieldwork[17]. I also invited patients and carers to engage in a role play game where they would switch roles to talk about issues from the perspective of the remaining role. When talking about issues, participants redefined the problems and suggested other issues and solutions. Their responses and ideas iterated my analysis calling attention to areas I had not previously considered.

These interviews were recorded leading to six hours of audio material. The recordings were transcribed verbatim by myself and coded for themes.

Ethical issues

In many HCI studies, ethical considerations are restricted to informed consent and ethics review board approval (Munteanu et al., 2015). TU Wien does not have an ethics review board, so it was not possible to get an assessment of the project. However, I made myself familiar with relevant ethical considerations and codes of conduct. My practice adheres to the code of conduct from the International Sociological Association (ISA, 2001), and the Association for Computing Machinery (ACM, 1992), which accounts for the fact that I was studying people's lives and reflecting about technologies. Furthermore, I actively reflected on my experience and the sensitive issues found together with my supervisor and colleagues, ensuring that upcoming issues were dealt in an appropriate way.

Regarding the formal procedures, I obtained informed consent[18] from all interviewed participants, after presenting myself, the project, and the reasons for interviewing them. In the first phase of interviews, 13 (out of 17 participants) provided written consent, while the remaining preferred to provide verbal consent. In the second phase of interviewing, all participants provided verbal consent, as interviews were informal. In the third phase of interviews, all participants provided written consent for their participation. I also took care to protect the privacy of participants. The excerpts were anonymised and the branch of the association in which participants meet was kept unnamed.

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[17]The quotes used during the interviews can be found in Section B.2 of Appendix B.

[18]An example of the informed consent form signed by participants can be found in Figure C.1 in Appendix C.

Although important, these formal procedures are not enough to ensure protection, privacy and respect for participants, especially when dealing with vulnerable audiences, such as people living with Parkinson's. A more active reflection of ethical consequences is necessary during the process of conducting such research. In-Action ethics (Frauenberger et al., 2017) reflection is needed to respond to ethical challenges as they arise. To give an example of how this ethics reflection plays out, I discuss some ethical issues I found while performing the interviews.

Being an interviewer is a position of great power. Questions direct the attention of patients and carers to their issues, which can make them feel uncomfortable and cry. Even tough appearing individuals go through difficult moments during their disease and face depression. Asking questions insensitively can be harmful to their psychological state. As a result, I reordered questions multiple times to ensure they were made at the right time. I also shifted questions to a future interview when patients were not feeling so well. However, sometimes people cried. I remember looking at patients and carers crying in front of me and thinking what I could do. I watched silently and gave them time, offered some water, added words of support, or a smile. Providing empathy was all I could do and, yet, it seemed to mean so much.

Interviews can also be rewarding for the interviewee. Patients and carers told numerous stories about their lives, some relevant and others not at all. As an interviewer I could have directed the conversation to focus more on the important issues for my research, but this did not seem appropriate for the relationship we were building. The interviews were like an exchange. Interviewees provided interesting answers to questions and I offered a listening ear for the stories they wanted to tell. The stories told were very varied, according to the things going through the participants' minds. Some conversations were not easy to listen to when they were packed with racist comments or ideological remarks I did not agree with. However, I did not preach to participants and provided them with as much attention as I could. This cultivated our relationship, but most importantly, it seemed to make the interviewees feel heard.

Early in the study, I made two commitments to myself regarding the participants in the study. I would treat participants in the most humane way possible and I would try to leave them happier than when we started the meeting. These ethical considerations helped me implement in practice what the informed consent and ethical review boards try to promote with the privacy, respect, and no harm principles. While formal ethics procedures have been developed from a biomedical perspective, they are much more concerned with avoiding causing physical pain than to act responsibly and in a caring way towards people who go through very tough moments. For this reason, in this study I reflected and adjusted my practice to leave patients comfortable, respected, and happy after they left a meeting with me.

3.3.2 Observations

To understand the encounters between people living with Parkinson's and their doctors I observed consultations (Spradley, 1980). The observation setting was an outpatient neurology clinic of a major public hospital in Portugal. The observation spanned several
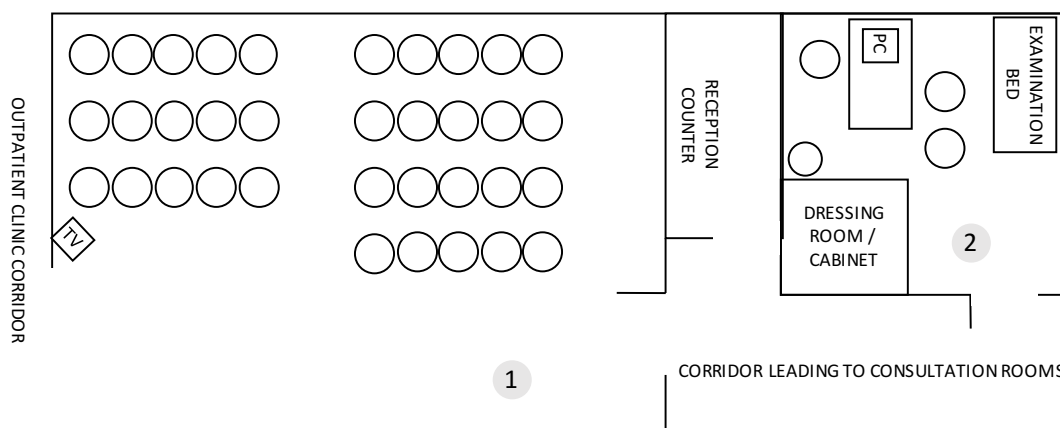
Figure 3.4: Areas where the observation at the hospital took place. On the left side there is the waiting room, and on the right side, the consultation room.

days and was always held in sessions with the same neurologist. The 14 sessions were with participants, who I recruited from the waiting room while they were waiting to see this doctor, and who agreed to let me sit in on their consultation. The observation itself was very focused and divided into two areas: the waiting room and the consultation room (see Figure 3.4). I conducted observation in these two areas with different levels of participation.

Observation area 1: Waiting room

The waiting room is, as the name says, the place where patients and carers wait before their consultations. On one side of the room there was a large passage to a wide corridor that connects the different outpatient clinics. On the opposite side of the room there was a reception desk and doors that lead to the consultation rooms. In the middle of the room there were around 30-50 sitting places. There was also a TV mounted on one of the walls.

When entering the waiting room, patients and carers walked directly to the registration desk to announce their arrival. Then, they would sit in one of the available seats or stand between the large corridor and the doors to the consultation rooms. When their turn came, patients were called by their name over the room speaker and were told which room they should go to. Patients and carers rarely left the waiting room as they might miss being called.

In the waiting room, my participation level was moderate, balancing between being an insider waiting in the room, and being an outsider that asks questions to people who are about to see their doctor (Spradley, 1980, p. 60). I used this opportunity to meet the participants, inform them about the study, obtain their consent to observe the medical consultation, and ask a handful of questions about their everyday life with the condition. These interactions with the participants were captured by hand-written

field notes, quickly taken when talking with them, and expanded once a break in the observations was possible.

Observation area 2: Consultation room

Once the patient's name was called over the speaker, patients and carers walked in the direction of the door that leads to the consultation rooms. Behind the door there was a corridor with rooms on both sides. On each consultation room there was a table with a desktop computer, an examination couch, a weight scale, and a blood pressure monitor. Around the table there were three chairs, one for the doctor, and two on the opposite side for the patient and carer. When more people were in the room, they were either standing or sitting on the examination couch. I was sitting on the same side of the doctor, but on a corner of the room, from where I could get an overview of all the people. The audio recorder was usually placed on top of the table.

In the consultation room, I opted for passive participation (Spradley, 1980, p. 59), behaving as a spectator and not interacting. The consultations were audio-recorded resulting in five hours of material, which was subsequently transcribed verbatim and added to the analysis as each observation session finished.

Participants

I did not collect much information on participants[19] at the hospital to avoid delaying the consultations, but can make two notes about them. Participants were very diverse from each other in relation to their Parkinson's history, ranging from few months with the condition to 15 years living with it. The patients were usually accompanied by a family member, who actively participated in the appointment (see Table 3.4).

Ethical issues

Since the observation was conducted in a hospital, it required authorization from the ethics committee of that institution. Therefore, months before starting the observations I submitted a request to the ethics committee, which was approved without changes. Each patient that I observed also received a specific informed consent form that followed the template of the hospital (see Figure C.2 and C.3 in Appendix C). The consent forms were signed by patients before consultations, or by their carer on their behalf when writing was an issue. There were two exceptions, in which patients preferred to give only verbal consent.

In the hospital, I assumed the same ethical position – of acting in the most humane way possible and, over the course of our interaction, make participants happier than when I initially met them – as when conducting the other methods. However, the hospital had some specific characteristics.

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[19]Participants from the observations are named according to a specific template. OP1 refers to the observed patient 1, while OP2_C1 refers to the first carer of patient 2.

Patient	Sex	Accompanied by
OP1	F	Daughter
OP2	F	Daughter
OP3	M	Son
OP4	M	Sister
OP5	F	Husband
OP6	M	Spouse
OP7	F	Daughter
OP8	M	-
OP9	F	Daughter
OP10	F	Husband
OP11	F	Daughter
OP12	F	Husband
OP13	F	Husband
OP14	M	-

Table 3.4: Characteristics of participants observed in the consultations.

One of the particularities of the consultation was the time-limited nature of the encounter. People usually came to the doctor every six months, and were given less than half an hour with their specialist. This was an important time slot, so I refrained from intervening as much as possible and took very little notes as not to call attention and disturb the consultation. It was more important for people to get attention from their specialist than for me to gather additional data at that moment.

Another issue was that my observation slowed down the work of the doctor. Each time I was observing consultations, the doctor had to open the electronic health record of all scheduled patients to check if they had Parkinson's. As the IT system was slow, this meant that the specialist always started the consultations with a relevant delay. Furthermore, getting the consent form signed when consultations quickly follow one after another was difficult and could result in some delay. For this reason, I quit observations as soon as I developed an overview of the process of the consultation, to avoid further disturbances in the work of the doctor conducting the consultations. This was not an issue for the research work as I was using other methods to understand the interactions with doctors.

3.3.3 Online ethnography

To better understand the life with Parkinson's and other forms of interactions with doctors I used online ethnography (Garcia et al., 2009). Online ethnography[20] is concerned with

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[20]Online ethnography also appears under different names in the literature, including Netnography, cybersociology, cyber ethnography, virtual ethnography, or as part of a larger definition of digital ethnography (Kozinets, 2002; Masten and Plowman, 2003).

studying social phenomena that are mediated by the Internet. I used this method to study two online communities, one dedicated to patients and carers, and another one that enables patients and carers to interact with neurologists. The analysis of these communities enabled a better understanding of how people live with the condition, especially concerning the interactions with doctors, and how people learn to self-care. Studying these online communities also gave material to confront and compare the data collected in person. Choosing online communities from countries other than Portugal was a deliberate choice to increase the likelihood of encountering differences between the distinct data collection sources.

The approach followed was similar for the two online communities. The analysis was based on the extant texts (Lofland et al., 2005) produced by the members and documented in their forum posts. I did not interact with the community members, neither online nor offline. The online forums contained hundreds of threads documenting interactions between members, so it was not required to use a greater degree of participation. It was possible to get an understanding of the interactions between members simply by reading the posts they exchanged. The following two sections provide more detail of the particular use of online ethnography in the two cases.

Online community for patients and carers

One of the communities was a forum for patients and carers living with Parkinson's[21,22]. The goal of studying this community was to better understand how people learned to self-care, as well as to obtain data that could be compared with the everyday practices that outlined in the interviews.

The community was English-speaking and was associated with a national Parkinson's Association of an European country – other than Portugal. This particular forum was chosen because it has a large number of posts (more than 40.000, excluding archives), multiple daily posts, moderation performed by patients and carers, and a policy of having posts publicly available without registration. The forum is structured in eight top-level folder areas, including 'About Parkinson's and health' and 'Living with Parkinson's'. Sub-topics are further structured into topic threads, started when a member raises a question. Links to archived folders were also available. All of the sub-topics (except those under Q&A and Archive) show current and active engagement. The forum also highlights the most liked and the currently active topics in separate folders. There is also a general search box that returns diverse results from the forum discussions as well as other pages from the association.

The analysis was focused on the content from 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 because they were the most closely related with the self-management of the condition. This judgement was based on each

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[21]The excerpts from participants in this online community are named as F1Mx, where x denotes the number of the participant.

[22]The online community investigated was left unnamed to ensure the privacy of its members.

folder's description and on an initial exploration across the different folders of the forum. Excluded from the analysis were folders such as those relating with the 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 between the five folders. The posts were read using a standard web browser, and when relating with data that appeared relevant (n=397), copied to Scrivener$^{\text{TM}}$ software, where they were coded and included in the analysis. I started by reading the older threads of the folders selected, which dated back to 2011. This ensured that the analysed conversations were closed, and that the same thread would not appear multiple times in the analysis.

Regarding the ethical considerations, I did not obtain written consent from the forum members, as their posts were publicly available. However, some actions were taken to ensure the anonymity and privacy of the community members, following advice from Bruckman (2006). First, the community remains anonymous. Second, the pseudonyms of the members were changed. And third, the posts were slightly edited to prevent search engines from linking to the original content. These measures were deliberately taken based on the sensitive content of the posts. People told very intimate stories with great detail about their lives and issues. Using unchanged quotes or pseudonyms would enable people to identify the patients or carers who wrote the posts and thus attract unwanted attention to their lives. Even if the posts were made in a publicly available forum, people did not necessarily expect to see such sensitive pieces of their lives published in research outlets. This expectation does not relate with the real privacy, but the privacy that participants expected (Walther, 2002). Nevertheless, it seemed appropriate to protect patients and carers from unwanted exposure to their issues and lives.

Online community for interacting with doctors

The other studied community was a forum in which patients and carers interact with neurologists[23]. The goal of studying this community was to understand interactions with doctors in a different setting. By including both the face-to-face setting, documented by the observations and interviews, and the online setting described in the online community, a greater level of comparison became possible.

The community chosen was the National Parkinson's Foundation (USA) online forum that offers a range of different sections including: 'Newly Diagnosed', 'Caregivers Forum', 'DBS Forum', or 'Ask the Pharmacist'[24]. This particular community was chosen for three reasons: i) doctors reply directly to posts from patients; ii) there is regular activity with weekly posts; and iii) the content is publicly available without registration.

The analysis focused on the content of the 'Ask The Doctor' section where patients and carers could ask questions about their particular case to a handful of specialised volunteering doctors from the association. 800 posts from the online community were read using a standard web browser, and when relating with data that appeared relevant, copied

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[23]The excerpts from participants in this online community are presented as they appeared online. Messages from patients or carers are all labelled under the "Guest___*" nickname, while the posts from doctors appear under the name of the poster (e.g., "Dr. Rodriguez").

[24]The online forum analysed is available at: http://forum.parkinson.org/.

and coded in Scrivener$^{\text{TM}}$ (n=332). I chose to analyse older threads of the forum, with closed conversations, and thus screened posts from 2007 to 2012. Becoming immersed in this community required reading a significantly smaller number of posts than the previous one because the interactions tended to adopt a structure of question-and-answer without much participation from other members of the community.

The content in this online community was also publicly available and partialy anonymised at the start. All posts from patients and carers appear under the pseudonym of 'Guest___*', so it is not possible to identify participants from the posts they make. The posts from doctors are signed by them and represent clinical advice or at least recommendations that were intended to reach a large audience. For this specific community, I opted for reproducing posts as they appear online, because the available information does not lead to unwanted attention to patients and carers. Even though the information is sensitive, it cannot be used to identify the people and so it can be reproduced without detrimental consequences.

3.3.4 Critical review of self-care technologies

To get an understanding of the opportunities currently promoted through self-care technologies, I conducted a critical review of these tools. This review was particularly important for contrasting the everyday life with Parkinson's, documented by the methods described before, with existing self-care technologies.

The review was qualitative and focused on the descriptions of self-care technologies in both research articles and webpages. The analysis included features, ways of operating, and the expected interactions; this all helped understanding the potential of self-care technologies to enable or inhibit certain activities and ways of engaging in self-care. Moreover, in the case of self-care technologies described in research papers, I also analysed the findings related with their use, mostly in feasibility studies, as another source of input to understand their functionalities. Analysing technologies by their description does not reveal the same results as observing their use in practice because users might appropriate the technologies in unexpected ways. However, in the absence of detailed pilot studies of these technologies, there is still much to learn from their descriptions, because technologies have inscribed into them well-defined courses of action (Akrich, 1992) that can influence the ways in which people self-care.

As will become clear in the following subsections, the technologies in the review origin from a varied set of venues. The idea was not to be comprehensive of the whole spectrum of self-care technologies, but rather to provide an overview of the existing technologies. The priority was to review self-care technologies for people living with Parkinson's, which afford a direct comparison with the fieldwork. However, I also reviewed self-care technologies for other chronic conditions in order to understand whether the same trends would be present in self-care technologies in general.

To be included in the review, technologies had to support one or more self-care activities of patients or carers. Excluded from the review were: technologies described in languages other than English, subsequent versions of technologies included in the review, or technologies for clinicians to use by themselves.

Phase 1: Review of self-care technologies for people living with Parkinson's

To locate self-care technologies for people living with Parkinson's, I used three strategies:

- Searched for 'parkinson' in *HCI Bibliography*[25], the proceedings of *PervasiveHealth*[26], and relevant journals in (bio)medical informatics, including *Health Informatics Journal*, *International Journal of Medical Informatics*, *Journal of American Medical Informatics Association*, *Journal of Biomedical Informatics*, *Journal of Biomedical and Health Informatics*, *Journal of Medical Internet Research*, and *Journal of Telemedicine and Telecare*;

- Searched for 'telecare', 'telehealth', 'ehealth', and 'self-care technology' in the archives of the *Movement Disorders* journal;

- Searched for 'parkinson' on the iTunes App Store[27];

The *HCI Bibliography* was chosen because it aggregates the main conferences and journals in the area of HCI/CSCW. The *PervasiveHealth* proceedings were included because while not part of *HCI Bibliography*, the venue publishes numerous HCI papers on self-care technologies in each edition. As relevant work existed in (bio)medical informatics, its key journals were also included, and the *Movement Disorders* journal was searched because it is the key venue for research on Parkinson's. The references of the papers that were relevant to the review were also followed for ensuring the search involved a breadth of journals and conferences, even if they were not part of the initial search. Moreover, I also searched in the iTunes App Store for capturing mobile technologies, that while not published in academic studies, patients and carers could access on their smartphones.

Phase 2: Review of self-care technologies for people living with other chronic conditions

The review of self-care technologies for people living with Parkinson's was complemented by a more general review encompassing self-care technologies for other chronic conditions in HCI/CSCW. The idea was to understand whether the technologies for other chronic conditions had promoted similar opportunities and ways of self-care as the technologies for Parkinson's reviewed.

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[25]HCI Bibliography is the main index aggregating HCI/CSCW research. It indexes the key journals and conferences in the area, including, *International Journal of Human-Computer Studies (IJHCS)*, *ACM Transactions on Computer-Human Interaction (TOCHI)*, or *Computer Supported Cooperative Work (JCSCW)*, and the conferences *Conference on Human Factors in Computing Systems (CHI)*, *International Joint Conference on Pervasive and Ubiquitous Computing (Ubicomp)*, or *European Conference on Computer-Supported Cooperative Work (ECSCW)*. HCI Bibliography is available at http://hcibib.org.

[26]The *PervasiveHealth* conference proceedings are available at: http://ieeexplore.ieee.org/xpl/conhome.jsp?punumber=1002011.

[27]iTunes App Store is the official portal of applications for iOS devices, such as the iPhone. It is available at: https://itunes.apple.com/us/genre/ios/id36?mt=8.

To locate self-care technologies for people living with chronic conditions, I[28]:

- Searched for 'chronic disease management', 'home care', 'home monitoring', 'patient-cent*', 'self-care', 'self-manage*', 'self-monitor*', 'self-reflection', 'Telehealth', 'Tele-care', 'telemonitoring', 'pervasive health' in *HCI Bibliography* and the proceedings of *PervasiveHealth*

The *HCI Bibliography* and the proceedings of *PervasiveHealth* were chosen because they represent the key venues for self-care technologies in HCI/CSCW research. The idea to search for general terms was to avoid directing the review to specific chronic conditions (e.g., diabetes), and instead get an overview of the area. Moreover, the references of relevant papers were also followed for opening the review to papers, that while following an HCI/CSCW perspective, were published in venues outside these databases.

3.4 My specific perspective

Recognising that the research I present is constructed, I would like to make clear the specific perspective I bring to this work.

I have been working with healthcare technologies for people living with chronic conditions for several years before starting the PhD. During this time, I observed older adults having difficulties using technology and imagined designs that could be more useful to their lives. I believed that technology could be helpful to people and that the reason for difficulties in use was a result of bad design. Research was for me a way of activism focused on improving the access of older people to well-designed technology. Since then, I stopped thinking that every problem was a source of bad design, but maintained the activist spirit focused on providing technology that helps people achieve their full potential.

Chronic conditions sparked my activist vein even stronger because the lack of well-designed technology might reduce one's quality of life. I witnessed in my close family the issues and tough negotiations that people living with chronic conditions encounter on a daily basis. So I was led to study how technologies could help people living with chronic conditions.

The idea of working with Parkinson's came as a reflection from the conditions I previously worked with. I had worked with diabetes, dementia, hypertension, and Parkinson's, and saw in the latter major challenges. Symptoms are quite strong, care networks quite complex, and technology not abundant. So it was a relevant condition to study for my PhD.

My position as a white male middle-class researcher working in an Austrian public institution has influenced my account as well. The same goes for my Portuguese origins

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[28]I would like to acknowledge the contribution of my co-authors Nervo Verdezoto, Geraldine Fitzpatrick, Morten Kyng, Erik Grönvall, and Cristiano Storni, in conducting the review of self-care technologies that was published in Nunes et al. (2015). In particular, the phase 2 of the review draws on some of this work and extends it considerably by, following references from the studies in that review, and analysing the reviewed self-care technologies with alternative analysis frames.

and my training in informatics engineering. All these characteristics have influenced my perspective and should help to understand my arguments.

3.5   Summary

This chapter described the methodology followed in this thesis. It touched upon the constructivist research stance, the grounded theory approach, the data collection methods used, and the specific perspective I bring to this work.

CHAPTER 4

The mundane self-care of Parkinson's

This chapter describes the mundane[1] activities that constitute the self-care of Parkinson's. It draws mostly on the in-depth interviews and the online ethnography of a community for patients and carers. The chapter answers, together with the next one, the first research question, of how people living with Parkinson's engage in self-care in everyday life. The findings point to a complex picture of self-care. People performed multiple activities, such as taking medication at specific times, but what is most interesting is the mundane ways by which people achieved these activities. 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 suited their other activities. Managing the condition also required people to constantly negotiate and to dynamically assess what was important for them at each point. The daily life with Parkinson's posed multiple challenges to patients and carers, most of which were not purely medical, but a result of adapting and integrating the condition into one's daily life. The contribution of this chapter lies in the ethnographic description of how people living with Parkinson's engage in self-care, as well as in the analytical characterization of self-care in regards to its mundane aspects.

The chapter starts by providing an ethnographic description of the self-care of Parkinson's. The following section discusses the findings of the fieldwork, and characterises a concept of self-care that includes the mundane aspects of daily life with the condition.

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[1]I use the adjective mundane in this thesis to refer to the practical, routine, or banal aspects that characterise daily life with a chronic condition. While referring to the mundane aspects of self-care, I wish to make a contrast with medicalized aspects of self-care, which mostly restrict to monitoring symptoms and performing treatment. By calling attention to the practical aspects, my hope is to broaden the concept of self-care itself.

4.1 Findings: The mundane self-care of Parkinson's

The fieldwork here presented describes how people self-manage Parkinson's in daily life[2]. In particular, I focus on the four main self-care activities that emerged from my analysis, namely: taking medication, exercising, adapting lifestyle, and accepting the disease. These activities are presented together with excerpts from the interviews and the online community for patients and carers.

4.1.1 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[3]. However, as people living with Parkinson's explained, getting to the right medication plan is a very complex and delicate activity[4]. 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.

> IP6: *This is a complicated disease, of course, because we [can] only walk when we take the medication. So, it [taking the medication] has to be [done] daily.*

Medication played an important role in the lives of many patients. For people like IP6, medication was essential for enabling any movement. As he explained in the interviews, the day only started after taking the morning pills because 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, IP6 said that the medication had to be taken "daily", but that is an oversimplification considering how many times patients needed to take their medication. Figure 4.1 shows the medication schedule of IP2. 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. IP2 also took medication for other conditions, which increased the burden of medication even more. Nevertheless, having to take three to five pills a day at different times is in itself a challenge.

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[2]The findings from this chapter have been partly scrutinised by patients and carers that were interviewed. As mentioned in Section 3.3.1, in the second phase of interviews, patients and carers participating in this study were given the chance to read an early draft of the analysis and comment on it. This draft evolved through analysing subsequent interviews, the online community, and with writing the thesis; however, the reported findings still bear resembles with the initial draft.

[3]When referring to medication for Parkinson's I 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.

[4]See Chapter 7 for an in-depth discussion of the complexity of choosing a medication plan.

Figure 4.1: Medication list/schedule of IP2.

Memory issues[5] caused by Parkinson's and (normal) ageing do not help patients remembering their medication, so if there is a sudden change in routines or a distraction, a pill can easily be missed[6]. Missing medication makes the symptoms return, so people living with Parkinson's used a diversity of approaches for reminding themselves about medication.

> F1M2[7]: *I setup alarms on my mobile! 7:30, 10:00, 12:00, 14:00, 16:00, 18:00, 20:00, 21:30. (…)*

Some strategies for reminding themselves of medication 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 F1M2, used the alarm function of the mobile phone to remind themselves at the right time. Besides strategies for controlling time, people also used the placement of medication as a reminder. For example, they kept

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[5]As mentioned in Section 2.3.2, Parkinson's can bring mild cognitive decline and with it a greater difficulty in remembering events at a specific time (prospective memory). Therefore, remembering to take medication can become harder for patients.

[6]Missing medication does not happen solely at home. Buetow et al. (2010) report that formal carers often miss giving medication to Parkinson's patients at the right time in formal care settings.

[7]Some excerpts of this thesis are preceded by codes, such as F1M2, that identify the participant that said or wrote them. In this particular case, the excerpt refers to participant 2 of the online community for patients and carers. There are two more naming templates relating to the participants in the interviews and observation. A quick guide to read them appears in the List of Abbreviations.

Figure 4.2: IP6 stored his medication over the TV so that he remembered to take it before meals.

medication on the kitchen table or on top of the TV to take it before meals (see Figure 4.2), or on the bedside table to take it before going to sleep[8]. Putting medication in specific places, as Danholt and Langstrup (2012) 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 keeping symptoms softened throughout the day. However, sometimes patients delayed their medication on purpose. For example, IP1 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 for attending numerous 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 medication. However, some activities are not compatible with having less control of the body. This was the case for consultations, when IP1 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

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[8]Some strategies for remembering medication uncovered in this study find a parallel in Palen and Aaløkke (2006) and Dalgaard et al. (2013).

patients to adjust their medication effect window to better fit their daily life activities[9].

Despite the advantages of delaying medication, the activity was not free of consequences. In fact, when patients delayed, they had to be especially careful about adjusting the following medication intakes.

> IP6_C2 - "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."

As this carer explains, the remaining medication schedule needs to be adjusted to keep the same temporal distance, be it three or four hours. Otherwise, the patient might have too much medication in the blood and start experiencing dyskinesia episodes. Also, 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 medication makes remembering to take it even more complex as people need to change their practices to fit in with the adjustment.

4.1.2 Exercising

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

The interviewed patients and online community members exercised very often. I commonly heard (or read) people saying that they engaged in exercise activities more than three times a week. And they were not talking about walking for 30 minutes around the block. 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 (see Figure 4.3), 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. (2011) 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 very active. For them, exercising was an essential part of living with the condition.

> F1M1: *Exercise is essential. Whatever form you can do it, exercise will make you stronger and keep your body fit for a longer period.*

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[9]Besides delaying their medication, some patients take more medication than usual before performing specific activities, such as driving. This behaviour was documented in Pinder (1990) and Gibson (2016); however, since only one participant in this fieldwork used that approach, it is not discussed in-depth here.

Swimming

Hydrotherapy

Cycling

Pilates Tai Chi

Running

Ski Gym Aquarobics

Yoga Golf

Physiotherapy

Figure 4.3: Tag cloud with formal ways of exercise of patients. Larger font size indicates that more patients mentioned that they participated in that form of exercise in the codes of the analysis.

People living with Parkinson's saw performing exercise as an important role that 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 (Goodwin et al., 2008; Speelman et al., 2011).

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.

> IP4: *I make a terrible effort. I make an effort. I walk slowly, but every day I go for a walk.*

When I interviewed IP4, 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 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 IP4 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.

IP6_C1: *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.*

Exercise can distract patients from worrying about their condition or from drifting into depression. For this reason, IP6_C1 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[10].

4.1.3 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[11] that include 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 may face 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 can be emotionally straining.

F1M3: *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?*

This patient talked about the difficulties of quitting activities and the need of having others performing them. Leaving work was very hard for this patient, but she missed even ordinary activities, the repetitive and boring work. Being unable to carry these necessary activities made the patient feel humiliated and 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 (2013) 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 ensured that the garden was taken care of, but, at the same time, 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,

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[10]Experimental studies were not able to prove the benefit of exercise in alleviating depression and improve mood (Goodwin et al., 2008), but patients did not seem to have any doubt of its beneficial role.

[11]Refer to Wressle et al. (2007) for a list of functional adaptations that may be forced by Parkinson's.

work that involved control of machinery, or even cooking because they could not safely manipulate knives. Activities might also become exhausting or impossible to perform 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 are 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 may feel that they lost a part of their identity.

> IP7_C1: *I have a driver's license since 30 something years ago and he never let me drive.*
>
> I: *Really?*
>
> IP7_C1: *Never! And now, do you think he feels good? Being driven by me, after he never wanted me to drive?*

IP7 was the family's driver for the past 30 years. However, due to Parkinson's, he had to pass the wheel to his wife. After more than three decades without sitting on the wheel, the carer often experienced difficulties and was not able to drive in highways. As a consequence, they often depended on others to go to numerous places. Moving to the passenger seat also challenged the identity of the patient. Being the family's driver was an important part of his identity that he could no longer perform today. Moreover, the patient felt responsible for the difficulties the carer experiences when driving, because he was the one keeping her from driving before. What seemed to be a straightforward change to implement, just passing the driving responsibility from one driver to the other, ended up being a quite complex adaptation to make.

Enduring fluctuations

The symptoms of Parkinson's do not always behave in the same way or 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 needed to get used to regular changes in their symptoms. As a result, people often planned their days with further detail, to ensure they could attend their activities. However, plans were not guaranteed to work and so people needed to reconcile them with not knowing how their bodies will act, and consequently, what they will be able to do at each moment. Martin (2012) labels this phenomenon as "chronic uncertainty" in the recognition of the impossibility to know how bodies will behave.

Earlier in the chapter I 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, one starts noticing that close to the time of the next intake, symptoms become stronger. This phenomenon is commonly referred as wearing off.

> F1M4: *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.*

When medication starts wearing off, symptoms slowly return. For this particular patient, entering the Off phase meant feeling cramps and pain in the feet. For other patients, the experience might be slightly different as they may suffer from other symptoms of Parkinson's. 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 as Gibson (2016) points out, 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 Portuguese winter – made them move with more difficulties and overall feel worse. In contrast, with warm weather, they felt their bodies were "lighter".

> IP5_C1: *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.*

People living with the condition attributed these fluctuations in the condition state to the weather itself, but 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 the 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.

> OP5: *If I do things relaxed, without getting nervous, I can do everything. At my speed, I do. But if I get nervous, then…*

Patients may try to avoid some of the complications of fluctuations, but they cannot control them completely. This being so, they need to adapt to living with some degree of uncertainty, as they may face harder moments every now and then.

4.1.4 Accepting 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 to drive, 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, I will continue reflecting 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 high 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[12]. They also compared Parkinson's with conditions such as Alzheimer or cancer, concluding that their disease was more benevolent than the others. In making these comparisons, people were not criticising other patients; instead, they were creating the conditions for better accepting their specific situation. Using what Forsyth et al. (1984) 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 can still do. This state of acceptance was not stable though. People also 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 lived with their current situation, day to day, without excessively thinking about it.

> F1M5: *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?*

Some days can be tough. During the time I spent in the association I witnessed episodes in which patients were feeling really down. However, when it happened, they were not left alone. Other patients and carers encouraged them to regain the strength to go on. Their words were similar to the ones that patients and carers used to motivate themselves to accept the condition. They mentioned others living in worst situations,

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[12] The belief that one has a mild case of Parkinson's seems to be cultivated in consultations. In fact, Pinder (1990) found that doctors consistently told their patients that their Parkinson's case was a mild one and that they would enjoy many years before their everyday lives were severely affected. Doctors emphasised how much could be done to control the condition as a way to encourage people to positively deal with the condition.

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 community that provides support[13].

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

> IP6: *This is something that has no cure mate. And adapting to it is even harder. You have to keep on going, put it behind you and try to forget you have it.*

Like IP6, many patients tried to put the condition behind their back. They could not escape Parkinson's symptoms, but thinking about them all the time did not help make things better 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 talked about hope.

> F1M6: *We all progress at different rates, take different drugs, and experience an endless variety of reactions. However, one thing we all have in common is the confidence that a cure will one day be found.*

Patients and carers frequently said that the cure for Parkinson's was close. This reality might be detached from today's scientific research expectations and outputs[14], but similar to the findings of Charmaz (1991), people hold on to the possibility of a breakthrough at any time. Believing that a cure was close gave people the motivation to bear their symptoms and the consequences of the condition every day. It gave them the strength to "fight" a condition that, at the moment, they cannot avoid.

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 pity looks, and having difficulties walking was easily confused with being drunk. As a result, patients often tried to hide their symptoms from others. To avoid displaying tremor, people would put their hands in the pocket, inside a newspaper or bag, or even under their bottom when seated. While walking, they would concentrate all their thoughts on the next steps to avoid making gait issues noticeable. When asked

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[13]Numerous studies have discussed the role of online communities in offering social support to its members. For more information on the subject refer to Preece (1999), Sandaunet (2008), and Newman et al. (2011).

[14]A lay explanation about the challenges of finding a cure for Parkinson's can be found at: www.pdf. org/en/chasing_parkinsons_cure.

why they hid symptoms, patients explained that they did not think their physical issues were problematic, but they did not want others to feel pity or have preconceived ideas about them. Patients felt what Goffman (1963) called stigma. Their bodies displayed characteristics that led others to see them and treat them negatively, assuming, for example, they would be frail or drunk. Some patients felt socially obliged to hide their symptoms for avoiding embarrassment and standing out.

Besides the stigmatisation of the symptoms, people also needed to accept changes to the image that they had about themselves. This was introduced before with the example of IP7, the man who could no longer be the family's driver, a role he greatly valued. Here I will provide another example, this time concerned with quitting work.

> IP5_C1: *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.*

After some years with the condition, IP5 was no longer able to work in the restaurant he owned with his wife, and, thus, had to retire. Before that, IP5 was a tireless worker. He came in before everyone, rarely made pauses, and was always concentrated on the needs of the clients. Working was 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 man 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 dependent. 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 something they need to do to continue living with quality.

Reflections from piloting the probes: The "I cannot forget..." probe and the mundane work of self-care

The probe "I cannot forget..." enabled users to record voice messages about things they did not want to forget. The expectation was that people would record messages where they would talk about being lucky for not having the worst symptoms or condition, as mentioned in this chapter. However, people used the technology in a different way. The participants recorded messages about the importance of remembering their medication and the dates of the medical consultations. They also suggested that the device would be more useful as a tool to record the medication intake when patients were by themselves. In their idea, the box should enable patients to record a message each time they took the medication and, by checking the box later, they would have a register of their intake, might they go and try to take it once more. It is clear from the voice messages and from this redesign idea that taking medication on time entails important work for patients and carers, adding to the results of this chapter.

4.2 Discussion

The findings presented above show that living with Parkinson's is complex and full of mundane challenges, aligning with Bramley and Eatough (2005), Solimeo (2009), and Gibson (2016). Taking medication does not simply happen as a matter of routine, as is implied in some studies (e.g., Cools (2006)); instead, it is the result of placing medication on the right places, controlling time constantly – with or without alarms – (Gibson, 2013, 2016), 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 (Wressle et al., 2007; Chiong-Rivero et al., 2011; Marr, 1991) force patients to abandon activities that were once important and, with them, the roles they used to play. Patients need to get used to living with a degree of uncertainty due to fluctuations in the condition state (Thordardottir et al., 2014; Haahr et al., 2011). 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 (Charlton and Barrow, 2002; Chiong-Rivero et al., 2011), try to put things into perspective, and find hope by holding on to the possibility of a cure.

The self-care of Parkinson's is a complex mix of fighting and adapting. It is about fighting when patients put in efforts to take medication on time, to exercise, or to pursue their activities. However, since Parkinson's is a progressive condition, it is also about adapting: adapting to different ways of doing things, or adapting to the fact that they are no longer able to do them. This negotiation is not instantaneous, nor is it easy. Despite the difficulties, patients and carers are in control of their choices and try to influence the condition to enable them to live the life they aspire to. External factors make these negotiations even more complex. Many participants reported that the cold rainy weather, for example, made them feel worse, because there were fewer opportunities for going out safely, and bulkier clothes made movements more difficult. Just like the weather, other external factors may make symptoms stronger, even when patients and carers do everything at their disposal to 'fight' the condition.

The different activities described in the fieldwork are part of the everyday life with Parkinson's, but hardly fit into a medicalized 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 (see next chapter). Patients and carers are the ones who need to make things work with the options they have at their disposal.

The findings reported in this chapter originate from research with people living with Parkinson's, so it is only possible to talk about mundane self-care for their specific case. However, previous research seems to indicate that some findings apply as well to people living with other chronic conditions. For example, Pols (2012) described that the self-care of COPD often involved the practical activity of balancing effort in activities during the day as a way to avoid damaging tissues. Also relating with COPD, Cicutto et al.

(2004) reported that performing exercise was challenging, due to the practical need of sharing energy with other activities, and finding places where exercising was possible (i.e., where to walk at the same level). Funnell and Anderson (2000) argued that people living with diabetes managed their condition while pursuing multiple goals, priorities, or family issues, which also suggests practical negotiations and challenges in living with the condition. Moreover, there is the classic study from Conrad (1985) that explained how people with epilepsy would play with their medication schedule and doses, not to go against their doctor, but to be better fit for activities such as studying or taking a test, or to evaluate whether their condition was getting better. Wagner et al. (2001) argues that living with the condition in practical terms is a common issue for essentially all patients and carers, even if challenges manifest in different ways. Since a chronic condition does not exist in isolation from daily life, people need to engage in self-care to live with quality despite their condition (Corbin and Strauss, 1988). The mundane work in which people engage in varies according to the condition, but seems likely to exist.

The fieldwork of this chapter relates with the analysis of interviews and the online community for patients and carers. There were no profound differences between the data originating from these two methods, although there were some. For example, people in the online community did not often write explicitly that they delayed medication. Besides messages relating to long-haul flights – in which people needed to adjust their medication to a different time zone – delaying examples were not very common. In the interviews however, multiple participants mentioned that they delayed medication for various reasons. Another difference between the two data sets relates to exercise. People in the online community engaged in a more diverse set of formal exercise activities, which is consistent with a larger member base; however, informal forms of exercise appeared only occasionally in that dataset although they were very common in the interviews. Besides these differences, the self-care practices of people living with Parkinson's in these two settings were essentially the same.

4.2.1   Towards a concept of self-care that considers mundane aspects

The everyday experience of living with Parkinson's calls attention to very mundane aspects of self-care. With this in mind, I now proceed to characterise the concept of self-care taking into consideration the practical dimensions that were outlined in the fieldwork. The properties of the concept I put forward should sensitise designers and researchers to important aspects of self-care that relate with how it is achieved in practice.

Performing self-care entails great work. Living with Parkinson's requires people to engage in numerous activities that can amount to relevant time and effort. For taking medication on time, for example, people place the pills in different locations, set up alarms on their mobile phones, and constantly look at their watches to make sure they do not miss a pill. Despite this effort, studies report that most patients do not comply or adhere fully to their medication schedule (Grosset et al., 2005). Non-compliance or non-adherence are disrespectful terms for people living with Parkinson's, because they do not recognise the effort of taking medication, so many times during the day, while dealing with memory issues, depression, and/or dementia. It should actually come as

a surprise that people in advanced phases of Parkinson's are able to deal with more than 20 pills a day. Moreover, the consequences of occasionally skipping or delaying a pill are not serious[15]. Apart from stronger symptoms and potential difficulties assessing symptoms in consultations[16], there are no consequences to digressing from the medication schedule. It is thus fair to say that the concepts of compliance or adherence do not present a great grasp to the experience of medication of people living with Parkinson's. What does present a good grasp is that taking medication at the right time, as any other self-care activity, takes great work. While medication might seem straightforward on a prescription sheet, ensuring one takes it at the right time requires a great deal of preparation, attention, and time to pursue it. Understanding the mundane aspects of self-care includes recognising that people engage in multiple activities and that these can amount to considerable time and effort. For people living with Parkinson's engaging in this work is not optional, but rather a consequence of living with the condition.

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. The interconnection between activities can be observed when IP6_C1 labels doing the dishes as a form of exercise. According to her, doing the dishes is very similar to physiotherapy activities because it requires the patient to exercise the arms, yet it has some additional advantages. The coordination of the arms in the activity demands concentration and thus keeps the head away from troubling thoughts. At the same time, doing the dishes is useful for the family, and for that reason, helps the patient feel more useful at home. It is hard to imagine that a medicalized 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., Ahlskog (2011))[17]. However, in doing so, this perspective disregards an activity with multiple benefits, interconnected with different practices, and well ingrained in daily life. Understanding self-care in practice entails understanding the self-care activities, but also the complex settings and interconnections in which they occur. Exercising, taking medication, or accepting the condition, for example, may seem separate activities in theory, but they are all interconnected when someone lives with the condition.

People negotiate and compromise. When living with Parkinson's, not everything is possible all the time, so people need to negotiate and compromise. These negotiations and compromises are made clear, for example, when people delay their medication. The medical guidelines for Parkinson's recommend medication to be taken always at the

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[15]While in the case of antibiotics taking medication at the right time is crucial, the same cannot be said about Parkinson's, because medication only addresses the symptoms of the condition. Surprisingly, though, there are studies investigating non-adherence in Parkinson's that motivate their work with the importance of taking antibiotics at the right time (e.g., Drey et al. (2012)).

[16]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.

[17]Doing the dishes would not even be considered exercise according to some definitions. For example, Speelman et al. (2011) restricts 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.

same time to sustain the effect of the drugs and avoid dyskinesia episodes, but in face of everyday activities and commitments, patients sometimes delay their medication. When delaying, people accept stronger symptoms during a given period, for the possibility of being 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 (Leopold et al., 2004; Grosset et al., 2005; Drey et al., 2012). By using the terms non-compliance or non-adherence to describe delaying, researchers 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 and Grosset (2007), 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, people living with Parkinson's were well aware of the consequences that delaying would have on their body, and it was the in-depth experience with the condition that motivated them to use that strategy. In fact, delaying was a practical adaptation to living with Parkinson's that people used to attend activities, even when their schedule did not fit with the medication plan[18]. Patients accepted the consequences of their actions and so endured stronger symptoms during a period so that they could have greater abilities at some later point when they needed it more. As a patient from the study of Pinder (1990) 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 medicalized perspective 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 go for an alternative solution that enables them to attend other priorities while not creating serious issues to their health. Negotiations and compromises are part of the everyday life with a chronic condition and should be acknowledged when thinking about self-care.

Self-care as dynamic. Living with Parkinson's is not the same everyday. 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 medicalized 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. (1988) in

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[18]Conrad (1985) previously reported that people with epilepsy changed their medication dose or timing for being fitter for educational exams or other intellectually demanding activities. The medication for epilepsy reduced the concentration and speed of their thought, so people would slightly decrease the medication to make a better use of their cognitive abilities. Similar to people living with Parkinson's who delayed medication, people with epilepsy were well aware of the consequences of their actions, and it was this in-depth knowledge that lead them to pursue these adjustments. As Conrad (1985) points in the study, this was not driven by a will to go against the doctors' recommendations, but a practical way to respond to their everyday life challenges.

referring to hypertension, or as a routine to be guided by doctors, as in Clark et al. (1991) in referring to multiple conditions, they portray a picture where self-care is 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 (Thordardottir et al., 2014; Haahr et al., 2011), and thus adapting on-the-go is inevitable. Fluctuations in the state of the condition are a characteristic of Parkinson's, but researchers have documented unpredictability situations in other conditions as well. Storni (2015b) has argued that diabetes is unpredictable because emotions, for example, can increase or lower the values of blood sugar, making it impossible to be sure of the outcome of self-care activities. Charmaz (1991) 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 regimen overwhelming, and thus the experience can greatly vary from time to time. Moreover, as the "bad days" cannot be predicted (Forsyth et al., 1984), 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 fluctuations can force people to adapt their activities and plan ahead for different possibilities.

4.3 Summary

This chapter presented the everyday practices that are involved in 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 aspects of self-care entails understanding that performing self-care requires *great work* in organising and performing activities. The activities are not isolated from others, 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.

The collaborations between patients and carers in the self-care of Parkinson's

This chapter[1] describes how patients and carers collaborate in self-care. The work presented draws on the analysis of the in-depth interviews and the online community for patients and carers. Together with the previous one, the chapter answers the first research question, of how people living with Parkinson's engage in self-care in everyday life. The findings show that patients and carers living with Parkinson's collaborate in the different self-care activities that were introduced in the previous chapter. Living with such a complex condition often led patients and carers to collaboratively adopt and adapt everyday arrangements to create a meaningful life. The documented collaborations call for reconsidering the idea that self-care is performed individually. The contribution of this chapter lies in the ethnographic descriptions of how patients and carers collaborate in self-care, as well as in the characterization of the concept of self-care as a set of collaborative activities.

The chapter begins with an ethnographic description of how patients and carers collaborate to build self-care. The second section discusses the findings of the fieldwork, and characterises a concept of self-care that considers the collaborations between patients and carers.

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[1]The content of this chapter was in part taken from Nunes and Fitzpatrick (2015).
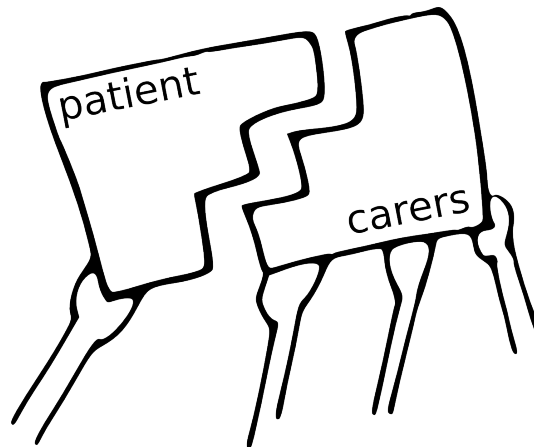
Figure 5.1: Self-care is collaboratively built by the patient and carers in their everyday life.

5.1 Findings: The self-care of Parkinson's as a collaboration between patients and carers

Patients and carers collaborate in the different self-care activities described in the previous chapter (Figure 5.1). To demonstrate this point, I will revisit each self-care activity and show how it is achieved collaboratively. In this exercise, I do not aim to be exhaustive but rather provide an overview of how the self-care of Parkinson's can be seen as collaborative.

5.1.1 Taking medication

Taking medication for Parkinson's usually involves swallowing a number of different pills at specific times to keep the effect of the medication lasting the whole day. To take medication at the right time, people placed it in specific spots and constantly controlled the time – sometimes with the help of an alarm of their mobile phone. These activities were not usually performed in isolation, but together with others.

> F1M7: *My husband has set the alarm on his mobile phone to go off every four hours. (...) it has helped remembering to take the tablets. During the first days, he missed by an hour and we had to recalculate the intake times. Thus, I understand why your husband is always looking at the clock. Parkinson's seems to have taken over our lives at the moment, but I am sure we will get used to it.*

For this couple, reminding each other about medication was a collaborative activity. Even though the patient was the one taking the pills, the carer had an alarm on his mobile phone to trigger when it was time for the medication. The responsibility for taking medication was also shared. That explains the use of "we" when talking about recalculating the medication intake time or getting used to reminding about medication.

Other participants had slightly different strategies, but these tended to fall into three types. In the first type, patients were very autonomous. They were the ones in charge of reminding themselves and taking their medication, so they kept an eye on the time or had an alarm to help them remember. Carers might participate in remembering about medication, but only through occasional reminders and more in a support role. In the second situation, carers participated more. Patients were still the ones who were taking care of medication, but carers needed to remind them often, as otherwise it would be forgotten. In the third situation, carers were the ones in charge of the medication. They were the ones controlling the time, bringing the medication to the patient, and putting it into the patient's hand to take. Interestingly, in this case, patients occasionally asked carers whether it was already time to take medication or if they had already taken it, in some way reversing the role of the first case where the patient was now in a support role.

Remembering about medication happened in different ways, but patients and carers seemed to collaborate in all of them. Either through occasional reminders or more systematic actions, the interplay of their actions ensured that the medication was taken on time, so that the symptoms were controlled, and the impact of the symptoms on their life minimised.

Reflections from piloting the probes: The "Remind me when it is..." probe and collaborations in self-care

The probe "Remind me when it is..." enabled people to receive medication reminders at specific times. The most interesting finding from the pilot was that participants integrated the probe into the collaborative ways by which they managed their medication. In the follow-up interviews, IP3_C1 talked extensively about how he set up the device in the living room, where he usually stays during the day, so that he would be able to hear the ring of the probe and act upon it. As his wife currently struggles to remember medication and often confuses pills, the carer has taken most of the activities related with medication, including splitting it into small doses for the day, and looking at a clock for knowing when to give the medication to her. The probe was integrated into this setting as a way to help the carer being aware of the time. "Remind me when it is..." was appropriated as a tool to support the role of the carer in the collaborations that lead to taking medication on time. There is also evidence that the remaining probes were used as part of a collaboration, because both patients and carers talked about their experience in trying them out and documenting their insights in the diary. These insights add to the findings from the chapter that show numerous collaborations in self-care between patients and carers.

5.1.2 Exercising

Patients with Parkinson's participating in this study exercised very regularly to keep their bodies fit. They engaged in numerous formal and informal forms of exercise, and used these activities to avoid slipping into depression. Carers often collaborated with patients in creating the conditions for safe and convenient exercise. They also played an important role in motivating patients to exercise.

The presence of carers was common during informal and formal exercise activities. IP4_C1, for example, joined her husband every morning for a walk around the block.

> IP4: *I always go for a walk in the morning with my wife. We go this way (points direction), and walk for half an hour.*

The presence of the carer motivated IP4 to walk, but it fitted other purposes as well. By holding hands with the patient, the carer provided the stability her husband needed for walking, as well as the safety of having someone around, might he trip and fall. In the premises of the association, some carers also joined the physiotherapy sessions together with the patients. During these sessions, carers performed the same exercises as patients, but they easily interrupted their activities to help patients with movements, pick up the materials that slipped away from their hands, or to simply motivate them to continue performing exercises. In these two examples, carers played a relevant role. They helped to remove obstacles that might prevent patients from exercising, such as fear of falling, or the difficulties of performing exercises by themselves. The coordinated actions of patients and carers ensured that exercise was carried out in a safe and convenient way.

Besides the routine work of facilitating the exercise of patients, carers also intervened when patients were going through depression. In these situations, exercise could help, so carers suggested it to patients.

> IP8_C1: *When I saw that he was sitting like this, putting the hand like this, I would know that he was having a bad moment. (…) I would say: come, come. Let's go for a walk. He would say: I have no strength. [I would reply:] Yes you do. Come on.*

IP8 was a very social person, but in specific situations, he would close in on himself and start getting depressed. The carer could sense the depression when she saw a closed curtain, dimmed lights, and a particular way of sitting and placing the hand. When depression kicked in, the carer would get things ready and motivate her husband to go for a walk with her. While walking, her husband would get distracted, speak a bit, and step out from the depressive thoughts, even though moments before he was not aware that he was struggling. The carer, on the contrary, could sense his depression by its external signs and made sure that she acted before things got worse. If IP8_C1 was not able to motivate the patient to exercise, self-care might not happen. The collaboration, in this case, was in the ability of the carer and the patient to coordinate their actions and reactions to make exercise happen and therefore address a negative symptom.

5.1.3 Adapting lifestyle

As the condition progresses, medication becomes less capable of addressing symptoms. Consequently, patients may be required to quit or slow down activities, or even get used to fluctuations in their condition state.

Stopping or slowing activities down

The restrictions Parkinson's brings to movement can hinder patients from performing specific activities. When such restrictions appear, carers are likely to participate more to make sure essential activities continue. The participation of carers was observed in different activities. The following excerpt focuses on cooking.

> IP10_C1: *She likes to cook, but I have to light the gas stove, peel the potatoes, and... (...) She likes to do it, but I have to be always by her side, because, if she falls...*

This carer was enabling the adaptation to the physical disability caused by Parkinson's. Cooking was dangerous for the patient because she often lost balance and fell. However, with the help of the carer, she was able to cook in a convenient and safe way. The carer's modest cooking abilities and his attention to preventing a fall compensated for the fine motor issues and the gait problems of the patient.

Stopping paid work was in many cases a necessity. When the body no longer responded adequately, continuing to work could even be dangerous. However, while leaving work might be positive for one's health, it was likely a hard change to make and accept for both patients and carers.

> IP5_C1: *I left [work] (...) because he lost a lot of weight. He would wake up at eleven and have breakfast. Then he would not have lunch. He would not take the medication for the heart, nor for anything. (...) I left and came home to be next to him. (...) I started giving him the medication at the right time, and he got well.*

Leaving work was very hard for the patient. He stopped taking the medication and lost hope in life. Facing such a situation, the carer decided to leave their business earlier than planned to help in the care of her husband. She started giving the medication on time and took action to re-instil the hope that her husband needed to keep living with the disease. Leaving work was therefore not an adaptation the patient did, but rather a change that the patient and the carer integrated into another way of living, that created the collective resources necessary for both physical and psychological care.

These adaptations are examples of the mundane and yet critical ways in which patients and carers collaborate to manage the physical consequences of the condition. Carers played a crucial role in enabling the adaptation to Parkinson's and yet, many people downplayed their own actions.
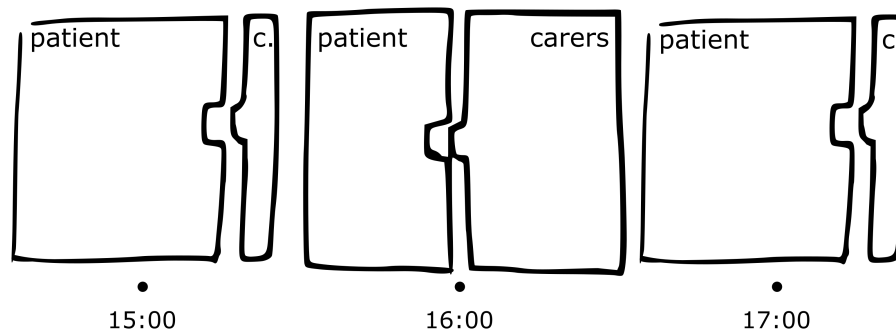
Figure 5.2: Fluctuations are likely to require adjustments in self-care, as patients will have their abilities restricted during certain periods. In these situations, the role of the carers probably becomes more visible, but collaborations occur throughout.

> F1M8: *I don't like to use the word carer and I hate it when someone tells me I do a wonderful job in looking after my husband. Caring for each other is what we both have done for the past 55 years. I am not going to stop it now.*

For F1M8, caring for her husband was just a way of continuing to perform the role of a spouse. During their shared life, F1M8 and her husband had always taken care of each other, and as Parkinson's appeared, they had to deal with it as well. However, caring for someone with Parkinson's did not define F1M8 as a carer. In her perspective, caring for the issues of Parkinson's was not different from the care she always provided to (or received from) her husband. The physical consequences of the disease challenged both the patient and the carer, which motivated them to find creative ways to achieve the day-to-day life they wanted to have.

Enduring fluctuations

Fluctuations are moments in which patients have stronger symptoms (Figure 5.2). Some factors can cause such fluctuations, including medication wearing off, a change to cold weather, or becoming worried about different situations. When fluctuations appeared, the collaborations between patients and carers were likely to be adjusted.

When patients became depressed, symptoms became stronger. This situation could be circumvented if patients got distracted, but very often patients were too overloaded by their thoughts to notice that they were not able to step out of them. Returning to the example of IP8_C1, one can see the important role that carers play in this situation. This carer used to go for a walk with her husband every day. She knew that IP8 would be more willing to walk if she also went, so she arranged her activities to be available to walk with him at least once a day. The carer did not want to tell her husband when to exercise, but always tried to motivate him and create the conditions that would make exercise easier to perform. Her role in exercise was that of an enabler. However, when symptoms became stronger, IP8_C1 became an even greater source of motivation, and the one responsible for choosing when to exercise. The trigger for changing the division

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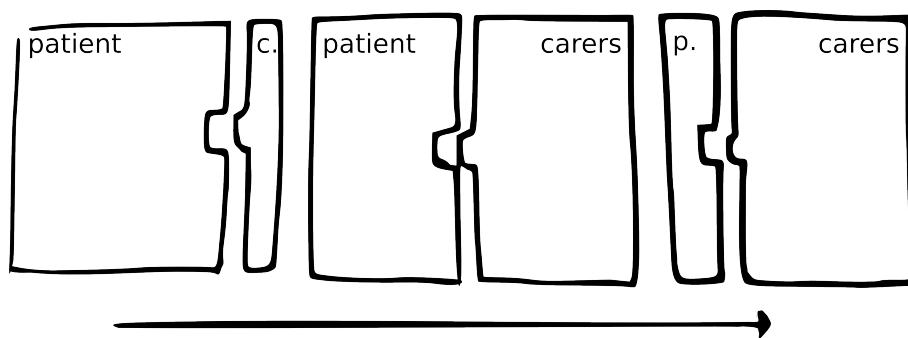
Figure 5.3: As the disease progresses carers are likely to take more parts of self-care from the patients, but the collaborations remain.

of self-care was the worsening in the emotional state of the patient. There was no explicit renegotiation of this new division, but rather a situated response to a difficult moment.

A similar example could be observed between IP5 and IP5_C1. The patient usually managed the emotions of the disease without great difficulty, however, in some situations, the symptoms were too strong, and he got very emotional.

> IP5_C1: "Oh? What is it [IP5]? I do not want to see you crying. Ok? Why are you crying now? Dying, we all do man. Don't worry with that, no one stays. Come on. Come on [IP5], I don't want you to stay like that. (...) Do you want to go to gymnastics [physiotherapy]?"

IP5 got very emotional when talking about dying and started to cry. The carer reacted quickly trying to understand why her husband was crying. As she discovered that it was a result of the disease, she tried to comfort her husband and make him stop. In doing so, the carer engaged more actively in the management of the emotions of the disease. It was not necessary moments before, but as the words triggered great sadness, a new self-care activity (comforting) was required. This self-care activity embodies a change in the self-care division. The carer was the one to react quickly adjusting the management of the disease to adapt to the issue that arose. Similar to the previous example, adjustments to the self-care work division were also of a practical in-the-moment nature, and no apparent negotiation took place.

What seems important to remember is that the division of care work will not be a definitive, static, or explicit decision, but a decision that is made along the way and that will have to be consistently monitored and negotiated as adverse conditions emerge and need to be accounted for. At each point, patients, but mostly carers, are vigilant of the current situation to understand how to adapt or act in face of the current situation.

5.1.4 Accepting the disease

Most patients and carers showed a deep acceptance of the condition. Parkinson's changed their routines, plans, and dreams and yet, people were able to put it behind their back

and continue with their lives. Accepting the condition was not something static that can be done on one occasion. On the contrary, accepting the condition required constantly re-affirming one's willingness to continue despite the problems. To facilitate acceptance, people compared their lives with more complicated ones, be it with people in more advanced cases of Parkinson's or who had conditions that they considered worse than Parkinson's.

> IP5_C1: *It is not the worst [condition] because Alzheimer's is much worse, isn't it?*

The carer in this excerpt made a comparison between Parkinson's and Alzheimer's, and concluded that the condition they lived with was not the worst one. Her statement was not innocent or meaningless. By comparing their case to that of someone with Alzheimer's, IP5_C1 motivated herself and her husband to accept the condition. After all, they did not receive the worse condition in the lottery, so they had reasons to be happy. Sentences like this were often repeated in interviews, signalling the need to constantly re-frame and re-assert their acceptance at different times.

Besides accepting their current situation, patients and carers had to prepare themselves for the future disease state. Having a progressive disorder meant that they were likely to experience stronger symptoms and with these, greater disability and loss (Figure 5.3). However, adjusting to the condition was quite complex.

> IP10_C1: *I didn't have to be concerned about it [reminding about medication], now I have to, because... Did you take it? Oh, I forgot. Now she starts [to forget]... But, there are so many [tablets], aren't there? At noon she has to take one, and I ask her and she forgot. It was unusual; she knew it [before].*

IP10 used to remember to take her medication at the right time. Now, that is no longer the case. Due to memory loss, she needs occasional reminders from the carer to ensure she takes the medication on time. The change caught them by surprise, but the patient and the carer quickly integrated it into their everyday life. This does not mean that the change was easy. The carer justified the forgetfulness with the fact that the patient took many pills. It is true that the patient was taking many pills, but she could remind herself with success for years. What is more probable is that the carer was putting, what Corbin and Strauss (1988) call a 'performance', to help his wife accept more easily that the condition is worsening. Realising one is losing abilities is hard, so the carer actively contributes to a re-framed acceptance of the Parkinson's by arguing that forgetting medication is something that could have happened to everyone.

Adaptations to the division of self-care seemed to be carefully thought out by carers. In particular, they needed to find a balance between encouraging autonomy and encouraging acceptance, while at the same time trying to re-define and maintain a life with quality. Encouraging autonomy helped keeping patients motivated to pursue with their self-care, ignoring some issues they might have. Encouraging acceptance helped patients adapting to the progression of the condition, but also made them understand they were no longer

able to do some things. Getting this balance right was not easy, but it was fundamental to living well with the disease.

> IP6_C1: *I'm not going to cut his beard if he can do it, right? I'm not going to hold his hand if he can walk. I cheer him up.*

IP6_C1 has been particularly clear about how she saw her role as a carer. She would help her husband doing all the things he was not able to do, but nothing else. If he was still able to do something, such as shaving, she would not do it for him. Rather, the carer would cheer the patient, and motivate him to keep pursuing his activities. As the symptoms increase, they would rethink what to do, but until then, her role was mostly to motivate.

Patients were also reluctant to start depending more on others, even for small things. Buttoning a shirt by oneself, for example, was essential to IP2, even if it took him three times as long as it used to take. The more patients insisted, the more they would be able to do in the future, so they did not want to stop doing anything they could.

> IP2: *I don't want to get used to depend [on others]… When dressing, for example. Sometimes I have difficulties in putting on my jacket and she [my wife] comes to help, but I don't want [the help]. Because if I get used to it, it is not good.*

Adaptations to the division of self-care were likely to happen as a result of the progression of Parkinson's. These changes were well thought out in order not to constrain patients from doing what they still can. Furthermore, the adaptation of self-care work division was accompanied by emotion management, ensuring the patient did not become demotivated by their loss of abilities.

5.2   Discussion

This chapter showed that the self-care of Parkinson's is highly collaborative. All self-care activities mentioned in the previous chapter can be seen as the result of collaborations between patients and carers. Previous work on living with Parkinson's had already uncovered collaborations in self-care. Daley et al. (2015) and Gibson (2016) mentioned that some carers participated in the management of medication. Martin (2012) reported examples of collaborations in medication, exercise, adapting lifestyle, and accepting the condition. Nevertheless, these studies did not talk about collaborations. Instead, the authors referred to the participation of carers as 'support', or 'help', which greatly undermines the work patients and carers do together. In fact, there are numerous studies that mention shifts of activities from patients to carers that omit any work done together (e.g., Wressle et al. (2007), Chiong-Rivero et al. (2011), McLaughlin et al. (2011), and Gibson (2013)). It is as if activities simply swapped from one actor to another, with no interaction or shared work. My fieldwork shows a different picture, though. Similar to the findings of Solimeo (2009), patients and carers were co-constructing and co-adapting to

life with Parkinson's *together*. Facing the difficulties of living with the condition, patients and carers joined their efforts to build a life with quality.

The collaborations between patients and carers could be observed in the ways people performed activities, but also in the ways they handled technologies. The fact that some carers had a medication reminder on their mobile phone or that IP3_C1 was the main user of the technology probe "Remind me when it is..." provides evidence that collaborations influenced as well the use of these technologies.

The existence of collaborations makes one reflect about the language that is used in self-care. As mentioned earlier, in this thesis I often refer to the expression of "people living with a chronic condition", to name patients and carers, because both actors experience the chronic condition, although carers do not experience it in their own body. The use of the expression "people living with a chronic condition" does not try to erase the differences between perspectives of patients and carers. Studying the different roles will bring valuable insights to understand self-care, but it will not be possible to get an overview of the self-care setting without considering the ways in which *both* patients and carers collaborate to achieve it. The use of the expression mentioned above captures the work that patients and carers do by themselves and together and, thus, offer a better grasp to self-care work.

Collaborations between patients and carers were present in both interviews and online ethnography, however, collaborations were clearer during the interviews. The reason for this might reside in my ability to follow the interviewees' leads in the interview and ask questions about the roles of patients and carers, which was not possible in the online community where I was playing a passive role. Nevertheless, the content of the posts in the online community shows numerous examples of common work and interconnected roles, which gives evidence that collaborations were also common in that community.

The argument about collaborations in self-care is rooted in examples from people living with Parkinson's, yet previous literature indicates that these may apply to people living with other conditions. For example, Corbin, Strauss, and colleagues documented collaborations between spouses living with distinct chronic conditions (Corbin and Strauss, 1984, 1988; Strauss et al., 1985). Charmaz (1991) also identified collaborations and argued that healthcare systems were too focused on patients, which downplayed the role of the carers as well as the consequences of the condition on themselves. In HCI, Ballegaard et al. (2008) argued that patients and carers living with diabetes collaborated in managing the condition. In a related note, Danholt and Langstrup (2012) argued that there is no 'self' in self-care because patients need other actors (e.g., relatives, clinicians) and entities (e.g., IT infrastructure, medication) to self-manage. In fact, carers become part of the infrastructure of chronic care "willingly or unwillingly" (Langstrup, 2013, p. 7) to help ensure that self-care happens.

It is realistic to expect that not all relationships between patients and carers are constructive and positive. In some cases they might be conflicting and problematic, bringing consequences to how the couple lives with the condition (Corbin and Strauss, 1984). For example, Seiler et al. (1992) found that patients with Parkinson's in satisfying marital relationships had lower depression scores than single patients; however, patients

in troubling relationships were the ones with the highest depression rates. When patients have conflicting relationships, they are likely to have issues in self-care, but this remains to be explored in future work, as conflicting relationships were not apparent in my fieldwork. In interviews they were basically non-existent, while in the online community, conflicts were rare. The small difference between the two methods might be due to the larger number of posts, but it could also be a result of finding a more neutral or non-judgemental community online. Most of the times, the forum threads mentioning conflicting relationships were related with the topics that discussed Dopamine Agonists medication and its effects on the behaviours of the people. As these drugs could bring impulsive behaviours, they were likely to bring great strain to relationships and to feed conflict until the medication was changed or adjusted to a smaller dose. Nevertheless, conflicting relationships were rare, which aligns with the work of other researchers studying Parkinson's everyday life (Solimeo, 2009; Martin, 2012; Gibson, 2013) or other chronic conditions (Corbin and Strauss, 1988). In reality, Solimeo (2009) and Martin (2012) reported that patients and carers felt even closer after the diagnosis, which gives weight to the idea that patients and carers united in face of the challenge of living with Parkinson's.

This chapter adds to the large body of research that studies collaborations in the healthcare setting in HCI and CSCW (Fitzpatrick and Ellingsen, 2013). Its contribution rests in the description of the collaborations between patients and carers in self-care. By exploring collaborations in self-care, this chapter complements prior research that analysed the collaborations between: the main carer and remaining members of the care network (including professionals) (Abowd et al., 2006), hospitalised patients and their carers (Miller et al., 2016), patients and doctors (Andersen et al., 2011), as well as between different clinicians (Kaplan and Fitzpatrick, 1997). This chapter also complements the growing area of work focused on the perspectives of carers (Chen et al., 2013; Schorch et al., 2016), by reflecting on the activities in which patients and carers collaborate.

5.2.1 Towards a concept of self-care that considers collaborations

The everyday life with Parkinson's points to important collaborations in self-care. For this reason, the chapter continues by characterising a concept of self-care that takes into consideration the collaborative dimensions identified in the fieldwork. The properties of the concept should sensitise designers to important aspects of self-care relating to the potentially existing collaborations.

Multiple actors. The self-care of Parkinson's is often the result of collaborations between patients and carers. When walking around the block, for example, patients are often joined by carers who, besides offering their company, take action to ensure that the exercise is safe and convenient. Some carers go to physiotherapy sessions as well, where they perform the same aerobic exercises, but also support patients in their movements, offer motivation, and a helping hand to pick up objects. These examples contrast with the concept of self-care, which is often framed as an individual endeavour. The word 'self-care' gives the idea of individual management, but the orientation for individual action does not end there. For example, the medical literature on exercise for Parkinson's

(Goodwin et al., 2008; Ahlskog, 2011; van Nimwegen et al., 2011; Speelman et al., 2011; Dontje et al., 2013) often depicts exercise as a set of activities oriented by professionals which deliver certain outcomes. The focus on the physical activities *per se* enables studies to compare the outcomes of different exercises, but it portrays a picture where exercise simply happens after hearing the instructions of clinicians. On the contrary, exercise is often the result of coordinated actions between patients and carers. Numerous patients would simply not exercise without their carers, because they would not feel safe going for a walk. Others would quit their physiotherapy sessions because exercises are hard and frequently confront them with their disability, for example, each time an object falls and they are not be able to pick it up. Having said this, it is important to recognise that there may be patients who mostly manage the condition by themselves. Patients may perform self-care in isolation as a result of exceptional life situations, not having access to a care network, or even by their own choice. Nevertheless, self-care cannot be considered an individual activity, but rather an activity that is likely to be done in collaboration, especially when people live with others. Recognising the collaborative nature of self-care entails considering multiple actors instead of just one, but at the same time, to adapt to the availability of the people involved in performing self-care.

Multiple perspectives to consider. The fact that both patients and carers play a role in building self-care does not mean that they have the same view point. Taking the example mentioned in the previous paragraph, when IP4 goes with IP4_C1 for a walk around the block, the patient is exercising, while the carer is offering company and ensuring the walk is safe and convenient for the patient. Having different perspectives on self-care seems clear when one considers a collaborative self-care where both patients and carers are involved, but that is not the case when one supposes the self-care is performed individually by the patient. For example, when van Nimwegen et al. (2011) or Dontje et al. (2013) refer to sedentary patients, they attribute the execution of exercise exclusively to the (willing or unwilling) patient. Since in their perspective self-care is individual, the responsibility for not exercising would lie solely on the patient. However, if one considers that both patients and carers are involved in exercise, it is straightforward to conclude that the lack of exercise might be attributable not only to sedentarism. It might mean that the carer was not available for exercising, or even that the patient and the carer had a dispute earlier in the day and do not feel like going for a walk hand-in-hand. Recognising that self-care is collaborative entails the acknowledgement that activities are performed by multiple people, embodying different perspectives depending on whether they are a patient or a carer.

Dynamic self-care divisions. The division of activities in self-care is not static. For example, IP5 does not usually have troubles in dealing with emotions, but when fluctuations result in stronger symptoms, the carer is likely to take a more active role in helping the patient to manage these issues. Adjustments in the division of self-care are common when living with Parkinson's because of the fluctuations in the condition state. Adding to the fluctuations, is the dynamic nature of chronic conditions because people experience "good days" – when symptoms are controlled and the 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 (Charmaz, 1991). When facing issues in their self-care, patients and carers adapt their work division to integrate their issues into a different (collaborative) way of management (Solimeo, 2009). Recognising that self-care is collaborative includes seeing the division of self-care work as temporary and likely to change if issues, in everyday life or caused by the condition, appear.

5.3   Summary

This chapter discussed how the self-care of Parkinson's is the result of collaborations between patients and carers. These findings question the common assumption that self-care is an individual activity and point to the need of approaching self-care through a different lens. This chapter makes clear that self-care is performed by *multiple actors* that participate in self-care with *different perspectives*. People divide self-care activities between them in a way that is practical, but they are ready to *adjust dynamically*, if needed.

Learning to live with Parkinson's

The previous two chapters demonstrated that people living with Parkinson's develop critical self-care skills. Taking medication on time, exercising consistently, adapting to fluctuations, or accepting the losses due to the condition all require extensive preparation, organisation, and experience from patients and carers. However, until now, there was no specific focus on how people learned to self-care the way they did. That will be the focus of this chapter. The work here presented draws mostly on the online ethnography of a community for patients and carers, and on the in-depth interviews. The chapter answers the second research question, of how people learn to perform self-care. The findings point that learning is lead by patients and carers focusing on the issues that concern them at the moment. The aim is to improve quality of life, so people negotiate different possibilities and making choices according to what is more appropriate to them. These findings contrast with previous literature, which expects learning activities to be coordinated by the doctor, who "trains" patients mostly in early phases of the condition to behave according to certain medical parameters. Quite the contrary, the fieldwork showed that patients and carers drive the learning activities, and they are also the ones investigating and negotiating self-care strategies for reaching a good life. The contribution of this chapter is in the ethnographic description of how patients and carers learn to perform self-care, as well as in the characterization of the concept of self-care that acknowledge that patients and carers develop knowledge.

The chapter begins by offering an ethnographic description of how people learn to live with Parkinson's. The following section discusses the findings of the fieldwork, and characterises a concept of self-care that considers how patients and carers learn to live with the condition.

6.1 Findings: Learning to live with Parkinson's

When I specifically asked people how they learned to live with the condition, most talked about their experience. IP7_C1 compared learning to live with Parkinson's to having a

newborn "*One learns with the routines and so*". Living with Parkinson's was for them the key to learn how to live with it. By experimenting and observing the routines, people were able to learn how to self-manage. Besides their personal experiences, patients and carers acquired information from multiple sources. Structured training was not common, but some participants in the interviews and of the online community had participated in training sessions at a local Parkinson's patients association. Learning from the experience of other patients and carers was deemed as vital, be it in person, or through the online forum, as it would show how others dealt with the same issues. Autobiographical books of people who had Parkinson's were also considered relevant for the same reasons. Then, there were the doctors, who helped people understanding numerous issues and validating some of their experiences. Moreover, the interviewed participants received information from the patient association, through regular emails, and a bi-monthly magazine. Members of the online community often exchanged blog posts and websites with each other, which indicates that the Internet was an important source of information for them. Family and friends also provided advice on how to accept the condition and proceed with a complex life. All in all, people used all the channels they had at their disposal to be able to learn about the condition.

In the rest of the section, I will explore in-depth some examples of how people learned to live with their condition. The description does not exhaust the learning experiences of patients and carers, but it provides an overview for understanding how they learn.

6.1.1 Building a repertoire of strategies to address daily issues

Learning to live with Parkinson's often translated as developing practical self-care strategies[1] for dealing with everyday issues. To better explain what a strategy is, I invite the reader to focus on Figure 6.1. The picture displays a classic model of shoes that has no shoelaces. This type of shoe was popular in the association premises, but I was not able to understand why in the beginning. One day, however, IP8_C1 explained to me that she bought this kind of shoe for her husband because he could put them on by himself without difficulties. Tying the shoelaces had become increasingly tiring and slow for her husband and, because of that, a reminder of his disability. By changing to shoes without shoelaces, the carer was able to decrease the time the patient needed to put the shoes on and, at the same time, remove an important reminder of Parkinson's disability. Shoes without shoelaces were thus not a fashion-driven choice, but an everyday strategy used to deal with the issues of fine motor skills. As addressing the symptoms of the condition was not completely possible, people found a creative way to avoid the issues raised when tying the shoelaces.

Everyday strategies were very diverse. They spanned from medicalized actions, such as addressing nausea with a Domperidone pill, to more mundane activities, such as using the mobile phone alarms for reminding about medication[2]. Patients and carers often

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[1] Self-care strategies, from now referred as strategies for brevity, are actions people engage in to deal with issues they face as part of living with a chronic condition.

[2] Refer to Chapter 4 for a thorough description of how people used mobile phone alarms to help them remember about medication.

Figure 6.1: Using shoes without shoelaces was a strategy used by patients to be able to put on the shoes by themselves. (Credits: https://www.flickr.com/photos/85546319@N04/14064895809/ ("foley-cover") by Robert Sheie licensed under CC BY 2.0).

came up with their own strategies to address their issues, but they also learned from the experience of others. Accessing the strategies of others gave people ideas to try and clues to understand how other people chose one strategy over another. What worked for others might not work for them, so people living with Parkinson's still had to put strategies to the test in their lives.

To better introduce the different characteristics of strategies, let us focus on an excerpt from a thread from the online community that discussed strategies for controlling tremor.

F1M9 (post #1): *Can anyone provide tips on how to control tremors?*

F1M10 (post #2): *(…) For me, it would be to avoid stress (…) I have tremor in my non-dominant hand. If I give it something to do, like put the hand in my pocket, sit on it, press it down on a table, it seems to work unobtrusively. Other activities make it worse. Holding a piece of paper makes it wave like a flag of surrender, or trying to type – keys rattle like automatic gun fire.*

Having the right medication (whatever that means for you) helped me as well.

I have learned these tips through trial and error. That is probably a tip in itself. (…)

F1M11 (post #3): *What works best for me is knitting, but that isn't always appropriate. I also have one of those squeeze balls for when I am watching TV, and the tremor is annoying. If that fails, holding one hand with the other, or sitting on my hand might work. It does mean that I am a bit of a fidget at the cinema. Thus I try to sit at the end of a row which helps as I can also stretch my back and legs more easily as there is not usually people behind. Taking medication brought the opposite effect in that my tremor, numbness in my hands and pains in my arms have all increased since starting on drugs.*

F1M12 (post #4): *(...) I've taken a few flights last year and found that listening to music helps. You can even pretend to strum along when you wear the earphones.*

F1M13 (post #5): *(...) If you have a device that offers games to play, like Sudoku, Angry Birds, or more up-to-date games, using your hands that way will help. Though probably not as much as knitting. (...)*

F1M14 (post #12): *A really interesting and absorbing book (or books) will distract the old parky and leave you in peace. Also music, not necessarily restful or gentle music. I find that rock music seems to tune out the Dyskinesia. No harm in trying it.*

F1M9 asked for tips on dealing with tremor and received multiple strategies from different people for addressing his issue. Having a set of strategies can be useful *per se*, because strategies that work for others might not apply to one's particular characteristics. Forum members recognised this need and often shared more than one strategy in their posts. Using this information, F1M9 can make, what Storni (2010) names as "mental plans", for addressing his issues when they appear.

The strategies shared in this excerpt were not only diverse but they tackled different issues. While all of them tried to get the tremor controlled, they had quite different assumptions. Tremor could be a symptom of Parkinson's, thus adjusting medication at the next consultation might help in reducing it. Tremor could also be the result of being nervous about something, and so engaging in some distracting activity, such as reading a book or listening to music, might help. Tremor could also be the result of an action and stopping that activity could help reducing it. If none of these strategies worked, the only solution might be to hide it. By providing F1M9 with strategies that have different assumptions, the members were not only providing ideas to act but also encouraging F1M9 to reflect on the situations in which his tremor occurs and what he would want a strategy to achieve (e.g., hide, distract, etc). Still, the patient will have to be the one, who identifies the cause of tremor each time and chooses an appropriate strategy to deal with it.

The provided strategies were contextualised to enable readers to understand for whom and in which circumstances strategies might work. In this excerpt, F1M10 wrote that her tremor is in the non-dominant hand. In doing so, she suggested that her advice might be useful to other non-dominant hand "shakers", but she also gave a signal to people with tremor in the dominant hand, that this advice might not be appropriate for them. People with tremor on the dominant hand might need different strategies, as sitting on it might not be the most useful when they need the hand to do other things. Besides making explicit their characteristics, members also provided detail of when they used a strategy. F1M11, for example, explains that she squeezes a ball when she is trying to watch TV and the tremor is annoying. In a different situation, maybe she would use knitting, but for watching TV, squeezing the ball is more suitable.

The excerpt contains some repeated strategies (e.g., listening to music or knitting) – a phenomenon that also occurs in other threads of the online community. In repeating

strategies, members were probably not parroting others, but giving weight to a specific strategy. It was common to read or hear patients and carers stating "we've heard a lot of people", "I've seen it mentioned", or "I've never seen it before", in some way validating or rejecting an idea based on its repetition in the community. When searching for advice, patients and carers may feel inclined to try out strategies that worked for many people than others with fewer proponents. Yet, if people see the advice providers as different from them – regarding symptoms, routines, age, etc. – they might end up choosing a strategy with fewer recommendations but backed up by people who share more similar characteristics with them.

In this case, F1M9 created a thread to ask a new question. He could have read some of the existing posts that mention tremor (1489 as of September 2015), but it would probably have taken too much time. Searching through so many threads would probably require him to be more specific in his search. However, there is something more to observe here. By creating a new thread, F1M9 is creating a space for receiving personalised advice for him. Even if the members speak in general terms, he can always ask them to shape their advice for his particular case, and that was not really possible in other threads. Advice only became personalised for him, when he asked the questions.

6.1.2 Probing possibilities and weighing options to arrive at one's current best state

Strategies are not universal. As each person living with Parkinson's has a particular set of symptoms, interests, habits, and social connections, it is impossible for the same strategy to work for everyone. Moreover, each strategy encapsulates a possibility, a way to do things, with advantages and inconveniences that need to be comparatively weighed. Patients and carers were thus continually negotiating and balancing their way to do things, to arrive at their best condition state.

> F1M15: *(…) I know DA's [Dopamine Agonists] have advantages. Whilst taking them, I felt great, however the mental damage was another story. I had to choose. I would either stay on the drugs and lose my family, or I would come off them. I ended up putting my family above my own 'feel good factor'. (…)*

F1M15 has taken a Dopamine Agonist for some time, but then she stopped. This medication was helping her move better, but at the same time, making her behave impulsively. F1M15 started shopping compulsively, and debts were piling up. She almost destroyed the trust her family members had in her, due to such a strong side effect. At some point, she had to take a step back and think about her self-management and her life. It was not possible to have everything, so she decided to stop this particular medication and be with her family. While the medication effect on the symptoms was strong, the treatment had detrimental consequences on other things she valued. F1M15's story is

probably an extreme example[3], yet Drey et al. (2012) also documents experiences of patients taking months to address very straining side effects. More problematic, as there is no right or wrong way of managing, patients and carers have to investigate what is the appropriate approach for them.

The negotiations people made to live a good life were not restricted to choosing different treatments. They appeared as well in more mundane activities.

> F1M3: *(...) I've never been a party animal, but I enjoyed going on holidays, visiting friends, theatre going, or even a simple country walk/picnic. I am not embarrassed of having Parkinson's, but I am always afraid of making arrangements as I might not be able to keep them, because of physical or emotional reasons. (...)*

F1M3 had troubles accepting invitations to events. Many times she would like to go, but she was fearful that her symptoms would not let her attend, so she rejected invitations upfront. The unpredictability of the condition often made people compromise, consider the available possibilities and what they value the most, to choose an option that led to the life they wanted to have. Even though the solution of rejecting invitations isolated and saddened the patient, it seemed to be the best compromise she could make for the moment.

Living a good life is dependent on the choices people make; thus patients and carers often try to understand whether they are enjoying the best quality of life they can. In the association premises, it was common to see people asking each other what symptoms they had and what medication they were taking. Part of this questioning could be due to curiosity, but people also had another interest. As one interviewee would confide to me, asking people about their symptoms and treatments was a way of understanding whether there was more appropriate medication available that they could try as well, for the possibility of gaining greater quality of life. A similar situation happened in the clinician's office when people asked about new medications coming to the market. This quest of patients and carers to understand whether they had the best quality of life available for them, using the current treatments, also appeared in the online community. F1M16, for example, was having strong nausea after increasing her dose of Sinemet®. She started taking Domperidone[4] for attenuating it, but the drug was not producing the promised effect, so she went to the online community to find an alternative strategy.

> F1M16: *(...) having decreased Sinemet to half a tablet, I noticed a more pronounced stiffness, aching, and tremor; but I can't stand the constant nausea feeling. I guess being stiff is the lesser of two evils. But thanks for the advice.*

Unfortunately, the members of the forum did not offer F1M16 any alternatives besides taking Domperidone. F1M16 thus understood that there was not much more she could do

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[3]Impulsive control behaviours are a side effect of antiparkinsonian medication, especially Dopamine Agonist (Gallagher et al., 2010), but not everyone gets them with the same intensity, and in many cases, medication is stopped before reaching such a strong impact on the lives of patients and carers.

[4]Domperidone is the name of a drug substance that relieves nausea and vomit.

and she had to stay with a lighter dose of Sinemet®. As a result, the patient re-adjusted her definition of quality of life to encompass living with stronger symptoms. Being stiff, as she explained, was the lesser of two evils, and for the moment, the best option at her disposal.

Arriving at one's best condition was crucial for someone living with Parkinson's, but it took knowledge from experience to know the alternatives, and reflection to realise what one values the most. Peers could help people know about possible alternatives used by others, as well as the advantages and shortcomings identified by them. However, what was appropriate for one person might not be for another one, so patients and carers had to be the ones weighing and reflecting about the lives they might want to live. Moreover, one's best condition state is a temporary arrangement that is likely to change as symptoms increase, new treatments appear, or the activities and priorities modify.

6.1.3 Getting to know what is caused by Parkinson's, medication, or something else

Parkinson's disease has a strong impact in daily life. On the one hand, there are the diverse symptoms of the condition, and on the other, the side-effects of taking a complex medication cocktail. As a result, when an issue appears people are not sure of its origin or how to solve it. This is exemplified on the following excerpt.

> F1M17: *I wonder if these weird smells that no one else around me smells are a symptom of Parkinson's, something to do with medication, or just something anyone can get.*

F1M17 noticed that something was not quite right with her sense of smell. However, she was not sure about the reason. It could be the condition, the medication she was taking, or simply the fact that she was getting older. Since F1M17 never experienced this situation, she went on the online community to access the experience of other patients and carers. The answers were not definitive, though. Some members argued that the condition caused the weird sense of smell, while others mentioned that it could be a side-effect of medication. Despite their disagreement, it was clear that others went through the same experience, which was enough for reassuring F1M17. Since other patients also sensed weird smells, there were fewer chances that the issue was caused by another disease, so there was no need to visit the doctor with urgency.

The weird sense of smell was so odd that F1M17 felt it could be a consequence of Parkinson's or its medication. Nevertheless, the effects of Parkinson's are so diverse that they can be easily mistaken by other causes. That was the case in the following excerpt.

> IP10_C1: *We have been married for 49 years, and now I can't talk with anyone. If I talk with someone on the phone and she knows it is a woman. She asks: [why] she called? What did she want?*
>
> I: *Is she being jealous?*

IP10_C1: *Exactly. I even say: she has never been concerned with that when young. She has never been concerned, but now...*

This carer mentioned that his wife was becoming jealous of his interactions with other women. It was not common before, but it started some weeks before the interview. For the carer, this was just a silly behaviour, but this situation might be much more complex. Some people with Parkinson's experience hallucinations or delusions, either caused by the condition or by medication such as Mirapex® or Requip®. Becoming jealous that their partner is having another relationship is one common example of being delusional. If noticed early, simple medication adjustments can make the delusion disappear; otherwise, the jealous attitudes might be confused for a sudden change in personality or interests, thus undermining this couple's relationship.

Patients and carers acquire a sense of direction when they know the cause of an issue. It tells them whether they should endure the issue, adopt a strategy recommended by others, bring it up during the next consultation, or go to the doctor sooner to address it. It is thus critically important to know whether a problem is caused by the condition, medication, or another source. If people do not try to learn about their issues, they will eventually accept something to be normal for their situation, and not seek for a way to address or change it. However, if people do pursue the causes for their health issues, they are more likely to identify some strategies to try and be able to arrive at their best condition state.

6.1.4 Gaining awareness of what to expect

Although people often talked about Parkinson's and their self-care with other patients and carers, participants were not always conscious that they were learning. Despite using strategies "invented" by others (e.g., mobile phone alarm, shoes without shoelaces) most people I interviewed struggled to answer what they had learned from others. There was one thing people usually mentioned, though: the lesson of seeing others in more advanced phases of Parkinson's.

IP5_C1: *We always learn something [with people in more advanced stages of Parkinson's]; we take a lesson for life. We see the reactions of others, the state in which they are at. And you start thinking that you might go through the same one day. That is a lesson for life.*

Seeing how people in more advanced phases of Parkinson's accepted the condition and self-managed was critical. It helped people in earlier phases to put their condition into perspective and to become aware of what to expect from their future. The members of the online community were not able to access the rich experience of meeting people in person – unless of course, they had contacts with other people living with Parkinson's outside of the online community. However, they still tried to understand what to expect by asking others in more advanced phases specific questions.

F1M18: *(…) These last few days she has got to the stage where she needs someone holding her up to stand. She cannot stand up and walk using the frame. Has anyone else come across a similar situation, knows possible causes, or is this the end stage of Parkinson's?*

F1M18 went online to get a sense whether the abrupt symptomatic worsening of his wife meant that she was entering the final stage of Parkinson's. F1M18 knew that Parkinson's was a progressive condition, however, he did not know what progression would mean in practical terms. Consulting other people in more advanced stages was an attempt to gain insights about what progression would practically mean, and a way to understand whether the experience they were going through was a common one. This particular post received a single reply showing empathy and recommending physiotherapy, but that was not the usual case. As progression and unpredictability are a certainty, people regularly exchanged experiences with other patients and carers to know what to expect from their future.

F1M19: *Does anyone use the Apomorphine via infusion pump? Mine arrives next week, but I would like to know if anyone experienced sleepiness or impulse control issues?*

F1M19 is going to start a new treatment for the condition: the apomorphine via infusion pump[5]. The reason why F1M19 posted on the online community was not related to the effectiveness or the (very complex) apparatus of the solution, but rather with its side effects. F1M19 heard or read somewhere that the medication can cause impulsive behaviours (e.g., gambling, shopping, hypersexuality) and sleepiness, and wonders whether it was a common side-effect for the people in the forum. This sort of preparation was what F1M15 and her carers missed. Had they been more vigilant after the medication change, and maybe the patient would have avoided some of the over-shopping and the associated consequences. In this case, F1M19 is acquiring an understanding of what to expect to prepare himself and his relatives for the first weeks of treatment.

The experiences of forum members with treatments were not restricted to specific side effects. Later in the conversation started by F1M19, another member discussed that he replaced the Apomorphine infusion pump with another infusion pen because he was constantly aware of the needle and had skin rashes. This person made his negotiation of the possible treatment options explicit. In other cases, members shared possible solutions to issues they had when using the treatment in practice. For example, one patient suggested using a specific cream to deal with the skin rashes that were caused by a medication patch.

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[5]The apomorphine infusion pump injects medication directly into the bloodstream through a needle that is inserted in the lower stomach or on outside of thighs (UK, 2014). This treatment is not common, but it is one of the options for people who often have fluctuations at random times, and extended periods of time in which (pill) medication does not work.

Reflections from piloting the probes: The "I was shaking like this..." probe and learning to self-care

The probe "I was shaking like this..." enabled people to capture tremor in a visual form. The idea was that people would record their tremors at different points, and use the printed plots to compare the intensity of movement in different situations. Unsurprisingly, the probe was not able to show big changes in the tremor plots. While people were trying different positions, including: sitting, standing, holding things, with and without the arm at a rest position, the results were always very similar as a result of overly simplistic movement sensing analysis. What became clear with the way people used the probe was that patients and carer engaged in serious investigation upon receiving the device. They tried different positions, at different times, and before and after taking medication, which evidences great experimentation. During one or two days they tried hard to see whether the tool could have a purpose for their self-care, but quickly understood that the results were always very similar and thus it could not be useful to their case.

6.2 Discussion

The findings show that people living with Parkinson's developed patient knowledge as a result of their experience with the condition. I argue that knowledge was created because, as Maturana would say, there was evidence of 'appropriate behaviour'[6]. Maturana and Varela (1992) explained that knowledge is deeply shaped by the experiences we have. We can only know what we do (or did). Experiences are the trigger, but appropriate behaviour is essential to develop knowledge. By responding appropriately to experiences, patients and carers learn to behave in the context of living with Parkinson's. Moreover, the word appropriate does not imply a generally accepted view of health or treatment, but a situated, specific, and personal aspect defined in the face of the current situation.

There is evidence that people living with Parkinson's engaged in appropriate behaviour. Having a set of strategies to deal with tremor, for example, shows that people were able to deal appropriately with tremor when it appeared. They knew what worked, in which situations, and for which type of symptom, so they could straightforwardly adapt their approach to different circumstances. Patients and carers investigated their symptoms and issues carefully, using the tools around them, such as the online community or the technology probe, to help them in that task. They actively tried to know whether they had reached the most appropriate treatment for them, which shows a commitment to achieve the most suitable self-care they could have. In addition, their active role in preparing for treatments, procedures, or progression, demonstrates an appropriate way to account for future changes in their condition state or self-care.

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[6]I already introduced the perspective of Maturana on knowledge in the methodology chapter (see Section 3.1), however, it is relevant to bring up some of its ideas once more to provide epistemological grounding to patient knowledge.

This chapter contributes with a description of the learning practices and the knowledge developed by people living with Parkinson's. While there is a significant body of literature studying patient knowledge in other chronic conditions (see Section 2.1.4), this is the first ethnographic description focusing on the particularities of learning and patient knowledge of people living with Parkinson's. For this reason, the discussion of the learning practices is done in contrast to the general literature around patient knowledge.

The insights from this chapter confirm that people develop practical strategies for living with the condition, either by themselves (Habicht et al., 2013), or inspired by the experiences of other people (Hartzler and Pratt, 2011). Particular to people living with Parkinson's is the amount of context that is offered when discussing strategies with others. In fact, advice usually included functional instructions or suggestions (e.g., 'sit on your hand'), contextual details to help identify the situation where it would be useful (e.g., at the movies), as well as personal characteristics (e.g., being left-handed). These contextual details were probably added due to the differences in Parkinson's cases and also the diversity of causes that can increase symptoms (e.g., weather, being nervous, Off phase medication).

Learning to live with Parkinson's entailed as well searching, exploring, and negotiating different alternatives for self-care. This included asking others about the options they made regarding their treatment, as previously argued in Sandaunet (2008) or Zhou et al. (2014), but it is more complex than that. The different self-care alternatives encapsulate different possibilities of life, with advantages and shortcomings, and so deciding upon self-care alternatives is the same as deciding on which life to live. People have to find what is the best self-care for them, because every patient is different in terms of symptoms, habits, routines, and values. This was made clear in the online community when members wrote sentences such as "whatever fits you best is the best strategy". Excerpts like this one contrast with previous work on online communities for other chronic conditions, which argued that members try to collectively agree on adequate strategies for self-managing the condition (Huh and Ackerman, 2012; Mamykina et al., 2015). The difference between those studies and this one is likely due to the symptomatic treatment of Parkinson's, and the radically different experiences with the condition people face; reaching a common agreement on what is important is close to impossible.

Besides deciding on different self-care alternatives, people consistently try to understand whether they reached the best quality of life they could have. As not everything is possible, people try to figure out what are the options used by others and evaluate whether they would fit their life. This explains why people often asked others about their symptoms, treatments, and side effects (Attard and Coulson, 2012), as well why they asked doctors for new treatments coming to the market. One's best state is complex to achieve due to the condition, medication, and lifestyle (Solimeo, 2009), but people are willing to constantly negotiate their options to keep improving their quality of life.

Finally, I also observed patient knowledge in tracking the origin of issues and in gaining awareness of what to expect in the future. Similar to Attard and Coulson (2012) and Pols (2012), patients and carers were many times confronted with the doubt of whether something they experienced was related with their condition. In particular,

people living with Parkinson's found it difficult to distinguish between their condition, medication, getting older, other causes, or just plain normal. Using the help of other patients and carers, they were able to get a sense of the possible cause of their issues, and thus get an idea of how to act upon an issue. Patients and carers also relied on similar others to understand what the condition could look (or feel) like in the future, and how specific exams or treatments might affect them, as in Sandaunet (2008) and Lowe et al. (2009). This was especially important for people living with Parkinson's because the condition is progressive and changes every couple of months or years. Gaining awareness of what to expect ahead reduced the anxiety of patients and carers, helped putting the condition in perspective (Charlton and Barrow, 2002), and enabled people to adjust self-care to deal with the issues they would face ahead.

6.2.1 Towards a concept of self-care that acknowledges that people develop patient knowledge

Recognising that patients and carers develop patient knowledge has important implications for the concept of self-care. This section will characterise the properties of the concept of self-care that concern the ways people learned to engage in self-care. These properties should sensitise designers and researchers working with self-care to better understand how people develop patient knowledge.

Learning as personal. The fieldwork has shown that patients and carers actively investigated issues of the condition as they appeared. When confronted with issues, such as difficulties tying up the shoes or weird smells, people searched for possible causes, examined connections between these and their issues, and experimented with different solutions. This investigator attitude is confirmed by studies of other chronic conditions, which even use the word detective to emphasise the investigation that patients and carers pursue to understand their condition (Mamykina et al., 2006; Corbin and Strauss, 1988). Nevertheless, some perspectives on self-care attribute a much more passive role to patients and carers. According to Clark et al. (1995) or Lawn and Schoo (2010), doctors would be the ones lecturing patients on all the aspects they needed to learn. On the contrary, this chapter showed that doctors are not the only source of condition-related information, nor are they the coordinators of the learning process that happens. Recognising that patients and carers develop patient knowledge entails accepting that they independently research the issues that appear to them in daily life, and learn about the aspects that are relevant to them.

Learning as a way to achieve a good life. The learning activities of patients and carers were often concerned with solving very practical issues. Tying up shoes by oneself, dealing with tremor, or reducing nausea episodes were some of the concerns described in this chapter. Having been confronted with these issues in their daily lives, people investigated and tried different strategies for increasing their quality of life in practical terms. The idea of learning as a way to improve one's quality of life contrasts with some perspectives on self-care that see learning, or patient education, as an opportunity to persuade patients to behave according to the best medical parameters or standards of

care, as in Nakagawa-Kogan et al. (1988), Clark et al. (1995), and Grosset and Grosset (2007). According to those perspectives, doctors would define a set of practices that patients and carers should perform for living well with the condition, and people would merely attend sessions and implement the principles in their everyday life. Quite the opposite, the fieldwork showed that learning for patients and carers is about trying to improve their current issues, not according to medical standards, but aligned with what seems to fit with their symptoms, practices, and values. Recognising that patients and carers develop patient knowledge requires one to consider that the goal of learning is not to be indoctrinated into a normative externally defined way of living, but rather to learn and practice the skills that lead to "an active and emotionally satisfying life in face of a chronic condition" (Lorig, 1993, p. 11).

Learning as a life-long activity. The fieldwork has shown that learning does not end in early phases of the condition. As time passes by, people develop new symptoms, face increased disability, or other sorts of new challenges that motivate them to adapt and adjust what they do and know. The example of F1M19 has been particularly clear in showing that people continued learning throughout the years. While this particular patient had lived for years with the condition, the prospect of starting soon with a new treatment, Apomorphine, led the patient to resort to the online community looking for advice on how to proceed and what to expect from the overall process. The idea that learning is a life-long activity contrasts with the more medicalized perspectives of self-care, arguing for structured programs to "train" patients in early phases of the condition (see e.g., Lawn and Schoo (2010)). This research claims that training makes patients knowledgeable to live with their disease, but in reality, learning does not end at that point. Had F1M19 learned everything in early phases of the condition, the question about Apomorphine would simply not make any sense. Recognising that patients and carers develop patient knowledge entails accepting that learning practices continue as years go by, and that progression and other issues of daily life will motivate people to change and learn.

Learning as choosing between multiple alternatives. The fieldwork showed that patient knowledge was not universal. As people had different symptoms, routines, interests, and values, the strategies adopted by them to address issues also differed. For example, while most patients addressed their nausea symptoms with a Domperidone pill, the strategy did not work for F1M16, and so she had to reduce her dose of Sinemet® as an alternative. Taking a Domperidone pill or reducing the Sinemet® dose are thus co-existing alternatives for reducing nausea, that might work for different people. Having multiple co-existing strategies contrasts with the more medicalized perspective on learning outlined above. A medicalized perspective on learning would expect people always to be lectured on one way to proceed, instead of multiple ones, which would maximise treatment in medical terms. However, what is appropriate for each patient is different, and only patients and carers can decide at each point which path to follow. Recognising that patients and carers develop patient knowledge encourages one to consider that people will have to learn multiple alternatives and decide themselves which one makes more sense to their characteristics, routines, and values, on a case by case basis.

6.3 Summary

This chapter investigated how patients and carers learn to live with the condition. The fieldwork shows that patient and carers drive the learning practices to address their current issues and achieve a good life. These findings question the assumption that learning is driven by doctors, lecturing people to adhere to one specific way of living. On the contrary, the chapter made clear that patients and carers learn to self-care *independently* and with a focus on solving their current issues *to attain a better quality of life*. Learning does not end in early phases of the condition, but rather is a *life-long activity* in which people negotiate and choose between *multiple possible alternatives* according to what is most appropriate to them.

The active agency of patients and carers in their medical care

The previous three chapters have described everyday experiences of people living with Parkinson's. In particular, I have focused on the mundane self-care work, on the collaborations between patients and carers, and on the process of learning to live with Parkinson's. This chapter[1] will discuss other important practices for people living with Parkinson's disease: the interactions with doctors. The fieldwork described here draws mostly on the observations at the hospital, online ethnography of an online community for interacting with doctors, and interviews with patients and carers. The chapter answers RQ3, of how people living with Parkinson's interact with their doctors. The findings show that people living with Parkinson's participate in the diagnosis and treatment decisions, engage in discussions to learn about certain topics, and address inappropriate medication. This active agency[2] contrasts with some perspectives on patient-doctor interaction that seem to attribute a more passive role to patients and carers in the interactions with doctors. The chapter contributes with an ethnographic description of how patients and carers interact with doctors, and a characterization of the properties of a self-care concept that acknowledges the active agency of patients and carers in these interactions.

The chapter starts with an ethnographic description of how patients and carers interact with their doctors. The following section discusses the findings of the work, and

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[1]This chapter extends Nunes et al. (2017). I will use the pronoun 'we' in recognition of the contributions of my co-authors Tariq Andersen and Geraldine Fitzpatrick to the analysis of the fieldwork.

[2]The word agency is used in this thesis to characterise the ability to contribute, influence, and decide on treatment. As Suchman (2009) explains, agency is inherently situated and tied to specific socio-material arrangements, which offer different capacities for action. People living with Parkinson's, for example, are usually motivated to participate in their care because of the ability to shape treatment according to their issues and aspirations (van der Eijk et al., 2011). Yet, their agency in care is often constrained by doctors who proceed under a paternalistic care model (Cahill, 1998) where patients are reduced to informants incapable of engaging in decision-making (Pinder, 1990; van der Eijk et al., 2015).

characterises properties of self-care that consider the active agency of patients and carers in their interactions with doctors.

7.1 Findings: The interactions between people living with Parkinson's and their doctors

Two times a year, patients and carers have a chance to discuss their issues with the neurologist and collaboratively adjust treatment. These occasions are critical for people living with Parkinson's because changes in medication can promote or hinder patients from performing specific activities. As the medication for Parkinson's is solely concerned with addressing the symptoms of the condition, being able to articulate well one's issues and discuss possible solutions is key to achieve a life with the quality that one aspires to.

In this section, we explore the interactions patients and carers living with Parkinson's have with their neurologists. In particular, we refer to five different interactions: i) Making explicit issues of concern; ii) Evaluating movement; iii) Discussing treatment adjustments; iv) Getting an understanding of what to expect; and v) Getting inappropriate medication revised. These categories will now be described in detail.

7.1.1 Making explicit issues of concern

Many symptoms of Parkinson's can be softened or removed using the right medication cocktail, so patients and carers carefully monitor the issues that appear and, during in-clinic consultations, report them to doctors. Neurologists support patients and carers in this task by asking questions such as: "How are you doing?", "Can you do everything you need in your day-to-day life?" and "Do you need help from others for performing specific activities?". In online exchanges, patients and carers usually express their concerns in the posts they publish, but doctors also prompt for additional information about the everyday experience. In both cases though, patients and carers are the ones defining the focus for the discussion and diagnosis[3], or in other words, what is important to address (or not) by what they mention to doctors.

Identifying issues of Parkinson's is not straightforward. As Parkinson's affects the brain, its symptoms appear in multiple areas and influence different functions. Furthermore, people have to investigate the issues caused by the condition, as well as the side-effects of the medication. Issues related with Parkinson's include motor issues such as tremor, or gait impairment, but also depression, delusions, and impulsive behaviours that one would not necessarily associate with a "movement disorder". Thus, patients

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[3]The word diagnosis is used here to name the identification and investigation of the causes of patient's issues. As Nunes et al. (2014) explain, diagnosis is not only about getting a name for the condition, but also addressing the agenda that the patients (and carers) bring to the consultation. In the case of Parkinson's medical care, finding out the condition's name is usually an activity that is held in the first encounters, but after that is settled, diagnosis becomes much more about understanding which of the identified symptoms is indeed an issue for everyday life, and what are the causes of such problems.

and carers adopt an attitude of actively investigating the issues they are faced with to understand whether and how they can address them[4].

> Guest___*: *When I have a slow movement problem I cannot walk slowly in a crowd in front of me, but I can walk very fast around them and continue to walk at a rapid pace, if I slow down to try to walk normally I can only maintain a turtle pace. Is this a common experience in movement disorders in beginning parkinson disease?*

This patient asked whether Parkinson's caused the gait issues they experienced when walking around others. In the reply, the doctor confirmed that this was an issue of the condition and that it could be fixed with medication adjustments. Interactions like these were frequent in the forum. Posting questions in the online platform enabled the patient to get some sense of direction on how to act regarding this issue. However, it is important to note that writing a post was often the last of a long line of actions by the patient (or carer). Before that, we can assume that the person was carefully observing the issue, comparing different situations, and reflecting on whether it always happened at the same time. This investigative attitude is essential if patients are to have their treatment optimised to their needs and preference.

Having identified an issue, patients and carers make their own judgment about whether it should be addressed with treatment changes.

> OP5: *I always wake up at 4 in the morning to go to the toilet. I have nights in which I have... My legs get very heavy, they hurt, and I have to get off the bed to cool them down. Then, I return to bed.*
> Dr.: *And then you can sleep, right?*
> OP5: *I can sleep then.*
> Dr.: *You can sleep then.*
> OP5: *These are little details. I don't think it is worth changing the medication [because of them].*

This patient has issues in the legs at night but does not think it is worth addressing them with medication. At first sight, refraining from treating a disturbing symptom could sound masochistic, but on a closer look, the excerpt reveals great reflection about the leg issue. The patient knows that there is no "silver bullet" in the treatment of Parkinson's; adding more medication might improve the leg issues, but bring other problems as well. In the whole picture, the leg issues are minor problems, "little details" as the patient calls them. She can still perform most daily activities satisfactorily, so trying out a new medication scheme does not seem like a requirement for her at the moment, especially when it might entail other consequences.

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[4]The investigator attitude has been previously documented in Chapter 6, when describing the patient knowledge involved in living with Parkinson's. Here, I focus mainly on how this part of patient knowledge is discussed with doctors.

7.1.2 Evaluating movement: Refraining from hiding symptoms and documenting unobservable issues

In complement to the issues reported by patients and carers, doctors also observe the body of the patient during consultations. Part of the observation is unstructured and happens throughout the appointment. However, at some point during the consultation, the doctor performs the neurological examination, a more structured movement assessment. The examination is not the same for every patient but usually includes walking along the corridor, being pulled backwards while standing ("pull test"), moving the elbow back and forth, opening and closing the hands fast, touching the finger alternately to the doctor's and one's nose, and following the finger of the doctor with the eyes. While observing the patient move, the doctor evaluates the rigidity of the muscles, symmetries in the body, difficulties in coordination, presence of tremor, gait impairments, and other characteristics of the condition. The doctor guides the neurological examination, but patients play an active role by letting their symptoms be visible (symptoms they might hide in everyday life), and by complementing the assessment with verbal details that cannot be observed.

Some symptoms of Parkinson's bring unwanted attention to the patient, so people learn to mask and hide their issues from others. Tremor is a common example of a symptom that people usually try to hide. However, during the movement assessment, people need to refrain from hiding their symptoms for the doctor to be able to observe them at their full potential.

> Dr.: *Now lets walk, with a fast pace, until the end of the corridor, ok?*
> *(OP8 walks)*
> Dr.: *You can come back, now.*
> OP8: *This hand is misbehaving [trembling]. (…) If I press my hand it stops.*
> Dr.: *No, let yourself relax.*

While walking, the hand started to tremble, and the patient began hiding it by pressing the hand. The doctor quickly asked the patient to relax and let his hand shake as she needed to observe the symptoms in all their strength. Here again, the contribution of the patient is essential to ensure that the doctor can gain useful information and that care is appropriate. Unless the person refrains from hiding the symptoms, the result of the movement assessment will be misleading. However, if the actions of both patients and doctors are aligned, the assessment can inform medication adjustments.

Symptoms are not always easy to observe. Sometimes, they only happen in specific circumstances that are not reproducible in the doctors' office (e.g., walking around a crowd, as shown previously). Other observation difficulties occur in the initial phases of the condition if Parkinson's symptoms are subtler.

> Dr.: *There is something I would like you to tell me. Before taking Madopar*
> *or Sinemet, because they are equivalent, were you better or worse?*
> OP2: *You know... I was never very [better]. At least, it did not seem to me.*

Figure 7.1: During consultations, patients and carers discuss with the doctor their disease state, their self-care, as well as the different strategies that have worked with other people, to find the best self-care fit to the life they want to have.

> Dr.: *So we are going to do it like this. I am going to remove the medication. You're going to get off the medication around one week before the next consultation. I will make a plan to show you how to do it, ok?*

The patient in the excerpt has some symptoms that could be caused by Parkinson's, but they could as well be due to the medication she has taken for years for another mental illness. When faced with parkinsonian symptoms, neurologists usually prescribe Levodopa to patients. If they get better, people probably have Parkinson's. If they do not, the condition might be a different one. In this specific case, improvements were not clearly visible to the doctor via the neurological examination. So the neurologist asked the patient whether she had noticed overall improvements since starting the medication. This feedback was essential, as the doctor could not observe the subtle changes felt in the activities of daily life. The observations of patients and carers provided the information to make a decision, which in this case, is to stop taking the medication and re-evaluate the symptoms a few weeks later.

7.1.3 Discussing treatment adjustments

One of the most significant moments of consultations is the discussion of treatment adjustments. During this exchange, patients, carers, and doctors agree on the medication to take during the next months and, as a consequence, define the activities patients will be able to perform. Doctors propose treatment options considering the symptoms of the patient, their activities and interests, existing medications, and their previous experience with other patients (see Figure 7.1). However, these suggestions are carefully scrutinised as only people living with the condition can assess whether they make sense.

IP2: *If I increase the dosage of Stalevo my movement problems improve, but I get dyskinesias. (…) Because the 150mg [pill] improves my gait significantly, but the problem is the dyskinesias. And so she [the doctor] reduced from 150mg to 100mg but shortened the intake period. I feel better with that [regimen].*

In this excerpt, the patient reflects about two recent medication plans and concludes that he "feels better" with the latest one. With that regimen, the dyskinesias disappear, and the walking is almost at its best. There are no straightforward treatment options for Parkinson's. Choosing the right medication, as Solimeo (2009) explains, is an exercise of finding balance in abilities and side-effects that is different for everyone. In any case, people living with the condition will be the ones weighing the various options provided by the doctor and choosing which direction to follow. Sometimes they will even choose paths that are against the doctor's recommendation.

Dr.: *You have a big gap between 8:00 and 15:00. This is even shameful [for me], but that is how Sir (…) likes to do it, right?*
OP3: *I have been doing it as the doctor instructed me to.*
Dr.: *No, I did not instruct you to do it like this. We ended up adjusting it in this way… This is a difference of 7 hours, right?*

This patient has a large interval between two medication intakes. Instead of the typical 3-4 hour interval to keep the effect lasting the day, this patient has 7 hours between two of his intakes. For the doctor, this interval is too long and inappropriate. For the patient, however, the medication regimen works just fine. He can do the activities he wants and the regimen fits well with his routines, so from his perspective there is no reason for changing it. The doctor tried to give arguments for making an adjustment, but as the patient finds it appropriate, "and he is the one living with it", the doctor refrained from further persuading the patient to change.

7.1.4 Getting an understanding of what to expect

In consultations or online exchanges patients and carers try to understand and prepare for the future[5]. This includes understanding how the condition will evolve, the potential a treatment has, and whether they will be able to pursue their activities in the future. Doctors provide information, but it is the people living with the condition who seek to inform and prepare themselves. The insights patients and carers acquire are valuable to them as they enable them to prepare their self-management for when these future situations arrive.

Guest___*: *It seems to me that a lot of the PD meds cause drowsiness. Do most PWP[6] continue to work full time jobs while being on the meds or do you*

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[5]Preparing for the future was previously mentioned in Section 6.1.4 when describing the patient knowledge of people living with Parkinson's. Seeing this theme appearing in interactions with doctors confirms that patients and carers use their doctors as sources of information to prepare themselves for their future condition state.

[6]PWP stands for people with Parkinson's.

find that most PWP usually cut back on work dramatically or quit altogether?
thank you, MJ
Dr. Okun: *This is a mixed bag. Many PD patients continue to try to work*
but must reduce hours, stress and anxiety which can all make symptoms worse.
Many PD patients also find it hard to work after the 5th year of the disease,
but this is highly variable as I have patients still working at year 20!

This patient (or carer) went online to ask if patients usually continue to work after starting medication. They know medication can cause drowsiness, and people might be too sleepy to concentrate or keep their eyes open. In reply, the doctor explained that some people quit their jobs while others continue with reductions in their schedule. Knowing this information helps this person prepare for the future. In case she is a patient, these insights help her in preparing to cut hours on her current job, or even finding a new one, should cutting hours be impossible. In case this person is a carer, knowing about these possibilities can encourage her to help the patient manage this loss, and prepare for her own work re-arrangements. Even though the question posed might be read as a general interest question, the consequences of having it answered have a significant impact on daily life.

Besides the progression of the condition, people also try to understand what to expect from their treatments.

Guest___*: *I'm currently taking .5mg Selegi[li]ne 2x/day and 2mg Requip*
3x/day. I am not experiencing any noticable side effects on this dosage. My
Neurologist says we can increase the dosage substantially slowly over time. Is
it likely that on increased dosages of Requip that I will experience side effects
of the drug?
Dr. Fernandez: *It is possible that you will experience side effects, but it is*
possible also that you will not. The only way to find out is to try it, right? I
personally do not go lower than 3 mg three times per day with my patients.
(...)

The patient asked in the forum whether they would experience side-effects with a higher dosage of the medication. In reply, the doctor put things into perspective and even mentioned that the patient was on a very low dosage, smaller than the one he would initially suggest to his patients. Side-effects might never materialise, but reading medication leaflets packed with potential side-effects might be daunting, and so referring to the forum was a way to get some answers quickly. In asking the question, this person received information that might help planning the future. Common to both excerpts is the agency of patients and carers in understanding and preparing their self-management for the future.

7.1.5 Getting inappropriate treatment revised

The medication for Parkinson's is very sensitive. Too little of it and the symptoms will not be softened, and if medication is too much, it can lead to undesirable side-effects. For

this reason, medication should be carefully adjusted. However, sometimes the medication regimen will bring more unwanted than beneficial effects and needs to be adjusted before the next consultation – up to six months away.

> Guest___*: *(…) I use lately 2 mg Mirapex, 3x a day at each meal, breakfast, lunch, and dinner, for a total of 6 mg per day. I have lately developed strong swelling of the ankles. My question is: Can this swelling be due to the Mirapex? I have no heart problems and I am sure it is not due to the heart.*
> Dr. Rodriguez: *Very likely is a result of the Mirapex and if bothers[o]me you will need to stop the medication or at least reduce the dosage (try 1.5mg tid)*

This patient recently increased the medication dosage and around the same time experienced swelling in the ankles. These events seemed connected, so the patient went to the forum looking for confirmation. The doctor explained that the swollen ankles could be due to the medication and suggested adjustments to ease the swelling until the patient could reach the doctor.

The Portuguese patients interviewed and observed did not use online forums but had other ways of getting their medication adjusted.

> IP10_C1: *We call the doctor and she… It is not easy getting her on the phone. But she [says:] take this or take that. She changes medication, over the phone, she does.*

Also, in this case, people were able to get their medication adjusted before the next consultation. As the medication plan brought unwanted side-effects, they phoned the doctor, discussed the adjustment, and implemented changes. The participants also mentioned that sometimes they went directly to the hospital to address problematic medication regimes. What is common between these examples is that patients and carers proactively created a way to access the doctor's advice between consultations. By using the forum, their mobile phone, or by visiting the clinic earlier, patients and carers created an alternative channel to access care and ensure timely adjustments.

7.2   Discussion

This fieldwork has shown that patients and carers are very proactive when interacting with doctors. During diagnosis, they voice their issues to the doctor and make explicit what is relevant for them. The interview is guided by doctors, but patients and carers are the ones defining which issues should be addressed, after carefully reflecting and investigating them in their daily lives. While undergoing the neurological examination, patients need to refrain from hiding symptoms, as they would do in public, for doctors to be able to observe them. They also detail other issues that cannot not be observed in the doctor's office. The treatment plan (or adjustment) is initially suggested by the doctor, but it is carefully scrutinised and interpreted by patients and carers, to evaluate how well it fits daily life and whether the adjustments in medication will be noticed in

the activities people want to do at each point. Furthermore, patients and carers are the ones creating an alternative channel for care when medication adjustments do not work out as expected.

Previous research supports the idea that some findings of this work might reflect as well the experience of people living with other chronic conditions. For example, Cicutto et al. (2004) described that people living with COPD presented a similar agency during their consultations, with patients defining issues to address and defending adjustments in medication timing to better fit their activities. In a similar note, Funnell and Anderson (2000) argued that doctors should understand the needs of patients with diabetes and work together with them towards the goals they want to achieve, because that is the only way to reach appropriate treatments. Anderson and Funnell (2000) and Glasgow and Anderson (1999) went even further on this point by arguing that patients with diabetes, their carers, and doctors should sit as equal when making decisions about their health as they all have important contributions to offer to medical decisions. The specific themes of the discussions that people engage in with their doctors probably vary from condition to condition, but it makes sense that people can influence their treatment when it has such a strong influence on their lives.

The active engagement of patients in their care is not exactly a new idea. Patient-centred care has been advocated for decades as a way to improve the quality of both acute and chronic care (Epstein et al., 2004). However, despite considerable discussion about shared commitments, decisions, and plans, in reality, things are much more structured and doctors end up making most decisions about the patient's health (Ong et al., 1995; Godolphin, 2009). This fieldwork, and the studies mentioned above offer a different picture, though, where patients and carers play an essential role in the shaping the decisions made in their interactions with doctors.

Having said this, it is reasonable to assume that not every patient and carer will participate in the diagnosis and treatment definition in the same way. Some patients and carers may prefer to leave some of the decisions to the doctor, especially in the beginning when they are learning about the condition and how to live with it. Towards more advanced phases of Parkinson's, the agency might also be reduced due to cognitive impairments (van der Eijk et al., 2011), or the doctors' prejudice that patients would not be interested or capable of understanding the condition and thus of participating in decisions (Pinder, 1990). Overall, surveys suggest that many consultations of people with Parkinson's are moderately patient-centred, with space for improving in information tailoring, emotional support, and the collaboration with the care team (van der Eijk et al., 2012, 2015). In any case though, patients and carers living with Parkinson's are often interested in being involved in their care (van der Eijk et al., 2011) due to the possibility of fitting treatment to address their everyday issues and aspirations.

The fieldwork discussed here relates with two settings, consultations at the doctor, documented by interviews and observations, and interactions in an online community, that stem from online ethnography. These settings have one main difference between them: the possibility of having patients, carers, and doctors at the same place at the same time. At the consultation, collocated interactions occur, while in the online community exchanges

are distanced in time and place. As a consequence of this fundamental difference, the interactions between patients, carers, and their doctors were different in these two media. For example, while interactions in the website tended to consist of a small number of messages exchanged, in the doctor's office interactions lasted between 15 minutes and half an hour, touching on multiple issues and subjects related to the condition. At the doctor's office, the body was observed and analysed, while in the online community issues were only textually described. Moreover, while interactions in consultations were part of a relationship that came from years before, interactions in the online community were brief and often lacked the context of the history of the patient. Still, despite these differences, patients and carers exhibited similar characteristics in the way they interacted with doctors. In both cases, patients and carers played a very active role in presenting their issues, discussing possible treatment adjustments, learning, and addressing problems in their medication. Regardless of the setting, patients and carers tried their best to influence their treatment to achieve the best results possible.

This chapter adds to the growing body of literature that describes the role of patients and carers as crucial to make medical care work appropriately. Previous work had called attention to how patients were essential in sending measurements remotely (Oudshoorn, 2008), bringing medical exams (Piras and Zanutto, 2010), exchanging information between doctors (Unruh and Pratt, 2008), and even retrain their medical team to offer good care (Riggare and Unruh, 2015). This chapter adds to these contributions by documenting the ways in which patients and carers are essential to reach appropriate medical decisions for their specific case. The role of patients and carers does not reside only in the preparation of materials for consultations or the implementation of treatment, but rather they are essential to the decisions that are made during consultations.

The findings from this chapter also confirm the collaborative nature of self-care that was described in Chapter 5. The patients I observed in the hospital were in almost all situations accompanied by carers, who, similar to Pinder (1990), Martin (2012), or Mentis et al. (2015), would participate actively in consultations. The patients and carers I interviewed documented that they also joined the patients during their consultations as a way to offer their contribution to the process. In the online community, both patients and carers asked questions to the doctors, which also gives evidence of collaborations. For these reasons, it is fair to assume that the collaborations in self-care also spanned the interactions with the doctors where self-care interacted with medical care.

7.2.1 Towards a concept of self-care that acknowledges the agency of patients and carers in interactions with doctors

Recognising the active agency of patients and carers has consequences for understanding consultations and other encounters in which self-care intersects with medical care. For this reason, I will now describe properties of the concept of self-care characterising the engagement of patients and carers when interacting with doctors. These properties should sensitise designers to relevant aspects of self-care relating to the interactions with doctors.

Active role in diagnosis definition. Patients and carers played a critical role in the diagnosis. The neurological examination could easily become misleading if patients hid their symptoms, or if patients and carers did not describe the differences between the observations at the clinic and the everyday experience. Moreover, patients and carers brought up many symptoms and issues to the discussions; and they were also the ones deciding how problematic each issue was. This active participation contrasts with some perspectives on patient-doctor interaction[7] that expect diagnosis to be performed only by doctors after collecting issues and complaints (Clark et al., 1995). Even the patient-centred care model, that advocates for shared decision-making, commonly understands the diagnosis and treatment definition as activities performed solely by doctors (Ong et al., 1995; Godolphin, 2009). This fieldwork favours a collaborative concept of diagnosis. Similar to Epstein et al. (2004), this chapter shows that diagnosing is about understanding issues from the standpoint of the lived experience, together with other complex needs, fears, or expectations. The doctor's role is thus not to decide, but to help people reflect on their situation and priorities, so they can articulate what is most important to address (Anderson and Funnell, 2000). Recognising the agency of patients and carers in medical care entails considering the crucial role they play in defining the diagnosis about their health, be it in the investigation of issues, or the reflection on whether each of them is worth addressing.

Active role in decision making. The fieldwork has shown that patients and carers participated actively in medical decisions concerning their health. While doctors suggested treatment adjustments, patients and carers scrutinised the potential of these to reach their needs and aspirations, and it was the collaborative engagements between all participants that resulted in appropriate treatment decisions. These collaborations in medical decisions were made clear with the example of the patient with a 7-hour interval between intakes, who kept to his old medication plan despite the doctor's advice to change it, because it served him well and there was little to gain from changing. Medical standards or preferences were not imposed on the patient against his will, instead, as Mol (2008) suggested, the patient was informed about their different options, together with their advantages and inconveniences, for them to be able to decide which path to choose. Collaborative decisions like this were common in the fieldwork; however, as mentioned before, the literature on patient-doctor interaction often portraits these encounters under a paternalistic model, where doctors solely make decisions. The regular use of the terms non-compliance or non-adherence[8] also indicates that medical decisions are not shared, because problems in implementing treatment or practical decisions are attributed to a willingness to go against the doctors "instructions". As Funnell and Anderson (2000,

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[7]The expression 'patient-doctor interaction' undermines the key role that carers play in interactions with doctors. Still, as this is an expression commonly used in the literature, it will be employed here.

[8]Chapter 4 brought up the question of medication adherence or compliance in Parkinson's. In particular, I questioned the use of the term when applied to the delay of medication, because it made seem the decision of delaying as erratic or pointless, in need of reducing or eliminating, when in fact, delaying was a sign of good adaptation to the condition. The terms non-compliance and non-adherence are discussed once more as they originated within a specific idea of the patient-doctor encounter where doctors make decisions.

p. 1709) elegantly put it, noncompliance only exists when there are "2 people working toward different goals". My fieldwork offers an alternative conceptualization to patient-doctor interactions where medical decisions are collaborative. All participants sit as equal partners at the table, in recognition of their specific expertise and the mutual commitment to reach the most appropriate treatment (Anderson and Funnell, 2000; Glasgow and Anderson, 1999). Making decisions collaboratively recognises that a treatment embodies both a clinical and a value judgment, and that the value judgement that matters is that of the patients and carers (Hamilton, 2014). Recognising the active role patients and carers play in medical care requires considering their participation in medical decisions and the implications that that has to offer to their care.

Active role in learning with the doctor. My fieldwork has shown that patients and carers actively sought to learn about their condition, treatment, and prospects during interactions with doctors. They often raised questions and directed discussions to certain topics to get information from their doctor. While patients and carers engaged actively in learning, literature usually refers to this activity as a passive one. The word used to name the learning that happens in interactions with doctors is usually patient-education, a concept that suggests that doctors educate the naïve patients that visit them. According to that perspective, patients do not understand the consequences of their choices, and so doctors need to educate and persuade them in specific ways (Lawn and Schoo, 2010). However, this point of view does not seem fair to describe the interactions captured in the fieldwork. In fact, patients and carers were well informed about their condition, that is why they raised issues in the first place. People sought advice on what to expect, what to look for, and what to consider, so that they could make informed decisions and prepare for the future. Recognising the active agency of patients and carers in their medical care entails understanding the role they play in preparing for the future through the questions and discussions they raise during interactions with doctors. Playing an active role may probably be the only way to get information from doctors because, as Pinder (1990) points out, doctors often avoid giving detailed information to people living with Parkinson's in fear of making patients feel depressed or stuck.

Active role in adjusting inappropriate treatment. Patients and carers living with Parkinson's were key to make medical care work. The participation in diagnosis, treatment discussions, and learning was an essential part of their intervention, however, the work of patients and carers did not end when interactions with doctors finished. While at home, people carefully observed the effects of starting an updated medication plan, in the patient's body and activities', and acted if a medication was inappropriate. When symptoms became worse or unexpected issues appeared, patients and carers quickly went to the doctor without an appointment, phoned their specialist, or went to the online forum, in search of a solution to their problem. The actions of patients and carers created ways to access medical care and ensured the disruptions in their everyday lives would be as short as possible. The fieldwork was full with examples where people had to adjust their medication quickly and yet, the literature for Parkinson's and other chronic conditions did not seem to discuss these experiences. It is as if the treatment was always perfect or at least good enough to wait until the next interaction with the

112

doctor, because there were no mentions to having consultations or phone calls before the next appointment[9]. Moreover, the accounts on self-care seem to be very stable in terms of activities, which gives the impression that such disruptions would not appear. My fieldwork however, shows that sometimes medication is badly received by the body and that medical care can be essential before the next appointment. In fact, that was the reason why patients often had the mobile number of their doctors, because situations like these appeared and they had to be solved. The common medication issues might be a characteristic of Parkinson's, because it is difficult to predict the effect that they would have in an individual (Pinder, 1990) as the body is very sensitive to medication. However, it is straightforward to expect that people with other chronic conditions might engage in similar actions if they change to a new medication or go through a new treatment that their body does not tolerate. Recognising the agency of patients and carers in their medical care entails recognising them as central to the implementation, monitoring, and correction of medication adjustments that work in unexpected ways.

7.3 Summary

This chapter discussed the active agency that patients and carers living with Parkinson's played when interacting with doctors. The findings question more traditional perspectives on self-care and patient-doctor interaction, which assumed patients and carers behaved passively. This fieldwork showed that patients and carers play an *active role* in *defining diagnosis*, *discussing treatment decisions*, *learning about the condition*, and *addressing inappropriate treatment plans*. This active engagement indicates that patients and carers enter interactions with their doctors as active contributors, willing to offer their perspective and contribute to better care. Patients and carers do not abdicate from the responsibility and agency they play in self-care in everyday life when entering the doctor's office.

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[9]In a focus group organised by van der Eijk et al. (2011), patients asked for follow-up telephone consultations after treatment changes for discussing side-effects, and requested email and phone contacts of their doctors to be always available to them, as a way to improve medical care. These requests suggest that these participants might have experienced the need to adjust medication before the next consultation, but these practices were not documented in the paper.

Review of self-care technologies

Having analysed how patients and carers engage in self-care, how they learn to live with the condition, and how they interact with doctors, this chapter focuses on investigating the opportunities promoted by self-care technologies. The work presented here draws on a critical review of self-care technologies[1], for Parkinson's and other chronic conditions described in scientific publications or listed in the iTunes store. The chapter[2] answers RQ4, of how self-care technologies support the everyday life with Parkinson's. The findings show that most technologies focused on medicalized aspects of self-care, and that they were primarily developed for individual patients to use. Moreover, the technologies showed good potential for facilitating learning and supporting interactions with doctors, although with some obstacles. This chapter contributes with a categorization of self-care technologies according to the properties or values outlined in the fieldwork.

The chapter begins with an overview categorization of the reviewed self-care technologies. The following four sections position the reviewed self-care technologies according to: the aspects of self-care they promoted (from mundane to medicalized), their role in supporting collaborations in self-care, their potential in promoting learning about the condition, and the agency patients and carers would potentially exercise in their technology-mediated interactions with doctors.

8.1 Overview of reviewed self-care technologies

Self-care technologies can influence the ways in which people self-care. By offering certain features, interactions, and assigning certain roles to users, technology can help shape how people perform certain self-care activities. The next sections will analyse how

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[1]A short description of each reviewed self-care technology can found in Table D.1 in Appendix D. The appendix can be useful to get a glimpse of a particular self-care technology, or even be used as a reference sheet while reading this chapter.

[2]This chapter extends work published in Nunes and Fitzpatrick (2015) and Nunes et al. (2017).

the characteristics of the reviewed self-care technologies promote or inhibit the values identified in the previous chapters. However, before starting that analysis, it is important to characterise the self-care technologies forming this review.

The review resulted in a total of 86 self-care technologies, 52 of which for people living with Parkinson's, and 34 other examples for people living with other chronic conditions. From the whole set, 58 were published in scientific journals and conferences from the years 2004 to 2015, and the remaining 26 found through the iTunes App Store.

The self-care technologies in the review promoted varied sorts of opportunities that tended to fall under the following seven non-exclusive categories: 1) Tools for tracking health-related data; 2) Tools to remind about medication; 3) Tools for supporting therapeutic activities; 4) Tools for suggesting self-care activities; 5) Tools for accessing information about the condition; 6) Tools for interacting with other patients and carers; and 7) Tools that enable remote interactions with the care team. These categories, emergent from the analysis, will be quickly introduced, together with examples of self-care technologies that they include.

8.1.1 Tools for tracking health-related data

The self-care technologies for tracking health-related data enabled people to record symptoms and data from the environment around them. The tracking was often supported by sensors, used while performing specific activities (active sensing) or while going about one's daily life (passive sensing). Alternatively, technologies enabled people to log issues by answering questionnaires or other prompts. The collected data was visualised, by either the patient, the doctor, or both, with the objective of learning more about the body and/or adjusting treatment. The technologies falling into this category were:

- For Parkinson's: Kinesia, Montfort iTug, myHealthPal, OneRing, Parkinson's Diary, PDApp, PD Life, PD Me, PD Me Tools, PDmove, REMPARK, SPARK, StudyMyTremor, TR_Meter, Video Recordings, @Point of Care

- For other chronic conditions: ADMS, AsthmaProbes, BoundaryWork, BP@Home, CHAP, CKDManagement, DailyAppropriation, eDiary, HeartPatients, ICT-BTMS, Jog Falls, MONARCA, PersuasiveSens, RemoteLogCam, Report-Asthma, SupportTeam, TiY, TLC-Depression, @Hand

8.1.2 Tools to remind about medication

Medication reminders triggered audiovisual alerts when it was time to take a medication. Most of the technologies ran on mobile devices, enabling people to receive reminders outside the home while performing their activities. Besides reminding people to take medication, some technologies presented visualisations displaying the medication compliance of the patient. The technologies falling into this category were:

- For Parkinson's: Beats Medical, myHealthPal, PDApp, PD Life, REMPARK, SMS reminders, @Point of Care

• For other chronic conditions: RemoteReminiscence

8.1.3 Tools for supporting therapeutic activities

The self-care technologies for supporting therapy essentially brought these activities from formal care institutions to the home. The activities supported varied from training speech, gait, balance, overall motor coordination, and others. These self-care technologies were usually framed as part of a relationship with the therapist and as a way to continue therapeutic exercises while at home. The technologies falling into this category were:

• For Parkinson's: Beats Medical, DAF Professional, eREHAB, iParkinsons, Jaw Drop Toolkit, Motor-Cognitive VR, Parkinson's Speech Aid, pd-FIT, SCRUMP, Speak Better, Speech Pacesetter, Speech Tool, Voice Analyst, Voice Game, Wii Fit, Wii with balance board, WuppDi!

• For other chronic conditions: COPD-Therapy, COPDTrainer, DialysisMachine, ONESELF

8.1.4 Tools for suggesting self-care activities

These self-care technologies monitor aspects of the condition or environment and suggest ways to address them. For example, **LApp** senses the speech volume and displays a visual cue to patients with Parkinson's if they need to increase it. **CuPiD** detects if a Parkinson's patient's gait is freezing and starts auditory cueing to help address it. In most examples, technologies captured and processed data using sensors and, when certain events were detected, triggered cues to signal the need to perform certain activities. The technologies falling into this category were:

• For Parkinson's: Cueing Swallowing, CuPiD, FOG cueing, GaitAssist, LApp, REMPARK, SpeechOmeter, Swallow Prompt

• For other chronic conditions: AssistingInsulin, RemoteLogCam

8.1.5 Tools for accessing information about the condition

The self-care technologies for informing people about their condition were another group present in the review. These technologies had varied focuses, from general information about symptoms and treatments of Parkinson's (as in **GoLearningBus**, **Parkinson's Central**), to news about the condition conveyed in the media (**PD Headline News**), or commentaries to scientific articles (**PD Monitor & Commentary**). The technologies falling into this category were:

• For Parkinson's: GoLearningBus, Parkinson's Central, PD Headline News, PD Monitor & Commentary

• For other chronic conditions: Food Quiz

8.1.6   Tools for interacting with other patients and carers

Another group of self-care technologies facilitated the remote communication with patients and carers living in similar situations. The ways of interacting were diverse ranging from writing posts (**Patient Innovation**), to participating in videoconference calls (**VideoCare**), yet the objective of connecting with other patients and carers was common. The technologies falling into this category were:

- For Parkinson's: Patient Innovation, PatientsLikeMe

- For other chronic conditions: VideoCare, Caring~Web, HIVForum

8.1.7   Tools that enable remote interactions with the care team

The self-care technologies for interacting remotely with the care team enabled patients to receive feedback about their health at a distance. The purpose of interacting with the care team varied, from attending remote consultations to attending remote therapy sessions. The members of the care team were also diverse, including doctors, nurses, or therapists. The interaction medium of technologies included videoconference, telephone, or text messages. The technologies falling into this category are:

- For Parkinson's: Video Consultations, Virtual Consultations, Virtual Housecalls

- For other chronic conditions: Caring~Web, COPD-Therapy, MAHI, MONARCA, myRecord, Telehealth videophones, Telephone CBT, VideoCare

8.1.8   Others

Besides the technologies in these groups, there were three examples that do not fall into any particular category. **Rides For Parkinson's**, for example, is a technology that people living with Parkinson's use to arrange rides if they need to go somewhere and were not able to ride a car. **EmotionMingle** is a technology for distributing care work amongst the care network of paediatric cancer patients, and **mobileWAY** a technology for letting patients with dementia know where their carers went and when they would come back, when carers attend activities outside the home.

8.2   Focus of self-care technologies: from medicalized to mundane aspects of self-care

Having provided an overview of the self-care technologies in the review, the chapter continues by positioning self-care technologies according to the values uncovered in the previous chapters. To start, I focus on analysing the aspects of self-care supported by self-care technologies. Chapter 4 showed that the everyday life with Parkinson's was full of practical activities aimed at self-managing the condition. While the medical literature often focused on the more medicalized activities of self-care, such as self-monitoring

symptoms or performing treatment, my fieldwork documented how self-care was often the result of numerous mundane activities people engaged in. The goal of this section is to investigate whether self-care technologies focused more on medicalized or mundane[3] aspects of living with Parkinson's.

Self-care technologies have the potential to support people in their everyday self-care work, by enabling certain activities, their preparation, or the overall juggling of mundane issues. However, this potential is dependent on the concept of self-care that is embodied in the self-care technologies. If a medicalized concept of self-care is internalised by designers, self-care technologies will probably be concerned with aspects such as self-monitoring or performing treatment, while if a more mundane one is acknowledged, the focus will be more broad in recognition of the complex work patients and carers engage in to achieve self-care. Moreover, it can be hard to categorise a self-care technology as either supporting medicalized or mundane aspects of self-care, because self-care activities are often interconnected. Nevertheless, there are signs that can help the categorization. For example, if self-care technologies afford usage with the doctor, there is a good sign that they might support more medicalized aspects of self-care. On the contrary, if a self-care technology is focused on a problem that cannot be easily solved in the clinician's office, then it probably fits the more mundane self-care aspects. Independent of the position of each particular technology, it is preferable to talk about a spectrum, instead of two contradictory categories.

8.2.1 Tools for tracking health-related data

The self-care technologies for tracking are divided between the medicalized and mundane ends of the spectrum (see Table 8.1). In principle, the self-care technologies for tracking would enable patients and carers to reflect about their data, and consequently learn about their condition, and thus promote practical adaptations in their self-care. That seemed to be the case with, **PD Me** and **TR_Meter** for Parkinson's, or with **AsthmaProbes** and **TiY** for other conditions.

However, most other reviewed examples show a much more doctor-oriented perspective. In fact, 25 out of the 35 self-care technologies afford usage with doctors, and the collected data restricts mostly to symptoms that are "clinically relevant". The purpose of tracking is, as the descriptions of **Kinesia** and **SPARK** refer, to enable doctors to "maximise the therapeutic benefit" or personalise "interventions for each patient" (Mera et al., 2012; Sharma et al., 2014). In 9 technologies, patients cannot even visualise the data they collected about their health. For these reasons, it is fair to argue that most self-care technologies for tracking position in the medicalized end of the spectrum, even if some can be considered as mundane.

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[3]Technologies for mundane aspects of self-care should not be confused with mundane technologies. Dourish et al. (2010, p. 171) defined mundane technologies as "technologies and applications that are commonplace, which lots of people use, such as mobile phones, texting, email, word-processing application". In this chapter though, the focus is not on whether technologies are commonplace, but rather on the types of opportunities that were supported by self-care technologies. When referring to technologies for mundane self-care, I refer to tools that support the practical life with a chronic condition.

Name (condition)	Passive sensing	Active sensing	Logging	Visualise data	Afford use with doctor
ADMS (other)	-	Glucose	-	Yes	No
AsthmaProbes (other)	Air quality	Peak flow	-	Yes	No
BoundaryWork (other)	-	Blood pressure, glucose, coagulation	-	No	Yes
BP@Home (other)	Noise, movement	Blood pressure	-	Yes	Yes
CHAP (other)	Glucose	-	Activity, meals, emotions	Yes	No
CKDManagement (other)	-	-	Symptoms	Yes	No
DailyAppropriation (other)	-	Yes	-	Yes	Yes
eDiary (other)	-	Glucose	-	Yes	Yes
HeartPatients (other)	-	Blood pressure, pulse, weight	-	No	Yes
ICT-BTMS (other)	-	-	Activity, blood pressure, glucose, medication	No	Yes
Jog Falls (other)	Activity, blood pressure, pulse	-	Food	Partial	Yes
Kinesia (PD)	-	Movement	Medication, symptoms	No	Yes
MONARCA (other)	Social activity	-	Mood, sleep, activity, medication	Yes	Yes
Montfort iTug (PD)	-	Movement	Symptoms	Yes	Yes
myHealthPal (PD)	-	Movement	Medication	Yes	Yes
OneRing (PD)	Movement	Movement	-	Yes	Yes
Parkinson's Diary (PD)	-	-	Exercise, mood, meals, medication, sleep	Yes	Yes

Table 8.1: Characteristics of self-care technologies for tracking.

Name (condition)	Passive sensing	Active sensing	Logging	Visualise data	Afford use with doctor
PDApp (PD)	Movement	Movement	Mood, activity	Yes	Yes
PD Life (PD)	-	-	Mood, symptoms, side-effects	Yes	Yes
PD Me (PD)	Reaction time	Balance	Symptoms, side-effects	Yes	No
PD Me Tools (PD)	Reaction time	-	Symptoms	Yes	No
PDmove (PD)	Movement	-	-	Yes	Yes
PersuasiveSens (other)	Activity	Glucose, weight	Meals, water consumption	Yes	No
RemoteLogCam (other)	Spasms	-	-	Yes	No
REMPARK (PD)	Movement	-	-	No	Yes
Report-Asthma (other)	-	Air flow, oxygen level	Symptoms	Partial	Yes
SPARK (PD)	Movement	Movement	-	No	Yes
StudyMyTremor (PD)	-	Movement	-	Yes	Yes
SupportTeam (other)	Location	-	Meals, personal care, sleep, stress	No	Yes
TLC-Depression (other)	-	-	Symptoms	No	Yes
TiY (other)	-	-	Categories of their choice	Yes	No
TR_Meter (PD)	-	Tremor	-	Yes	No
Video Recordings (PD)	-	Movement	Complaints, symptoms	No	Yes
@Hand (other)	-	-	Blood pressure, weight, mood	Yes	Yes
@Point of Care (PD)	-	-	Activity, medication, mood,< symptoms	Yes	Yes

(Table 8.1 – continued from previous page)

Name (condition)	Schedule type	Supports snooze?	Supports delay?	Visualises compliance data?
Beats Medical (PD)	Single	No	No	No
myHealthPal (PD)	Single	No	No	Yes
PDApp (PD)	Single	Yes	No	No
PD Life (PD)	Single	No	No	Yes
RemoteReminiscence (other)	Single	?	No	No
REMPARK (PD)	Single	No	No	Yes
SMS reminders (PD)	Single	No	No	No
@Point of Care (PD)	Single	?	No	Yes

Table 8.2: Characteristics of medication reminders.

8.2.2 Tools to remind about medication

Medication reminders belong to the medicalized end of the spectrum. While these technologies help integrating medication routines into daily life, the reviewed examples exhibit certain features that adhere to a medicalized perspective on medication (see Table 8.2). For example, all analysed technologies use 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 people to take medication at the exact point when the alarm was triggered. Moreover, the inability to delay medication also limits the support the technology offers when people need flexibility to attend their activities outside their usual On phase hours. Together, these characteristics enforce structured routines on patients (and carers) that cannot be easily changed or adjusted, and that attribute priority to medication at all times. In addition, half of the medication reminders collect information about missed medication, displaying it as a compliance plot or summary (see Figure 8.1). Knowing when medication is missed could be important for optimising reminding strategies; however, by displaying a percentage of compliance, reminders imply that skipping medication is always a sign of non-compliant behaviour that should be eliminated. For these reasons, it is fair to say that medication reminders sit on the medicalized end of the spectrum.

8.2.3 Tools for supporting therapeutic activities

The self-care technologies for supporting therapeutic activities sit in the medicalized end of the spectrum as well. The specific focus of these technologies varies, but the overall motivation is to bring therapeutic activities from medical care institutions to the home. As Table 8.3 shows, therapists themselves rarely provide the feedback given in the reviewed technologies, but technologies mimic the advice these professionals offer in the clinic. For example, in Speech Pacesetter, an application for training reading pace, patients see visual cues over each word and hear a metronome sound that seeks to replace the feedback speech therapists would give to keep an understandable reading pace. Moreover, in Jaw Drop Toolkit as well as in other 10 examples, the medicalized perspective is even more explicit as the description of technologies underline that the

122
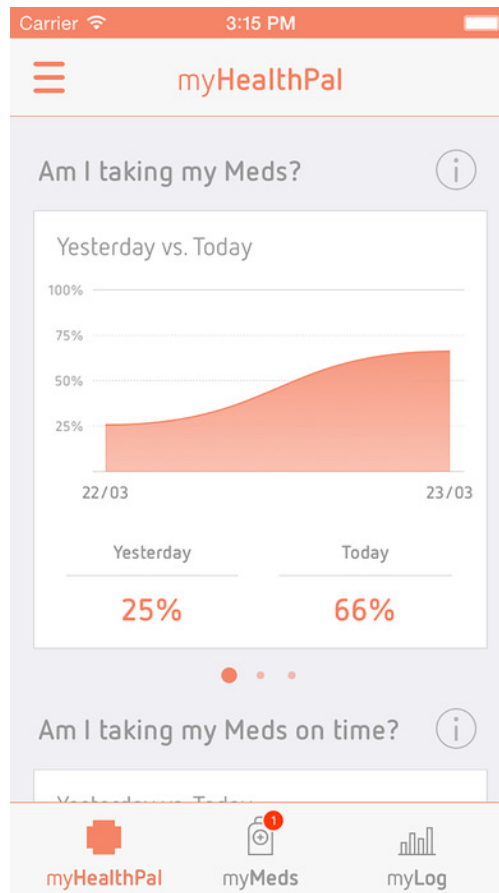
Figure 8.1: **myHealthPal**, an application for reminding people to take medication, includes a plot showing the medication compliance (Credits: http://www.myhealthpal.com/).

technology use should occur under the guidance or support of a therapist.

There are some examples of technologies that replace repetitive activities with serious games as a way to motivate people to perform them, such as **SCRUMP** or **WuppDi!**. However, while being more engaging, these technologies still promote therapeutic activities as they are performed in a medical setting. Thus, they are still positioned in the medicalized end of the spectrum.

8.2.4 Tools for suggesting self-care activities

The self-care technologies for suggesting self-care activities appear on the mundane side of the spectrum. As Table 8.4 shows, the activities promoted by these technologies are varied, but all of them deal with practical issues of living with a chronic condition. While addressing the symptoms is not entirely possible, the technologies can offer patients the tools to reduce the problems caused by them, such as the excess of saliva (**Cueing Swallowing**), or to reduce the inconveniences resulting from the symptoms, such as the

Name (condition)	Focus	Engagement	Feedback	Setup
Beats Medical (PD)	Dexterity, gait, speech	Repetitive exercise	Auto	Patient
COPD-Therapy (other)	Mobility	Remote session	Therapist	Therapist
COPDTrainer (other)	Limb movement	Repetitive exercise	Auto	Therapist
DAF Professional (PD)	Speech	Repetitive exercise	Auto	Patient
DialysisMachine (other)	Dialysis	Repetitive treatment	Auto	Patient
eREHAB (PD)	Speech	Remote session	Therapist	Therapist
iParkinsons (PD)	Speech	Repetitive exercise	Auto	Therapist
Jaw Drop Toolkit (PD)	Speech	Serious game	Auto	Therapist
Motor-Cognitive VR (PD)	Dual task ability	Serious game	Auto	Therapist
ONESELF (other)	Mobility	Repetitive exercise	Auto	Patient
Parkinson's Speech Aid (PD)	Voice	Repetitive exercise	Auto	Therapist
pd-FIT (PD)	Dexterity, gait	Repetitive exercise	Auto	Patient
SCRUMP (PD)	Balance, posture	Serious game	Auto	Patient
Speak Better (PD)	Speech	Repetitive exercise	Auto	Therapist
Speech Pacesetter (PD)	Speech	Repetitive exercise	Auto	Therapist
Speech Tool (PD)	Speech	Repetitive exercise	Auto	Patient
Voice Analyst (PD)	Speech	Speech characterization	Auto	Patient
Voice Game (PD)	Speech	Serious game	Auto	Patient
Wii Fit (PD)	Cognition, mobility	Serious game	Auto	Patient
Wii with balance board (PD)	Balance, mobility	Serious game	Auto	Patient
WuppDi! (PD)	Mobility	Serious game	Auto	Patient

Table 8.3: Characteristics of self-care technologies for therapy.

Name (condition)	Trigger	Sensors used	Produced event	Activity suggested
AssistingInsulin (other)	Manual	-	Display insulin dose	Adjust treatment
Cueing Swallowing (PD)	Time	-	Vibration	Swallow saliva
CuPiD (PD)	Gait freezing	Movement	Auditory cueing	Adjust gait
FOG cueing (PD)	Gait freezing	Movement	Auditory cueing	Adjust gait
GaitAssist (PD)	Gait freezing	Movement	Auditory cueing	Adjust gait
LApp (PD)	Low volume	Sound	Visual cueing	Speak louder
RemoteLogCam (other)	Spasm	Movement	Vibration	Relax limb
REMPARK (PD)	Gait freezing	Movement	Auditory cueing	Adjust gait
SpeechOmeter (PD)	Low volume	Sound	Visual cueing	Speak louder
Swallow Prompt (PD)	Time	-	Vibration	Swallow saliva

Table 8.4: Characteristics of self-care technologies for suggesting self-care activities.

dangerous situations arising from freezing of gait (**FOG cueing**). In any case, addressing practical issues of the condition positions these artefacts in the mundane end of the spectrum.

8.2.5 Tools for accessing information about the condition

The self-care technologies for informing people about their condition appeared on both the medicalized and the mundane parts of the spectrum (see Table 8.5). Towards the

Name (condition)	Use	Covered topics
Food Quiz (other)	Play serious game	Calculate/guess carbohydrates in food
GoLearningBus (PD)	Read texts, play quiz	Symptoms, treatments, causes, diagnosis
Parkinson's Central (PD)	Read texts	Symptoms, treatments, living with PD
PD Headline News (PD)	Read texts	Fundraising, latest research, living with PD
PD Monitor & Commentary (PD)	Read texts	Latest research

Table 8.5: Characteristics of self-care technologies for accessing information about the condition.

Name (condition)	Engagement	Expected users
Caring∼Web (other)	Exchange emails	Carers
Patient Innovation (PD)	Write posts, exchange messages	Patients, carers
PatientsLikeMe (PD)	Write posts, exchange messages, log data	Patients, carers
VideoCare (other)	Videoconference	Carers
HIVForum	Write posts	Patients

Table 8.6: Characteristics of self-care technologies for interacting with other patients and carers.

medicalized end, one finds technologies such as **GoLearningBus** and **Parkinson's Central**, which offered information about medical aspects of the condition, including diagnosis, symptoms, and medication. The description of **Parkinson's Central** even states that the goal of the technology was to answer the questions that "come up between visits to your neurologist", which positions the technology as a source of medical information. **PD Monitor & Commentary**, which offers commentaries to the latest research on Parkinson's is also medicalized, because it conveys the latest medical insights about the condition.

Towards the more mundane end one finds **PD Headline News**, which offers news from multiple Parkinson's patient associations. The news touch on latest research and fundraising, but there is a great emphasis on the everyday life with the condition, which leads one to position it on the mundane end. **Food Quiz**, a technology for children with diabetes, also appears on the mundane end of the spectrum, because it teaches children a practical activity – the calculation and estimation of carbohydrates in food.

8.2.6 Tools for interacting with other patients and carers

The tools for interacting with other patients and carers were essentially mundane as they enabled patients and carers to engage with others in the same life situation (see Table 8.6). While all sorts of topics would come up in discussions, people often discussed practical issues and solutions for the mundane problems they faced, thus these technologies are positioned in the mundane end of the spectrum.

Name (condition)	Engagement	Care team member
Caring~Web (other)	Exchange text messages	Nurse
COPD-Therapy (other)	Attend remote therapy session	Physiotherapist
MAHI (other)	Exchange text messages	Educator
MONARCA (other)	Receive advice regarding reported data	Nurse
myRecord (other)	Exchange text messages	Cardiologist
Telehealth videophones (other)	Attend remote consultation	Nurse
Telephone CBT (other)	Attend remote therapy session	Psychologist
VideoCare (other)	Attend remote consultation	Nurse
Video Consultations (PD)	Attend remote consultation	Neurologist
Virtual Consultations (PD)	Attend remote consultation	Neurologist
Virtual Housecalls (PD)	Attend remote consultation	Neurologist

Table 8.7: Characteristics of self-care technologies for interacting remotely with the care team.

8.2.7 Tools that enable remote interactions with the care team

The self-care technologies for interacting remotely with the care team sit in the medicalized end of the spectrum. As Table 8.7 shows, the activities supported by the reviewed self-care technologies vary, yet there is a common focus of continuing medical care remotely. Being so, this group of self-care technologies supports the more medicalized aspects of self-care.

8.2.8 Others

The remaining self-care technologies fit in the mundane end of the spectrum. In fact, all three self-care technologies seek to support very mundane activities. In EmotionMingle, the goal is to distribute work among carers. In mobileWAY, the purpose is to facilitate the communication between patient and carers when they are not together, and in Rides For Parkinson's, the aim is to get a car lift for someone with Parkinson's.

In summary, there are four groups that support more medicalized aspects of self-care, two that support mundane areas, and two groups where self-care technologies fit across the spectrum. This group analysis shows a prominence of medicalized self-care technologies over mundane ones, but it is hard to know the magnitude of the difference. However, if one compares the numbers of self-care technologies in both ends of the spectrum, this difference becomes much more evident. In fact, there are 57 self-care technologies on the medicalized end, 26 on the mundane end, and three examples that have characteristics that position them on both parts (Caring~Web, REMPARK, VideoCare). This shows that the medicalized self-care aspects are the dominant focus of self-care technologies.

8.3 Expected users and collaborations in self-care technologies

From the analysis of the aspects that have been supported in self-care technologies, I now shift to investigate the expected users of self-care technologies and the support that is offered to enable collaborations between patients and carers. Chapter 5 showed that the self-care of Parkinson's was largely performed collaboratively between patients and carers. Living with a complex condition like Parkinson's led patients and carers to adapt their everyday activities to ensure the issues of the condition were addressed, or at least minimised. Self-care technologies can have an important influence in enabling or hindering patients and carers from participating and collaborating in self-care, thus this section analyses the expected users of self-care technologies as well as the potential interactions between them.

Contrary to the previous section, this one does not analyse the seven groups of technologies, but rather investigates each technology individually. The groups of self-care technologies outlined in the overview are not very different in terms of the users they expected or the collaborations accounted for, thus it makes more sense to analyse each self-care technology individually.

Most self-care technologies for Parkinson's were designed for being used individually by patients (see Table 8.8). The orientation for individual use can be observed in two main ways:

1. *Technologies are described as designed for patients.* In most cases, web pages or research articles make explicit the expected users of a specific technology. In the case of Parkinson's, descriptions mostly point to patients as the users (see Table 8.8). From 52 self-care technologies for Parkinson's, 44 are described as being suited for patients. Eight descriptions of self-care technologies admitted carers might exercise a role, but collaborations were only mentioned in two cases;

2. *The design methods chosen in studies focus mostly on patients.* Carers are often missing from interviews or workshops held during the conceptualization or design of the technologies. From 10 studies that detailed the conceptualization and design of self-care technologies for Parkinson's, all of them included patients, while carers only participated in 4 of them – the same number of studies in which healthcare professionals took part.

Six technologies are described as being useful to both patients and carers, but that does not mean that technologies support collaborations. For example, the tracking self-care technologies **Parkinson's Central** and **Parkinson's Diary** are both described as being suited for patients and carers, but their interfaces do not offer profiles, sessions, or even options to communicate with other devices, that could support collaborations. Even though patients and carers could in theory share the application on the same device, it seems more likely that designers assumed either the patient or the carer in their replacement would use the application individually. The online communities of **Patient**

Innovation and PatientsLikeMe have a similar issue. While patients and carers could have different accounts and participate collectively, the focus is on interacting with other peers and, thus, these web communities do not support the work patients and carers could do together. As a result, even though both patients and carers could be part of the same community, they interact individually with it.

The only two self-care technologies for Parkinson's supporting patients and carers to collaborate relate to the gaming consoles with exercise games (Wii Fit, Wii with balance board). Using these tools, patients and carers can exercise together as they would, for example, when walking together around the block. In fact, collaborations in self-care technologies are usually restricted to connecting patients with their doctors (e.g., eREHAB, Kinesia, REMPARK), or with other people who live with the same disease, for example in communities such as Patient Innovation. Only rarely does one find technology that has focused on helping patients and carers self-manage their condition together.

The argument about individual self-care technologies holds as well for other chronic conditions. From 34 self-care technologies for conditions other than Parkinson's, 24 were designed for patients to use in isolation, and 4 others for carers to use by themselves. The self-care technologies promoting collaborations between patients *and* carers were restricted to 6 examples. And excluding self-care technologies for parents to interact with children with chronic conditions, such as ADMS or AsthmaProbes, from this group only 4 examples are left (mobileWAY, RemoteReminiscence, SupportTeam, @Hand).

Name (condition)	Expected user(s) at home	Participants involved during design
ADMS (other)	Patient & carers	Patients, carers
AssistingInsulin (other)	Patient	Patients
AsthmaProbes (other)	Patient & carers	Patients, carers
Beats Medical (PD)	Patient	-
BoundaryWork (other)	Patient	-
BP@Home (other)	Patient	Patients, doctors, nurses
Caring~Web (other)	Carers	-
CHAP (other)	Patient	-
CKDManagement (other)	Patient	Patients
COPD-Therapy (other)	Patient	Patients, physiotherapist
COPDTrainer (other)	Patient	Patients
Cueing Swallowing (PD)	Patient	Patients, carers
CuPiD (PD)	Patient	Patients
DAF Professional (PD)	Patient	-
DailyAppropriation (other)	Patient	-
DialysisMachine (other)	Patient	-
eDiary (other)	Patient	Patients, doctors, nurses
EmotionMingle (other)	Carer	Carers
eREHAB (PD)	Patient	-
Food Quiz (other)	Patient	Patients
FOG cueing (PD)	Patient	-
GaitAssist (PD)	Patient	Patients, doctors
GoLearningBus (PD)	Patient	-

Table 8.8: Expected users of self-care technologies

Name (condition)	Expected user(s) at home	Participants involved during design
HeartPatients (other)	Patient	-
HIVForum (other)	Patient	-
ICT-BTMS (other)	Patient	-
iParkinsons (PD)	Patient	-
Jaw Drop Toolkit (PD)	Patient	-
Jog Falls (other)	Patient	Doctors
Kinesia (PD)	Patient	-
LApp (PD)	Patient	Patients
MAHI (other)	Patient	-
mobileWAY (other)	Patient & carer	Patients, carers
MONARCA (other)	Patient	Patients, doctors
Montfort iTug (PD)	Patient	-
Motor-Cognitive VR (PD)	Patient	-
myHealthPal (PD)	Patient	-
myRecord (other)	Patient	Patients, carers, various clinical staff
OneRing (PD)	Patient	-
ONESELF (other)	Patient	Patients, physiotherapists
Parkinson's Central (PD)	Patient or carer	-
Parkinson's Diary (PD)	Patient or carer	-
Parkinson's Speech Aid (PD)	Patient	-
Patient Innovation (PD)	Patient or carer	-
PatientsLikeMe (PD)	Patient or carer	-
PDApp (PD)	Patient	Patients, doctors
pd-FIT (PD)	Patient	-
PD Headline News (PD)	Patient	-
PD Life (PD)	Patient or carer	-
PD Me (PD)	Patient	-
PD Me Tools (PD)	Patient	-
PD Monitor & Commentary (PD)	Patient	-
PDmove (PD)	Patient	-
PersuasiveSens (other)	Patient	-
REMPARK (PD)	Patient	Patients, carers
RemoteLogCam (other)	Patient	Patient
RemoteReminiscence (other)	Patient & carer	-
Report-Asthma (other)	Patient	-
Rides For Parkinson's (PD)	Patient	-
SCRUMP (PD)	Patient	Patient, carer
SMS reminders (PD)	Patient	-
SPARK (PD)	Patient	Patients, carers, doctors
Speak Better (PD)	Patient	-
SpeechOmeter (PD)	Patient	-
Speech Pacesetter (PD)	Patient	-
Speech Tool (PD)	Patient	-
StudyMyTremor (PD)	Patient	-
SupportTeam (other)	Patient & carer	-
Swallow Prompt (PD)	Patient	-

(Table 8.8 – continued from previous page)

Name (condition)	Expected user(s) at home	Participants involved during design
Telehealth videophones (other)	Carer	-
Telephone CBT (PD)	Patient or carer	-
TiY (other)	Patient	Patients, doctors, nurses, pharmacists
TLC-Depression (other)	Patient	-
TR_Meter (PD)	Patient	-
VideoCare (other)	Carer	-
Video Consultations (PD)	Patient	-
Video Recordings (PD)	Patient	-
Virtual Consultations (PD)	Patient	-
Virtual Housecalls (PD)	Patient	-
Voice Analyst (PD)	Patient	-
Voice Game (PD)	Patient	Patients
Wii Fit (PD)	Patient & carers (opt)	-
Wii with balance board (PD)	Patient & carers (opt)	-
WuppDi! (PD)	Patient	Patients, physiotherapists
@Hand (other)	Patient & carer	Patients, carers
@Point of Care (PD)	Patient	-

(Table 8.8 – continued from previous page)

In summary, the large majority of self-care technologies has been developed for a single user – the patient. Carers are rarely included, and collaborations between patients and carers are virtually absent.

8.4   Role in supporting learning about the condition

Having analysed the expected users of self-care technologies, I now focus on the role technologies played in supporting learning about the condition in everyday life. Chapter 6 has shown that patients and carers developed (patient) knowledge by living with the condition. When confronted with issues, people investigated their causes and tried different strategies for addressing them. Patients and carers often sought to understand whether they had reached their best possible self-care state, and prepared in advance for treatments, procedures or the condition's progression.

In this section, I analyse the role promoted by the sub-group of self-care technologies that facilitates learning about the condition. This sub-group is made of 45 self-care technologies belonging to three categories outlined in the overview, namely: i) Tools for tracking health-related data; ii) Tools for accessing information about the condition; and iii) Tools for interacting with other patients and carers. These categories are analysed in detail here.

8.4.1   Tools for tracking health-related data

The self-care technologies for tracking, such as Parkinson's Diary and Montfort iTug, can potentially help people learn about their condition and body. Using the provided plots, people can quantify the severity of symptoms, identify patterns in daily life and

reflect on the causes that might be at the origin of these. Despite the potential of these technologies though, there are several characteristics that might hinder learning.

One issue that can be easily observed in self-care technologies for Parkinson's is the lack of variety in tracking features. As Table 8.1 shows, logging in self-care technologies for Parkinson's is restricted to a small number of characteristics, such as medication or (motor) symptoms, and sensing is focused on movement issues alone, which limits the potential of learning to a sub-set of the condition's issues. For other conditions, there are other features being monitored, but tracking is still mostly limited to a small number of symptoms. TiY is an exception, where people living with diabetes can track any categories of their choice.

Another issue preventing patients from learning is the inability to visualise the data they collected. This is the case in 4 self-care technologies for Parkinson's and 8 for other chronic conditions. While REMPARK and Kinesia, to cite two examples, enable patients to capture or report data about specific symptoms of the condition, only doctors can visualise the data produced. Patients cannot access their own data, which reduces their ability to learn. The patients may still reflect about their condition each time they track a symptom or log an issue, but the opportunity for technology-mediated analysis is missed by not giving them the tools for reflecting more thoroughly and directly on their data.

8.4.2 Tools for accessing information about the condition

The self-care technologies for accessing information about the condition can also be useful to inform learning. As Table 8.5 shows, the analysed examples offer insights from different areas, varying from diagnosis to the latest research. However, there is an overall concern with giving access to information about their condition. Moreover, the analysed technologies seem to be especially important for the earlier phases of the condition, when people are learning about the diagnosis, symptoms and treatments. Apart from PD Headline News and PD Monitor & Commentary, which provide insights into latest research around Parkinson's, the technologies do not offer great grasp for learning in intermediate or advanced phases of living with the condition.

8.4.3 Tools for interacting with other patients and carers

The self-care technologies for supporting the interactions between patients and carers can play an important role in learning. As evidenced in my fieldwork, being able to access others living with the same condition can enable people to exchange strategies, discuss experiences, and gain valuable insights about the condition. The engagement of people can be varied as Table 8.6 shows, but there seems to be an overall commitment in the reviewed technologies to give space for people to discuss issues that are relevant to them. While these platforms were often started for enabling general conversations, people appropriated them for sharing and discussing strategies for dealing with day-to-day issues of the condition (Hartzler and Pratt, 2011; Huh and Ackerman, 2012). Moreover, there is no medical frame surrounding these technologies, although all platforms have some

sort of moderation.

In summary, the results show that self-care technologies have good potential for supporting learning in general, but there are some restrictions that reduce the ability of patients to learn.

8.5 Agency in technology-mediated interactions with doctors

The analysis now turns to investigating the potential agency patients and carers can play when using self-care technologies for supporting their interactions with doctors. Chapter 7 showed that patients and carers exercised a very active agency in their interactions with doctors. They co-defined the diagnosis, engaged in discussions about treatment adjustments, directed learning to certain topics, and acted when medication adjustments were inappropriate. Their active agency was not a coincidence of circumstances, but rather a consequence of their socio-material arrangements. While at home, patients and carers carefully investigated issues that appeared, reflecting on which activities and routines were essential, and which ones could be stopped or adapted. These engagements helped people enlist issues, priorities, doubts, or other topics to potentially bring up in consultations. It was also important that patients had access to the mobile phone number of their doctor or the online community to be able to adjust inappropriate medication before the next medical consultation.

Investigating self-care technologies can help understanding the sort of agency patients and carers will potentially exercise if these technologies are integrated into the healthcare infrastructure. In this section, I analyse the agency promoted by the sub-group of self-care technologies that affords interactions with doctors in consultations. This sub-group is composed by 29 technologies originating from two categories of tools, namely: the tools for tracking health-related data, and the technologies for enabling remote interactions with the care team[4]. Table 8.9 presents an analysis of the features of the technologies in terms of how they capture and present data, as well as the interactions they facilitate with doctors.

As agency is complex to analyse, this section is organised according to the main activities or interactions that were outlined in Chapter 7, namely: i) Investigating issues; ii) Participating in discussions; and iii) Fixing inappropriate treatment.

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[4]Not all self-care technologies for tracking or for interacting with the care team afford interactions with doctors. Multiple technologies for tracking do not mention interactions with doctors in their descriptions, which leads one to conclude that sharing data or insights in a consultation was not expected or accounted for (ADMS, AsthmaProbes, CHAP, PD Me, PD Me Tools, TiY,TR_Meter). Moreover, there were numerous self-care technologies for interacting with the care team that targeted nurses (Caring~Web, VideoCare, Telehealth videophones), therapists (COPD-Therapy, Telephone CBT), or educators (MAHI), that while being part of the care team, afford very different interactions than neurologists in a consultation.

8.5.1 Investigating issues

As mentioned before, self-care technologies for tracking health-related data, such as **PDApp** and **PD Life**, can support patients in investigating issues and thus better learn about their body and condition (see Section 8.4). The collected data can also inform discussions with a neurologist, by showing changes in symptoms, providing data about daily life, or eliciting doubts about the condition or self-care. Nevertheless, despite such potential, some characteristics might be hindering users from bringing more insights to discussions with doctors.

The limited variety of features that can be logged or sensed by self-care technologies limit the discussions with doctors to certain issues. As most self-care technologies for Parkinson's in Table 8.9 solely enable the tracking of specific motor symptoms, patients cannot use these technologies to investigate other issues of the condition. Consequently, the potential of technologies for tracking health-related data to fuel discussions with clinicians is restricted to specific motor issues.

Another obstacle to the investigation of patients is the inability to visualise the data they collected. While **Kinesia**, **REMPARK**, **SPARK** and **Video Recordings** might be very useful for adjusting treatment of Parkinson's, by concentrating the analysis on the doctors, they hinder people from investigating issues by themselves. Patients may be compelled to reflect about the reasons that led to reaching a particular state each time they track an issue, however, their investigation is more restricted.

8.5.2 Participating in discussions

Most self-care technologies in the review potentially supported the discussions with doctors. In some cases, technologies enabled discussions to take place through videoconference, such as **Virtual Housecalls** and **Virtual Consultations**. In other cases, self-care technologies could be used to feed discussions with issues identified while tracking or analysing data, such as **PDApp** and **OneRing**. Participating in discussions about one's health is essential to play an active role in care, so it is positive that many technologies support and, in some cases, even potentially enrich the discussions with issues from everyday experience.

However, there were three cases in which the technologies eliminated discussions with doctors altogether. For example, **Video Recordings**, a technology where patients answer questionnaires about symptoms and perform specific movements in front of a video camera, patients are not involved in discussions. Once tracking and logging are complete, the data is transferred to the doctor who updates the medication plan. Even though patients play a role in collecting the data, they are rendered as passive actors, who instead of contributing with their lived experiences, only produce the data stream that informs the decisions of doctors.

8.5.3 Fixing inappropriate medication

The reviewed self-care technologies did not account for the possibility of getting inappropriate medication, since patients could not signal their need for treatment adjustments

through the technologies. For example, the technologies for enabling remote consultations, such as Video Consultations, did not enable patients to initiate videoconference sessions. And while numerous self-care technologies enabled logging, it was not possible to report that medication needed revision. The inability to trigger medication adjustments through these technologies does not imply that corrections were impossible. One can extrapolate that patients would still be able to phone doctors or go to the clinic sooner as with the fieldwork participants. However, by not providing direct paths within the technology, people might have missed a more straightforward process for adjusting medication.

In summary, the results show distinct levels of agency among the self-care technologies, in regards to the ability to investigate issues and participate in discussions. Moreover, there is also an overall lack of agency in adjusting inappropriate medication.

Name (condition)	Hardware at home	Use	Passive sensing	Active sensing	Logging	Visualise data	Remote sharing	Able to discuss
BoundaryWork (diabetes or cardiovascular)	Sensors, PC	Patients use sensors to monitor health state. They show the collected data to doctors in the clinic.	-	Blood pressure, glucose, coagulation	-	No	No	In-clinic
BP@Home (hypertension)	Tablet, sensors	Patients use sensors to monitor blood pressure. Data about noise and movement are also captured. Patients can analyse data by themselves or with doctors	Noise, movement	Blood pressure	-	Yes	Auto	In clinic
DailyAppropriation (diabetes, hypertension)	Sensors	Patients use sensors to monitor health state. They show the data to doctors in the clinic.	-	Blood pressure, glucose	-	Yes	No	In clinic
eDiary (diabetes)	Sensors, smart-phone	Patients use sensors to monitor their health. The data collected is analysed by themselves or with the doctor.	-	Glucose	-	Yes	Auto	In clinic
HeartPatients (atherosclerosis, hypertension)	Sensors	Patients use sensors to track health status, and send the collected data to doctors. Doctors analyse data and call patients when issues arise.	-	Blood pressure, pulse, weight	-	No	Auto	In-clinic
ICT-BTMS (diabetes)	Smart-phone	Patients log data. Doctors analyse the data and send feedback to the patient.	-	-	Activity, blood pressure, glucose, medication	No	Auto	No
Jog Falls (diabetes)	Sensors, smart-phone	Patients wear sensors, and log data. They can visualise some aspects of their data, while only doctors have access to all the data and visualisations.	Activity, blood pressure, pulse	-	Food	Partial	Auto	In-clinic

Table 8.9: Characteristics of the self-care technologies for interacting with doctors

Name (condition)	Hardware at home	Use	Passive sensing	Active sensing	Logging	Visualise data	Remote sharing	Able to discuss
Kinesia (PD)	iPad, sensors	Patients perform activities while wearing sensors, and log data. Doctors analyse the data in the clinic and adjust treatment.	-	Move-ment	Medication, symptoms	No	Auto	In clinic
MONARCA (condition)	Smart-phone	Patients log data. Smartphone collects data in the background. Patients can analyse data by themselves or with doctors.	Social activity	-	Mood, sleep, activity, medication	Yes	Auto	In clinic, re-motely
Montfort iTug (PD)	iPhone	Patients perform activities holding the iPhone, and log data. They analyse data by themselves or with doctors.	-	Move-ment	Symptoms	Yes	Option	In clinic
myHealthPal (PD)	iPhone	Patients perform activities on the iPhone, and log medication. They analyse data by themselves or with doctors.	-	Move-ment	Medication	Yes	Option	In clinic
myRecord (cardiac arrhythmias)	Cardiac device, PC	Patients wear cardiac device. The data is analysed remotely by the doctor who calls the patient to discuss issues, or invites them to visit the clinic	Heart state	-	Complaints	No	Auto	In clinic, re-motely
OneRing (PD)	iPhone, sensors	Patients wear ring during the day, or hold iPhone for some seconds, to track movement. They analyse data by themselves or with doctors.	Move-ment	Move-ment	-	Yes	Option	In clinic
Parkinson's Diary (PD)	iPhone	Patients log data. They then analyse it by themselves or with doctors.	-	-	Exercise, mood, meals, medication, sleep	Yes	No	In clinic
PDApp (PD)	Android, sensors, PC	Patients wear sensors that track symptoms. They analyse and annotate data to discuss with the doctor.	Move-ment	Move-ment	Mood, activity	Yes	Auto	In clinic

(Table 8.9 – continued from previous page)

Name (condition)	Hardware at home	Use	Passive sensing	Active sensing	Logging	Visualise data	Remote sharing	Able to discuss
PD Life (PD)	iPhone	Patients log data. They analyse data by themselves or with doctors.	-	-	Mood, symptoms, side-effects	Yes	No	In clinic
PDmove (PD)	iPhone	Patients play game that tracks their movement. They analyse data by themselves or with doctors.	Move-ment	-	-	Yes	No	In clinic
REMPARK (PD)	Android, sensors	Patients wear sensors that track symptoms. Doctors review the data in the clinic and adjust treatment.	Move-ment	-	-	No	Auto	In clinic
REMPARK (PD)	Android, sensors	Patients wear sensors that track symptoms. Doctors review the data remotely and adjust treatment.	Move-ment	-	-	No	Auto	No
Report-Asthma (asthma)	Android, sensors	Patients wear sensors that track symptoms, and log data. Doctors analyse the data.	-	Air flow, oxygen level	Symptoms	No	Auto	In-clinic
SPARK (PD)	Android, sensors	Patients wear sensors that track symptoms, and log data. Doctors review the data and adjust treatment.	Move-ment	Move-ment	-	No	Auto	In clinic
StudyMyTremor (PD)	iPhone	Patients perform activities while holding iPhone. They analyse data by themselves or with doctors.	-	Move-ment	-	Yes	No	In clinic
SupportTeam (Pos-traumatic stress disorder)	Smart-phone	Patients and carers log data. Doctors analyse the collected data.	Loca-tion	-	Meals, personal care, sleep, stress	No	Auto	In clinic
TLC-Depression (unipolar depression)	Telephone	Patients log data by answering questions prompted by a telephony system. Doctors are alerted when data is alarming.	-	-	Symptoms	No	Auto	Re-motely

(Table 8.9 – continued from previous page)

Name (condition)	Hardware at home	Use	Passive sensing	Active sensing	Logging	Visualise data	Remote sharing	Able to discuss
Video Consultations (PD)	Camera, PC	Patients use videoconference to attend consultations.	-	-	-	-	-	Re-motely
Video Recordings (PD)	Mic, printer, PC	Patients record activities and note complaints. Doctors review the data and adjust treatment.	-	Move-ment	Complaints, symptoms	No	Auto	No
Virtual Consultations (PD)	Camera, PC	Patients use videoconference to attend consultations.	-	-	-	-	-	Re-motely
Virtual Housecalls (PD)	Camera, PC	Patients use videoconference to attend consultations.	-	-	-	-	-	Re-motely
@Hand (undefined long-term)	Tablet	Carers log data about themselves and the patient. They analyse data by themselves or with the doctor.	-	-	Blood pressure, weight, mood	Yes	Auto	In clinic
@Point of Care (PD)	iPhone	Patients answer prompts. They analyse data by themselves or with doctors.	-	-	Activity, medication, mood, symptoms	Yes	No	In clinic

(Table 8.9 – continued from previous page)

8.6 Discussion

This chapter showed that existing self-care technologies have mostly focused on the medicalized aspects of self-care. In some cases, the medicalisation was expected as technologies enabled remote consultations or therapeutic sessions at home. In other technologies, such as medication reminders or tools for tracking health-related data, the medicalisation perspective was not expected, but multiple signs point in that direction. The idea that self-care technologies have been mostly medicalized aligns well with previous work. A review of technologies for paediatric patients with chronic conditions – including asthma, diabetes, and psychiatric disorders – concluded that technologies were mostly focused on medicalized aspects, such as showing diaries of symptoms, tracking glucose values, or technologies for communicating remotely with doctors (Gentles et al., 2010). In a similar direction, Archer et al. (2011) argued that technologies for self-monitoring and others associated with personal health record have often been doctor-centred. Storni (2014) also claimed that blood glucose meters embodied a medicalized perspective because they only displayed and stored glucose measurement values. Even though patients often made written notes about the reasons for getting a specific value, to learn from their experience, this additional information was usually not supported, as doctors did not need it. This chapter adds to this body of work in the sense that it shows that the medicalized perspective is often present in the self-care technologies for Parkinson's and in general in self-care technologies published in the area of HCI.

The chapter also argued that self-care technologies were largely individual and designed for patients to use. Carers were rarely included in the conceptualization or design phases of development, and they were hardly ever users. Moreover, collaborations were almost absent. However, it is also important to mention that the orientation for individual use did not determine how technology was used in the end. In fact, some technologies in the review designed for the individual use of patients ended up being appropriated[5] by patients and carers as part of a collaboration. For example, in **eDiary**, patients watched the recordings of the consultations together with carers. In **BoundaryWork**, carers emailed test results to doctors, and in **DailyAppropriation**, the carer played an important role in teaching the patient how to interpret blood glucose measurements. The design for individual use did not seem to hinder patients and carers from collaborating, but it did not help them coordinating their actions either, so the point about self-care technologies promoting individual engagement in self-care still maintains. In either case, the present chapter advances previous literature in explaining that self-care technologies have been mostly individual and designed for patients. While some studies pointed to collaborations using self-care technology (Ballegaard et al., 2008; Danholt and Langstrup, 2012; Langstrup, 2013), no study had previously argued that self-care technologies were essentially individual.

The current chapter demonstrated that self-care technologies had potential to con-

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[5]Appropriation is a concept derived from anthropology that is related to making something one's own. In HCI, this concept appears to name the phenomenon by which users adapt and adopt technology to the specificities of the situations they have at hand (Dourish, 2003).

tribute to the development of patient knowledge, but there were obstacles. The inability to visualise the collected data or the limited variety of tracking features in tools for tracking health-related data, reduced the ability to learn from one's data. Moreover, the technologies for accessing information about the condition focused mostly on early phases of the condition. While this is the first study characterising self-care technologies in regards to the potential they present for promoting learning, previous work has contributed in that direction. For example, Storni (2014) argued that technologies for people with diabetes did not seriously consider the lay expertise developed by patients. His argument is based on the impossibility of documenting glucose measurements with notes (as mentioned above), as well as in the inability to track issues beyond a small number of pre-built categories, which severely restrict the investigation people could do. Mamykina et al. (2015) reflected on the support that online communities offered to people with diabetes and concluded that these technologies did not enable them to collectively make sense of their knowledge, as information was repeated and spread over threads. Still, they recognised the role online communities could play in supporting people in learning.

Finally, this chapter also showed that self-care technologies offered varying levels of potential agency to patients and carers when interacting with doctors. They could help people explore their concerns and bring more issues to discuss, yet the reduced tracking characteristics and the impossibility to analyse one's data limited this potential. Moreover, people could not be present in all discussions about their health, and it was not possible to fix medication plans that did not work out. The insights about varying levels of agency also represent a novel contribution from this work.

8.7   Summary

This chapter discussed the opportunities promoted by self-care technologies. The findings showed that most self-care technologies were *medicalized*, that they were developed for being *individually used by patients*, that they had *potential for learning and for enabling an active agency* in interactions with doctors – despite presenting some obstacles. The characterization of self-care technologies offers novel insights about self-care technologies, and enables comparisons with the findings of the ethnographic informed chapters.

Discussion

This chapter documents and discusses the misalignments between the self-care of Parkinson's and existing self-care technologies. It draws on the comparison between the fieldwork data – obtained through the in-depth interviews, observation sessions, and online ethnography – and the critical review of self-care technologies. The chapter answers the RQ5: how self-care technologies align with the self-care of patients and carers, and what are the critical issues to consider when designing based on how people live with the condition. The contributions of this chapter are the identification of misalignments between the self-care of Parkinson's and existing self-care technologies, a discussion of the reasons that may have lead to these misalignments, and finally a set of design considerations to minimise or address these misalignments.

The chapter starts by bringing together the properties of the self-care of Parkinson's brought up in the fieldwork chapters. Then, it describes the misalignments between self-care technologies and the self-care of Parkinson's. Following is a discussion that associates the misalignments identified with the incorporation of medicalized values in the design of self-care technologies. Finally, I present design considerations to address or minimise these misalignments.

9.1 The self-care of Parkinson's

Before discussing the misalignments between self-care technology and the self-care of Parkinson's, I would like to bring together the properties of the self-care of Parkinson's (see Figure 9.1). In summary, the self-care of Parkinson's is mundane, collaborative, based on personal investigation, and active (in both everyday life and interactions with doctors). These properties are quickly summarised here.

Living with Parkinson's entails important mundane work. Taking medication, exercising daily, accepting the condition, and organising the day around fluctuations requires patients and carers to invest significant time and effort. Self-care activities are not

Mundane work	Collaborations	Learning	Consultations
• Performing self-care entails great work • Activities are intertwined and ingrained in daily life • People negotiate and compromise • Self-care as dynamic	• Multiple actors • Multiple perspectives to consider • Dynamic self-care divisions	• Learning as personal • Learning as a way to achieve a good life • Learning as a life-long activity • Learning as choosing between multiple alternatives	• Active role in diagnosis definition • Active role in decision making • Active role in learning with the clinician • Active role in adjusting inappropriate treatment

Figure 9.1: Properties of the concept of self-care outlined in this thesis.

separated, but rather intertwined and ingrained in the everyday life of patients and carers. The experience with Parkinson's can change dramatically from hour to hour due to fluctuations in the symptoms. Consequently, people learn to plan ahead their activities and adapt to different situations. Patients and carers also learn to negotiate and compromise at each moment according to what is best for them.

The self-care of Parkinson's is a collaborative endeavour of patients and carers. In face of the multiple difficulties involved in self-care, people unite efforts to make things work. The division of activities is different from case to case, and related with the specific arrangements where patients and carers find themselves at. It is also temporary, as fluctuations may require changes in the work division. Moreover, while patients and carers engage in self-care together, they do so from their particular perspective.

Patients and carers develop valuable knowledge from their experience with the condition. They reflect on possible causes for their issues and experiment with different strategies to address their concerns. Their learning activities happen throughout their experience with the condition because progression, new treatments, or other life issues often lead people to revise their self-care and patient knowledge. The differences in symptoms, routines, preferences, and values, give rise to radically different experiences of Parkinson's and, as a consequence, distinct ways of living with the condition. What works for some people does not work for others, so people carefully reflect on the strategies they can use to reach their best self-care state.

People living with Parkinson's engage in self-care consistently and, thus, play a very active role in interactions with clinicians. Patients and carers co-define diagnosis, by bringing up symptoms and other problems they observe in their everyday experience.

They also participate in decision-making by defining relevant issues to address, and scrutinising the potential of treatments to improve their quality of life. Patients and carers do not passively receive information, but raise questions and direct discussions to topics that concern them. Moreover, patients, but especially carers are very diligent in addressing treatment adjustments that do not work, ensuring that treatment is adjusted on a timely basis and thus the consequences of having inappropriate medication reduced.

9.2   The misalignments between self-care technologies and the self-care of Parkinson's

In contrasting the fieldwork with the review of self-care technologies, I identified four misalignments between self-care technologies and the ways in which patients and carers engaged in self-care. I will go through each of the misalignments following the order by which they appeared in the manuscript.

The first misalignment was related with the aspects of self-care that were of focus in self-care technologies (see Chapter 4 and 8). While the self-care of Parkinson's was full with *mundane and practical activities* to self-manage the condition, self-care technologies were mostly focused on supporting the more *medicalized aspects of self-care*, such as self-monitoring symptoms or performing treatment. In fact, the number of self-care technologies focusing on supporting the medicalized aspects more than doubled those that were concerned with supporting the mundane practical work of patients and carers.

The second misalignment was concerned with the types of users of self-care technologies and the collaborations supported between them (see Chapter 5 and 8). While the self-care of Parkinson's was often performed as part of a *collaboration* between patients and carers, self-care technologies were mostly designed to support *one user in isolation*, which in most cases was the patient. Moreover, only a very reduced number of self-care technologies enabled collaborations between patients and carers in some way, which contrasts with the collaborative ways in which self-care was achieved in everyday life.

The third misalignment is related to the role of the self-care technologies in supporting learning about the condition (see Chapter 6 and 8.). The fieldwork showed that patients and carers investigated issues that appeared, as well as ways to address them in their everyday lives. Self-care technologies supported this *investigative attitude* in general, but there were some problems. In particular, most self-care technologies restricted tracking of health-related data to *very few features*, and there were some technologies that did not enable people to *analyse their data*. Moreover, the tools for accessing information about the condition focused *mostly on beginners*, even though patients and carers learned about their body and condition in all of its phases.

The fourth and final misalignment concerned the potential for agency that self-care technologies attributed to people in their interactions with the doctor (see Chapter 7 and 8). The fieldwork showed that patients and carers were extremely active in their engagements with doctors, co-defining diagnosis, engaging in discussions, and acting to address medication adjustments which were inappropriate. The self-care technologies supported an active engagement in general, but there were also issues. As mentioned

above, self-care technologies for tracking limited it to a *small number of features* and, in some cases, did not enable people to *analyse their data*, which restricts the ability of patients and carers to investigate issues and bring them to discussions. Patients and carers could participate in most discussions, but some technologies enabled decisions to be taken *when patients and carers were absent*. Furthermore, no self-care technology offered ways to *ask for appointments or request medication adjustments*, hindering patients and carers from seeking adjustments using self-care technologies.

9.3 The misalignments as evidence of a medicalized perspective on self-care technologies

The misalignments between self-care technologies and the self-care of Parkinson's seem to be a consequence of incorporating a medicalized perspective of self-care into the development of self-care technologies. Previous work (Fitzpatrick, 2011; Storni and Bannon, 2012) had suggested that, in migrating technologies from the hospital to the home, designers did not rethink the values that were at their origin, and thus ended up reproducing the perspectives from formal care into self-care technologies. This study seems to align with their intuition. In fact, self-care technologies seem to fit well within a traditional consultation, where *one doctor*, receives *one patient*, and is in charge of *diagnosis, treatment, and patient education*. To develop this point, I will connect each misalignment with a theoretical perspective on self-care introduced in Chapter 2.

When designers conceptualise self-care as an extension to medical care, as framed in Nakagawa-Kogan et al. (1988), Clark et al. (1991), and Worth (1997), it is not a surprise to observe so many self-care technologies focusing on *medicalized aspects* of self-care, such as tracking symptoms and enabling therapeutic activities. These are in fact the activities that afford collaborations with doctors and fit into the more medicalized areas of self-care. The result would have been different if the designers conceptualised self-care as a set of mundane activities, performed by people living with a complex condition, who need to make tough negotiations, choices, and adaptations, and where medical aspects are only one part, as portrayed in the work of Corbin and Strauss (1988), Funnell and Anderson (2000), Wagner et al. (2001), and Cicutto et al. (2004). The challenges of: i) attending events outside the medication schedule, ii) keeping the head occupied to avoid depression, iii) adjusting roles as activities become impossible to perform, iv) living with uncertainty because of fluctuation, and v) accepting the condition, are all examples of issues in the everyday life of Parkinson's documented in Chapter 4, but as they fall outside of the medical aspects of self-care, they have not been tackled by designers of self-care technologies.

When designers see self-care as an individual activity, performed by either patients or carers as in Shoor and Lorig (2002), Clark et al. (1991), or Bettio and Plantenga (2004), it will not come as a surprise that they design technology to support the self-management of those specific *individuals in isolation*. That is indeed implied with the individualistic perspective attributed to self-care. However, had designers viewed self-care as a collaborative engagement of patients and carers, as argued in Corbin and Strauss

(1984), Corbin and Strauss (1988), or Danholt and Langstrup (2012), the end result would have probably better accounted for collaborations.

When designers expect learning activities to be coordinated by doctors, as argued in Clark et al. (1995) or Lawn and Schoo (2010), it makes sense that self-care technologies for tracking *restrict analysis to doctors*, or include only a *handful of tracking features* that are relevant for the medical work and "patient education". The doctor would then use that information to lecture the patients and carers. However, had designers adopted a perspective on self-care that recognised the pivotal role of patients and carers in learning, and the possibility of improving one's quality of life with the gained insights, as demonstrated in Pols (2014), Mol and Law (2004), or Storni (2015a), probably tracking would not be as restrictive for patients and carers.

When designers see patients and carers as mere informants to the doctors who see them, as in Clark et al. (1995) or Ong et al. (1995), it is straightforward to expect that, as mentioned above, they can only *track a handful of features* that are relevant to the doctor's work. They might even be *absent from medical decisions* because the doctor is the only one responsible for them. However, had designers conceptualised the medical encounter as a session for advising the people who are in charge of dealing with a chronic condition every day, as in Funnell and Anderson (2000) or Bodenheimer et al. (2002), self-care technologies for interacting with doctors would probably offer a more active role to patients and carers. While clinicians would still be given tools to inform and support their analysis, patients and carers would benefit from technologies to experiment with their health, learn about the condition, and reflect about their self-care. The tools of patients and carers would enable them to be better prepared to take the most from their interactions with doctors, calling attention to the issues they faced, and the values that were relevant for them.

The designers who developed the analysed self-care technologies were probably not trying to incorporate medicalized values into the self-care technologies. They could have been led by literature, interactions with clinicians, or their own personal values (Akrich, 1992). However, in adopting a medicalized frame, technology risks "limiting patient empowerment and silencing their voices and concerns" (Storni, 2014, p. 401), because medical models cannot tame the complexity and diversity of living with a chronic condition (Fitzpatrick, 2011), nor the negotiations and adaptations that result of that experience (Aarhus and Ballegaard, 2010). For technology to be successfully integrated, it is crucial for it to recognise that patients and carers need to attend to their everyday life in parallel to their health issues (Ballegaard et al., 2008).

9.4 Design considerations for better aligning self-care technologies with the self-care of Parkinson's

The four misalignments represent relevant contrasts between the fieldwork and existing self-care technologies, however, these misalignments might be addressed or minimised through design changes. For this reason, this section offers design considerations that designers and researchers might explore when designing technologies or redesigning

existing ones. Each consideration draws on insights from the fieldwork and the review, and offers at least one example of how the consideration might be applied to the design of self-care technologies. The goal is not to be prescriptive, but to offer ideas to explore and think with when engaging in design. Furthermore, while considerations derive from all chapters of the fieldwork, they are grouped according to the misalignment they seek to address.

9.4.1 Supporting the mundane self-care work of patients and carers

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. If one applied this consideration to the design of a medication reminder, researchers or designers would need to shift their focus from solely promoting compliance/adherence[1] (see Figure 8.1), to investigating how and why people delay or skip their medication. Instead of developing a technology to fit medical processes and standards, the goal would be to create a medication reminder that supported the practical work of patients and carers. Focusing on the mundane activities and issues of patients and carers also opens up the design space to problems, such swallowing saliva (**Cueing Swallowing**) or speaking louder (**LApp**), which were not previously addressed because they did not represent a clinical challenge of Parkinson's. 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 with the condition in practical terms.

Support negotiations and compromises. As living with Parkinson's involves negotiating and compromising, self-care technologies should support people in making informed decisions about their health. The self-care technologies for interacting with other patients and carers, such as **Patient Innovation**, **PatientsLikeMe**, or the online communities analysed in the fieldwork, were especially appropriate for enabling discussions about the impacts of different self-care strategies on daily life. However, other self-care technologies could also contribute to informing people about the impact of different self-care activities. For example, medication reminders could display information on how to proceed when delaying medication, i.e., keep the time interval between pills, or even inform people living with Parkinson's about the different impacts of skipping medication when users selected the "Skip" button of the reminder screen for the first times. Rather

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[1]The overall idea of pushing towards compliance within self-care technologies does not make much sense, considering the active agency that patients and carers demonstrated in their medical care. Being compliant or adherent suggests that doctors make decisions and that patients and carers simply implement them in their everyday life. On the contrary, interactions with doctors were truly collaborative with patients and carers offering very relevant contributions to diagnosis, treatment decisions, etc. Thus, it is important that designers consider and empower these collaborations and not push technology to adhere to more traditional ways of medical care where the doctor makes all decisions and supervises the compliance of patients over distance. After all, as Palen and Aaløkke (2006) argue, designing to track medication adherence does not support the medication intake in practice.

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, so that users can interpret and apply the principles to 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 at the same time, 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, a technology for tracking health-related data should 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 complex and dynamic, and that self-care technologies need to adapt to variable condition states and engagements in self-care.

9.4.2 Supporting collaborations in self-care

Support multiple users. Since self-care is often the result of collaborations between patients and carers, self-care technologies should be designed to support multiple users collaborating with each other. One option is to provide a single device or application that is physically shared by patients and carers to enable them to work together in self-care (e.g., RemoteReminiscence or SupportTeam). An alternative option is to offer multiple connected devices or applications that mediate self-care collaborations (e.g., ADMS, AsthmaProbes, mobileWAY, or @Hand). In any case, it is important to ensure that both patients and carers can use the self-care technology as part of their engagement in self-care. Failing to support either patients or carers will reduce their chances of using the self-care technology to engage in the self-care of Parkinson's.

Offer different perspectives to each user. While patients and carers collaborate in numerous activities, they engage in self-care from their specific perspective. To acknowledge these distinct engagements, self-care technology should be designed in a way that offers different interfaces, aligning with the specific characteristics of patients and carers. This can be achieved by providing adapted interfaces in the same application or device, as in SupportTeam, or by making available multiple devices or terminals adapted to patients or carers, as in mobileWAY. Moreover, there should be some flexibility for patients and carers to define the functionalities and roles they take because different people divide work in distinct ways. Either way, having distinct interfaces should enable a more holistic understanding of self-care. For example, when collecting data about symptoms, both patients and carers could answer prompts from their own point of view. This would result in a richer feed of data to reflect upon, or discuss with doctors during consultations.

Provide dynamic collaborations and roles. Fluctuations in symptoms often force adaptations in the division of self-care activities between patients and carers. Acknowledging this dynamic work division encourages the development of self-care technologies where collaborations and roles are not strictly defined but handled fluidly[2]. One way to achieve this could be to offer duplicate interfaces on the devices of patients and carers, so that they could take the activities usually assigned to the remaining role when their contribution was not possible. If one applied this consideration to a medication reminder, carers would be able, for example, to receive the reminders on their mobile when patients had stronger symptoms; patients would also be able to receive the reminders on their device during the moments when carers were not with them. Another possibility is to use the self-care technology to help in the distribution of self-care work between carers, as is in EmotionMingle. Other options might be possible as well, but the important point is that self-care continues being performed when people living with Parkinson's adjust their work division.

Use collaborations as the unit of analysis. Recognising the collaborative nature of self-care motivates as well a reflection on the participants involved during the design of self-care technologies. As both patients and carers are involved in self-care, they should be included in the design of self-care technologies, from user research to evaluation. It might be useful to involve patients or carers separately to understand their specific role and perspective about the remaining role, but also in groups of patients and carers to get a broad picture of self-care and the collaborations it entails. Failing to involve either patients or carers will provide a fragmented perspective on self-care.

9.4.3 Supporting the development of patient knowledge

Support independent learning. Since people living with Parkinson's investigate issues and test different solutions for themselves, self-care technologies should offer functionalities that support their investigation. For example, self-care technologies for tracking health-related data could enable patients and carers to visualise and analyse the data they collect, as in PDApp or Montfort iTug. This would enable patients and carers to investigate issues that appear in their everyday life, and to compare different solutions or strategies based on the impact on their symptoms. Moreover, if self-care technologies are used to feed discussions with the doctor, patients and carers would be better prepared for the discussions as they are able to reflect on the data before entering the doctor's office. Recognising that patients and carers develop patient knowledge entails offering them the necessary tools to support their autonomous learning.

Support learning about one's practical issues. The development of patient knowledge is often connected with the practical need to address everyday issues. While patients and carers were not usually concerned with learning about the biomedical characteristics of Parkinson's, they were eager to find strategies to deal with the issues

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[2]Miller et al. (2016) argued a similar idea when suggesting that technologies for inpatients should adapt to different care configurations. Their argument was based on the uncertainty that surrounds the condition of inpatients in the hospital.

they had because of the condition. As learning activities are motivated by practical concerns, self-care technologies for Parkinson's should be designed to provide practical information for people to try. Instead of solely offering information about medical aspects of the condition, as in **Parkinson's Central** or **GoLearningBus**, self-care technologies that target learning should collect practical strategies to deal with everyday issues. **Patient Innovation** and the online communities studied in the fieldwork are good examples that go in this direction, collecting numerous strategies and enabling people to discuss their advantages and inconveniences. However, there might be other ways of supporting people in learning about practical issues that concern them. Acknowledging that patients and carers develop patient knowledge requires designing technologies that enable them to learn about the things that concern them in their everyday life.

Acknowledge multiple co-existing alternatives. Finding solutions for practical issues can be challenging because what works for some people differs from what works for others. Thus, when providing strategies, self-care technologies should not offer a one size fits all solution, but rather collect a set of alternatives for dealing with a specific issue. Each strategy should be presented with the rationale for using it, the advantages it brings, and the inconveniences it might generate. Patients and carers will be the ones considering each strategy to see what they should try for themselves. In previous work, Mamykina et al. (2015) defended the importance of presenting a multiplicity of alternatives for the same issue. She suggested that knowledge in online communities could be organised just like Pinterest[3] where people would group ideas according to a topic, to be able to host different concurrent perspectives for the same issue. This is an interesting idea on how to operationalise multiple perspectives appearing online; however, independent of the approach, it is important to enable multiple perspectives to co-exist in technology as a way to integrate patient knowledge effectively.

Support learning at different phases of the condition. Learning to self-care is a life-long activity. Progression, new treatments, or other life issues often lead people to revise their self-care and patient knowledge. Thus, self-care technologies should support learning during all phases of the condition. Providing technology that is relevant to people in different phases of the condition can be quite complex, because, as Schorch et al. (2016) explain, users may require distinct content, features, and overall guidance. Providing relevant content is perhaps the easier step. For example, self-care technologies for accessing information about the condition, such as **Parkinson's Central** or **GoLearningBus**, could provide content that is relevant to all phases Parkinson's, instead of solely focusing on issues that concern early phases. However, ensuring that the features and overall guidance of the technology are relevant in different phases of the condition requires technology for learning to be designed and tested with people in different stages. Without involving people at various phases, it is hard to ensure that the learning features are relevant to many people living with Parkinson's.

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[3]Pinterest is an online social network where people collect visual ideas according to topics that they choose. The online community is available at https://pinterest.com/.

9.4.4 Supporting an active agency in interactions with doctors

Support the investigation of issues to discuss at the doctor's office. Since patients and carers often bring up issues in consultations, self-care technologies should support people in eliciting issues to discuss in these encounters. For example, self-care technologies for tracking can be useful for uncovering issues, problems, or topics that people might want to discuss with their doctors. However, it is important not to restrict the features that can be tracked or logged. Swollen ankles, pain in the legs, or problems walking around a crowd – all of which are mentioned in the fieldwork – could not be straightforwardly tracked or logged with the reviewed technologies. Recognising the agency of patients and carers entails offering them tools that support a rich investigation of issues. Making available self-care technologies that are open to capture different symptoms without restriction to certain aspects or symptoms, as Storni (2011) suggests, may be useful in enabling people to get in contact with more issues and thus better learn when interacting with doctors.

Support an active participation in medical decisions. People living with Parkinson's play an important role in decision-making, thus self-care technology should support their participation in discussions at the doctor's office. Being face-to-face can help achieve this objective, but there might be alternatives, such as using videoconferencing as in Video Consultations, Virtual Consultations, Virtual Housecalls, or phone calls as in myRecord. Independent of the approach, self-care technologies should ensure patients and carers can participate in the decisions about their health, because removing them can have negative consequences. For example, when patients with diabetes were removed from the interpretation of glucose values in a patient record, they felt frustrated because numbers did not explain their decisions or the context in which they acted (Piras and Zanutto, 2014). In myRecord (Andersen et al., 2011), a technology where doctors could remotely diagnose and adjust an implantable pacemaker, the decisions became much harder after excluding patients to the point that they had to be later re-introduced. However, when patients and carers were indeed included there were benefits to the care received. The doctors addressed issues after analysing measurements they did not consider before (Aarhus et al., 2009; Andersen et al., 2011; Nielsen, 2015), and interpreted values differently after understanding the context in which they occurred (Andersen et al., 2011; Langstrup, 2008). Recognising the active role patients and carers play in medical decisions involves developing tools that enable them to be "present" when decisions are taken about their health. Even if the symptom data is sent remotely, collaborative discussions are the only way to ensure the treatment addresses relevant concerns and fits with everyday life.

Support the adjustment of inappropriate treatment. Patients, but especially carers, were very diligent in ensuring that treatments that did not work were adjusted on a timely basis and thus the consequences of having inappropriate medication reduced. To acknowledge this active role, self-care technologies should enable patients and carers to trigger the need for treatment adjustments. For example, in technologies for enabling remote consultations, patients could start videoconference sessions or request a consultation sooner. Moreover, in the tracking technologies where doctors could adjust

medication remotely, patients or carers could signal the need for adjusting previously prescribed treatment. The inability to trigger treatment adjustments through existing technologies does not imply that these corrections were not possible. It might be the case that administrative services or others enabled people living with Parkinson's to call their doctors or to go to the clinic without an arranged consultation, however, by not providing paths within the technology, people might have missed a more straightforward process for adjusting a failed treatment plan. Recognising the role patients and carers have in addressing inappropriate medication changes requires technology to be designed in a way that enables treatments to be adjusted when they do not work. To achieve this, it might be relevant to offer patients and carers the tools to reach their doctor for advice, or at least, to have a path within the infrastructure that enables them to signal a quick need for medical care.

9.5 Summary

This chapter documented the misalignments between the self-care of Parkinson's and existing self-care technologies, discussed the medicalized values behind those misalignments, and proposed design considerations for addressing them. Findings show that there were four misalignments: the focus of self-care technologies (*medicalized instead of mundane*), the expected users (*mostly individual patients instead of patients and carers collaborating*), the role in promoting learning (*supporting an investigative attitude despite some issues*), and the potential of agency offered in technology-mediated interactions with doctors (*also presenting issues despite pointing to the right direction*). These misalignments seem to be a consequence of incorporating *medicalized values* into the development of self-care technologies. Moreover, the chapter contributed with design considerations to *focus on the mundane* self-care work, *support collaborations* in self-care, *promote learning* opportunities, and *supporting an active agency* in interactions with doctors.

CHAPTER 10

Conclusion

Having presented and discussed the findings of the thesis, this chapter concludes my work. It starts by pulling together the contributions made with this thesis, positioning each of them in regards to previous work, and within the research tradition of HCI and CSCW. Then, I compare the characteristics of Parkinson's with those of other chronic conditions, to get a sense of the applicability potential of this work. Then, I discuss the overall findings and approach in relation to the constructivist criteria advanced in the methodology. Finally, I discuss the limitations of this work and ideas to build on this thesis in future work.

10.1 Contributions made

To recap, the goal of this work was to investigate how self-care technologies aligned with the everyday self-care experience of patients and carers living with Parkinson's. As numerous self-care technologies achieved a low uptake, I engaged in ethnographic fieldwork and a critical review to study how existing self-care technologies aligned with the self-care of Parkinson's. This analysis resulted in the identification of several misalignments and triggered the discussion of design considerations to better align technologies with the everyday life with the condition.

The *first contribution* of this thesis is an ethnographic description of the self-care activities of people living with Parkinson's. Chapter 4, 5, 6, and 7 presented detailed descriptions of how people engaged in self-care in practice (RQ1), how they learned to perform self-care in that particular way (RQ2), and how they interacted with their doctors (RQ3). These chapters add to the ethnographies of Pinder (1990), Solimeo (2009), Martin (2012), and Gibson (2013), which while investigating the everyday life with Parkinson's, focused on aspects other than self-care. This particular ethnographic description does not lead directly to considerations or implications to the design of self-care technologies, but it can lead to a better understanding of the setting people are designing for. As

Dourish (2007) explains, ethnographic descriptions can make researchers and designers rethink ideas and assumptions that underline the development of technologies, or inspire them to work around issues that were not previously understood or known (e.g., delaying medication).

The *second contribution* of this work is a characterization of the concept of self-care in the context of Parkinson's. Each fieldwork chapter (4-7) advanced properties of the concept of self-care in answering RQ1-3. The properties emerging from the analysed fieldwork (see Figure 9.1), were discussed in regards to related work on Parkinson's (Pinder, 1990; van Nimwegen et al., 2011; Thordardottir et al., 2014), other chronic conditions (Nakagawa-Kogan et al., 1988; Funnell and Anderson, 2000; Storni, 2015b), or more general accounts on self-care (Charmaz, 1991; Corbin and Strauss, 1988; Lawn and Schoo, 2010). To this body of work, this thesis contributes with empirically informed analytical properties that are relevant in the self-care of Parkinson's. Similar to the first contribution, the second one does not lend itself practically to implications or considerations for the design of self-care technologies, but rather, by characterising the properties of self-care, should inform and inspire designers to think about the self-care concept they incorporate into the self-care technologies they develop.

The *third contribution* is a review of self-care technologies. Chapter 8 is the first review to analyse the ways of self-care enabled by self-care technologies available for Parkinson's (RQ4). This work adds to previous reviews of technology for neurologists dealing with Parkinson's that focused on clinically-oriented remote monitoring (Godinho et al., 2016), and the clinical impacts of telemedicine technologies for that condition (Achey et al., 2014). Unlike these previous reviews, the work presented in this thesis focused on the perspective of patients and carers engaging in self-care. Moreover, since the chapter also reviews self-care technologies for other conditions, as published in HCI and CSCW, it provides an overview of self-care technologies more in general. The review should enable researchers and designers to understand areas of work that have been explored, types of users and collaborations supported, ways in which technologies supported learning, and the potential for agency offered in interactions with doctors. In essence, the review enables researchers and designers to gain an understanding of previous work on self-care technologies thus informing their design process.

The *main contribution* pulls all empirical chapters together identifying four misalignments between self-care technologies and the everyday self-care of Parkinson's, and proposing design considerations for addressing these misalignments (RQ5). This contribution is presented in Chapter 9 and is discussed here in its three parts.

The *identification of misalignments* between self-care technologies and the self-care of Parkinson's contribute to the body of work that has investigated the low uptake of self-care technologies, such as Hardisty et al. (2011) and May et al. (2011). Moreover, the existence of four relevant misalignments seems to confirm that patients and carers in the studies of Mort et al. (2013) and Sanders et al. (2012) had valid reasons for fearing that technologies would force them to change their self-care. In fact, had the patients and carers from my fieldwork used the self-care technologies reviewed, they would have been forced as well to change their perspective on self-care and their self-care activities in

meaningful ways. This contribution should help researchers and designers in identifying areas of self-care technologies to investigate in detail as a way to better align them with the everyday self-care of patients and carers.

The identified misalignments do not seem coincidental, but related with an incorporation of *medicalized values* in self-care technologies. With this contribution, the thesis confirms previous work by Fitzpatrick (2011) and Storni and Bannon (2012) that suggested that self-care technologies had embodied medicalized values because designers did not rethink the values behind technologies when changing from formal to informal care settings. As that seems to be the case, the thesis motivates designers to consider the self-care values that they are incorporating into the self-care technologies they develop.

This brings us to the *design considerations*, the second part of the main contribution. The considerations draw on the fieldwork and on the review of self-care technologies, and should be used as a tool to think with while designing. They are not supposed to be applied directly to a certain technology, but rather be explored while engaging in the design process. These considerations add to the large body of work within HCI and CSCW that aims to improve the self-care technologies that are available for people living with chronic conditions (Ballegaard et al., 2008; Storni, 2011; Bardram et al., 2013; Fitzpatrick and Ellingsen, 2013), by offering ideas on how to reduce the misalignments between self-care technologies and the self-care of Parkinson's.

10.2   Applicability of the findings to other conditions

My PhD research focused on Parkinson's and the self-care technologies developed for people living with this condition. As a result, the findings from this work contribute to the understanding of self-care and the design of self-care technologies for that particular condition.

However, some insights of this study may apply as well to other chronic conditions that share similarities with Parkinson's. While only readers will be able to evaluate the applicability of the findings to their own context, contrasting Parkinson's with other chronic conditions helps get a sense of the amount of overlap. In this section, I compare Parkinson's with diabetes, hypertension, and COPD[1]. My comparison is based on the literature reviewed in this thesis, as well as on the medical descriptions of the conditions in Kasper et al. (2015).

The symptoms of Parkinson's, diabetes, hypertension, and COPD are very different, thus the self-care activities cannot be the same. However, multiple studies have described self-care activities that, similar to those of people living with Parkinson's, could be characterised as mundane (Cicutto et al., 2004; Pols, 2012; Storni, 2010) and collaborative (Corbin and Strauss, 1988; Charmaz, 1991; Pols, 2012). Some studies investigating these conditions argued that patients develop patient knowledge by themselves (Pols, 2014; Storni, 2015b; Mol and Law, 2004), and there was work documenting an active agency of patients in medical interactions (Funnell and Anderson, 2000; Glasgow and Anderson,

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[1]I chose these particular conditions because they are some of the most common chronic conditions in terms of prevalence and amount of research around self-care

1999). Even if these studies did not frame their results in the ways I articulate them here, they fit within the conceptualizations I have put forward in this thesis.

Besides similar self-care engagements, Parkinson's, diabetes, hypertension, and COPD have in common the fluctuations in the condition state (see Table 10.1). Patients with any of these conditions can get worse symptoms from one minute to another due to expected causes, such as the weather, food, or physical effort, or unexpected ones, such as certain emotions. The presence of fluctuations suggests that the unpredictability of living with the Parkinson's may not be solely a characteristic of this condition.

There are also some particularities that do not seem to find an equivalent in other chronic conditions. One of them is the inability of medication to address symptoms completely. While people living with diabetes, hypertension, and COPD have medication that can temporarily address symptoms, the medication for Parkinson's can only soften them. In fact, no medication for Parkinson's is comparable to an insulin shot at lowering the glucose level, a beta blocker at lowering blood pressure, or a Bronchodilator at opening airways and enabling people to breathe better. In the majority of the cases, people living with Parkinson's experience symptoms despite taking medication, which forces them to negotiate and compromise on a very regular basis.

Another particularity of Parkinson's is the On/Off phases. In the other mentioned conditions, medication does not lose effect with time. In Parkinson's however, medication is likely to lose effect since intermediate phases of the condition. As a consequence, people living with Parkinson's may be forced to live with strong symptoms for some periods during their day, while people living with other conditions are likely to have a more stable condition state.

All these conditions can bring stronger symptoms with time, but their cause and rate of progression are different. While the degeneration of the brain is the sole cause of progression in Parkinson's, in diabetes, hypertension, and COPD, progression can be attributed to genetic characteristics and the self-care of people. This difference is important as people living with Parkinson's cannot do much to change their future condition state, while other patients and carers may be able to.

Moreover, the rate of progression is, in general, faster for Parkinson's. Instead of getting stronger symptoms every couple of decades or years, patients with Parkinson's can have increasing symptoms after some months. This means that their experience with the condition requires more changes and adaptations, than the other mentioned conditions.

In essence, there are a couple of parallels between the conditions regarding the self-care engagements, fluctuations, and the progressive nature of the diseases, which suggests that some insights from this study may relate to diabetes, hypertension, or COPD.

10.3 Findings discussed in regards to constructivist evaluative criteria

In the methodology section, I referenced criteria for evaluating research conducted within a constructivist stance (Section 3.1.2). The five criteria mentioned – credibility, rightness,

	Parkinson's	Diabetes	Hypertension	COPD
Fluctuations (cause)	Emotions, medication wearing off, and weather	Emotions, exercise, and food	Emotions, food, and weather	Dust, emotions, and physical effort
Progression (cause)	Related with degeneration	Genetics, lifestyle	Genetics, lifestyle	Genetics, lifestyle
Progression (rate)	Months to years	Years to decades	Years to decades	Years to decades
Medication (impact)	Soften symptoms	Lowers blood glucose	Lowers blood pressure	Reduces breathing difficulties
Medication (effect duration)	Limited, with presence of On/Off	Regular	Regular	Regular

Table 10.1: Quick comparison between Parkinson's and diabetes, hypertension, and COPD.

resonance, usefulness, and transferability – were advanced by researchers in the social sciences, to guide the evaluation of constructivist accounts. As I finalise this thesis, I return to the evaluation criteria to explain how the findings, methods, and overall approach fits with them.

The study demonstrated *credibility* in different ways. The fieldwork was the result of sustained engagement with people living with Parkinson's for several years, employing different collection methods, and involving participants from different countries. Moreover, some participants even had a chance to comment on my interpretation about them, as they were presented with an earlier version of Chapter 4 and with the technology probes. The critical review of technologies was also thorough and diverse, including 86 examples of technologies presented in papers from different scientific areas, as well as mobile applications published on the iTunes store. Besides its thoroughness, this study offers credibility through the extensive use of quotes, figures, and references throughout the text, enabling readers to see the connection between the data, findings, and the argument that is made about them.

The criterion of *rightness*, which evaluates the fitting of the findings under a particular context and theoretical frame, was also ensured. The findings build on the literature on self-care, self-care technologies, and Parkinson's, and the contribution is discussed extensively in regards to previous work in these areas.

The study reveals *resonance* in the sense that the findings did not stay at surface level, but rather reinterpreted meanings that were previously taken for granted. Just to give an example, the insight that most self-care technologies are developed for individuals to use in isolation is a new insight from this thesis, which orients the attention to the types of users and collaborations existing in self-care technologies, in ways that were not

done in the literature before.

In regards to *transferability*, or the ability to transfer insights from the study to other contexts, this work offered relevant details about the methods and argument so that readers can judge the applicability of the findings to their own settings. At the same time, the study discusses very diverse literatures which could help promote the transferability of the findings to other domains. For example, since the literature discussed around self-care is not restricted to Parkinson's, but includes studies from people living with diabetes, hypertension, and COPD, researchers working with these conditions, might consider some of the insights applicable to their participants as well – as previously discussed. However, only readers will be able to make that assessment.

The study is *useful* in the sense that others can potentially use it in practical ways. For example, researchers or designers can explore the design considerations outlined in Chapter 9 to develop self-care technologies that are potentially better aligned with the everyday self-care of patients and carers living with Parkinson's. The conceptualization of self-care described in Chapters 4, 5, 6, 7 can also be used, for example, when designing self-care technologies as a way to think about the ways of self-care that are being promoted. Moreover, Chapter 8 can be useful to provide an overview of the opportunities that have been explored in self-care technologies for Parkinson's.

10.4 Limitations

This study has been primarily concerned with studying the misalignments between self-care technologies and the everyday self-care of Parkinson's. Using ethnographic informed methods and a critical review of technologies was a useful approach to identify the misalignments and propose ideas on how to tackle them, however, this study does not indicate concrete or practical ways to address the misalignments. While the design considerations suggest ideas to explore during the design process, there is no way of guaranteeing that applying these principles will lead to self-care technologies that better align with the self-care of people living with Parkinson's. That remains to be evaluated in future work. However, by keeping design considerations at a more conceptual level, this work remains faithful to the fieldwork conducted and analysed. Design considerations are thus not a plan to apply, but a tool to think with. They are ideas relevant to investigate while engaging in design.

The findings of this study are limited to the context of Parkinson's. Even though some insights might be transferable to the context of other chronic conditions, this is neither guaranteed nor attempted with this study. Having said this, I have put great effort into discussing literature from other chronic conditions to increase the comparison in the analysis, and investigate the specific characteristics of the context of Parkinson's. For example, the fieldwork is discussed in regards to other chronic conditions, the critical review involves self-care technologies for conditions other than Parkinson's, and design considerations discuss studies that involved technologies for other conditions as well. Discussing literature from other conditions should help readers applying the findings

from this thesis to their particular contexts, even if the thesis did not try to assess the transferability of the findings *per se.*

I should also make clear that the findings from the fieldwork are situated. Even though I studied participants coming from three countries and with different methods, the sample is not representative of all experiences with Parkinson's. For example, most if not all participants are from Western countries and might have different practices from those coming from the global south or developing countries. Apart from the participants in the online ethnography, I did not involve anyone with young- or juvenile-onset of Parkinson's (<40 and <21), and there were few participants living in nursing homes. Moreover, the interviews and observation were conducted in an urban town in Portugal. Recognising these characteristics reminds us the situated nature of this work that, like all studies, only accessed a glimpse of the experience of people. However, it is relevant to say, that while not representative, the findings from this study are relevant and should be useful to the scientific community.

10.5   Future work

One opportunity for future work would be to develop self-care technologies that do not feature the identified misalignments. For example, it would be interesting to develop a medication reminder that was more focused on the mundane issues of self-managing medication, or a technology for exercising that better acknowledge collaborations with carers. Engaging in participatory design methods would enable the exploration of different design alternatives for implementing the principles outlined in this thesis into practice. Moreover, once the self-care technology was developed, it would be relevant to understand whether and how patients and carers would adapt their practices to the self-care technology.

In a similar way, it could be interesting to pilot some of the self-care technologies analysed in the review to assess whether and how patients and carers adjusted their way of self-care when using them. Getting an understanding of how my fieldwork participants personally felt about these changes would also be relevant. To evaluate these technologies, one could use ethnographic methods with a small group of participants for a couple of months.

The third line of work emerging from this thesis is the need to study how patients and carers participate in the design of self-care technologies. Patients were often involved in the design of self-care technologies, but in the end, these technologies were still individual and focused on medicalized issues. One is led to think that the participation was not very intense or that issues raised by patients were not taken into account. To study how people participate in the design of self-care technologies, it would be interesting to make a literature review of studies in the area. Complementing this approach, one could interview designers and researchers designing these technologies as to understand how people were involved in practice and how they were able to put their mark into the design.

Another alternative to build on this work would be to investigate the misalignments in other conditions. Diabetes, hypertension, or COPD could be interesting case studies as these conditions have been the focus of numerous projects developing self-care technologies. Performing this work would enable one to understand the misalignments present in those contexts and, at the same time, uncover issues that apply to self-care technologies for different conditions.

APPENDIX A

Technology probes

The technology probes were used as a tool for inquiry in this thesis. Patients and carers were offered one or two technology probes to use during a week and, after this period, were interviewed about the self-care issues that motivated the development of the probes. This appendix details the design rationale, the technical details, as well as the initial use experiences of participants with each of the probes.

A.1 Technology probe "Remind me when it is..."

A.1.1 Design rationale and prototype details

The probe "Remind me when it is..." (Figure A.1) was designed to trigger conversations about the challenges of taking medication on time. Since earlier interviews, it was clear that participants faced some challenges in remembering about their medication. The time for the pills would easily pass by if they were not always checking the time or using medication reminders. With "Remind me when it is...", the goal was to offer users a medication reminder that they could easily set up, as a way to open conversations about missing pills, strategies for remembering, and how medication reminders could be of use.

The prototype was developed using an Arduino Mega microcontroller, a breakout module providing a real time clock, a buzzer to sound the alarm, 24 female connectors for 6.35 mm jacks (one for each hour of the day), a couple of 6.35 mm male jacks as dongles to define when to alarm, LED lights, a power adaptor, and an on-off switch.

To set up a reminder, users would turn on the switch and simply insert dongles into the 24 female connector jacks. There were two types of dongles. One of them triggered an alarm at the hour written over the female connector sharp (e.g., 11:00). The other triggered an alarm half an hour after the time written over the female connector (e.g., 9:30). The two dongles appear in Figure A.1, with the labels "certas" (sharp) and "e meia" (and a half).

Figure A.1: Technology probe "Remind me when it is..."

A.1.2 Initial use experiences

"Remind me when it is..." was used by IP3, and mostly, by IP3_C1. The carer placed the device in the living room, where he spends most of the time, to hear the alarm sound. He set up one reminder in the morning, one at noon, one at dinner time, and one at the time they usually go to bed. IP3_C1 chose this schedule because these were the times when his wife needs to take her medication.

IP3_C1 saw the usefulness of having a medication reminder because it would alarm at the right time to take medication. However, he saw some pitfalls in the technology probe. First, the alarm sound volume was too low for him. He talked about situations in which he would leave the living room for some reason, and would not hear the alarm ringing. Second, "Remind me when it is..." was too big to transport and needed to be connected to the plug to work. This meant that he could not take the reminder with him when they went outside the home. To address these two issues, IP3_C1 suggested that the technology probe should be made into a smaller form factor that could be easily transported or worn. The ideal for him would be to make it into the size of a necklace, that his wife would like and always wear. Unlike a mobile phone, she would not forget it

while going outside because she would already be wearing it.

The third issue raised related with the lack of connection between the medication reminder and the medication plan. IP3_C1 argued that the device should be able to tell the person what medications are scheduled for that particular time. Alarming would not be enough for his wife to use, as she would easily confuse the pills she had to take. The carer suggested that the medication reminder should play a voice message saying which medication to take. This would ensure in his perspective that his wife would be able to take the right medication at the correct time, even if he was not around her.

A.2 Technology probe "I cannot forget..."

A.2.1 Design rationale and prototype details

The probe "I cannot forget..." (Figure A.2) was designed to investigate the acceptance of Parkinson's and the role of remembering some messages in that acceptance. During the first interview phases, patients and carers talked about how they needed to remind themselves that they were not the worse case of Parkinson's, that they still could do many things, or that their condition was not the worse one. Remembering these messages was for them a way of accepting the condition and keeping their motivation levels up. With "I cannot forget...", my aim was to offer users a way to record messages like these to remind themselves when they most needed.

Each participant received four small boxes (size of a ring case) that can record a 10-second voice message to be heard at a later time. Each prototype was developed using a wooden box, an off-the-shelf electronic kit that could record 10 seconds of audio, a reed sensor[1] and a magnet to trigger the sound playing, a button for starting recording, and a 3D printer support that stores and protects the electronics underneath.

Each time the user opened the box, they heard the last message recorded by them. They could also record a new voice message, by pressing and holding down the button.

A.2.2 Initial use experiences

"I cannot forget..." was used by three groups of patients and carers during one week (IP3, IP3_C1, IP5, IP5_C1, IP6, and IP6_C1). The participants used the probe to record several messages, but the topics that they chose can be categorised into two. The first, and most common, were messages relating to the need to take medication at the right time. The second, was about the need to remember their medical consultations. While I expected patients and carers to mention others with worse cases of Parkinson's or having conditions they considered worse, as they did in the interviews, that was not the case. Participants did not think about those sorts of messages and ended up recording messages about important things to remember when someone has Parkinson's.

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[1]The reed sensor is a small electronic component that reacts to an electromagnetic field. When a magnet is close, the circuit opens, but once the magnet goes apart, the circuit closes. In this case, opening the lid made the magnet become more distant and so triggered the circuit to play the recorded audio.

Figure A.2: Technology probe "I cannot forget..."

When speaking with participants, it became clear that they were not entirely sure what they should record with "I cannot forget...". I got the impression that for them this technology probe was a useless device. In fact, during most of the interviews I was told about conversations that patients and carers had asking each other about what to record in the technology probe.

Interestingly, two groups of patients and carers suggested that the device should be adapted to record the medication intake. According to IP3_C1 and IP5_C1, patients can easily forget that they took the medication and take it again. This is not a problem when they are around, but if these carers left for some reason, they feared that the patients might take their medication again by mistake. For this reason, both IP3_C1 and IP5_C1 suggested that the box should enable patients to record a message saying that they took the medication. If patients tried to take medication again, they would open the box and realise that they already took it. This redesign idea was interesting because it takes the voice recording and the remembering aspects of the probe, turning it into a completely different idea.

Figure A.3: Technology probe "I was shaking like this..."

A.3 Technology probe "I was shaking like this..."

A.3.1 Design rationale and prototype details

The probe "I was shaking like this..." (Figure A.3) was designed to trigger conversations around the investigation of symptoms and other issues of the condition. Earlier interviews offered many examples suggesting great observation and reflection on symptoms, thus it was relevant to explore these practices. The reason for focusing on tremor was because it is one symptom that is hard to measure without technology. With "I was shaking like this...", users were able to get a picture of their tremor at a particular moment in time.

The prototype created includes an Arduino Due microcontroller, a thermal printer, a 3-axis movement sensor attached to an arm strap, a button to start recording, and a power adapter. Once the user presses the recording button, the technology probe starts a 10-second collection of movement data from the movement sensor. Every 300 milliseconds, one line of the plot is printed in the receipt paper using an 'x' (see Figure A.4). The further the 'x' distances from the centre, the greater the acceleration of movement was. In this prototype, every little movement had a great influence on the plot because data was only lightly filtered.

A.3.2 Initial use experiences

When using "I was shaking like this...", users (IP2, IP5, and IP5_C1) engaged in a thorough investigation of their tremor. They tried the technology probe before and after medication, while standing and sitting, and with the hand relaxed or supported. Testing all these conditions enabled patients and carer to understand the positions in which tremor was stronger, and that the output of the probe was fairly stable.

After one or two days of experimentation, they stopped using the probe because, as IP5_C1 explained, "the result does not change that much". While the tremor of the patients increased a bit in some occasions of the day, the probe was not able to capture these changes. The lack of sensibility of the probe was expected due to the very superficial treatment of the acceleration data. However, it was interesting to observe that people very quickly spotted this inability of the probe. IP2 concluded that the "result is more related with the position of my hand than with anything else", which points to the limitations of the probe in providing meaningful insights about one's tremor.

Another insight from using the probes was related with the position of the sensor. While I expected that participants would only be interested in tracking the tremor in their hands, IP2 told me that it would have been more interesting if the device could measure the tremor in the legs. The tremor in the hands was not problematic for him, but the one in the legs was more concerning as his legs kept shaking when he was speaking with me.
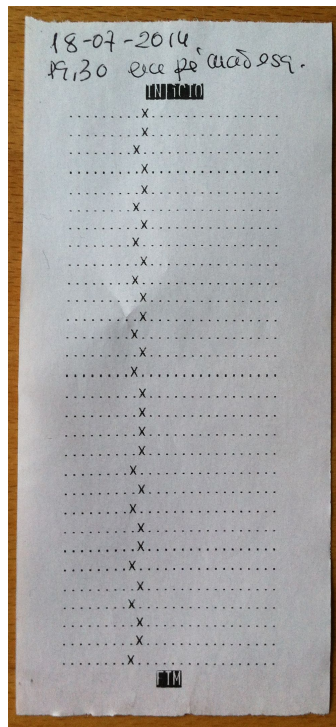
Figure A.4: Output plot of the technology probe "I was shaking like this...". Notes on top mean that it was taken on the July 18th while standing, with the sensor attached to the left hand.

Notes on the fieldwork

This appendix offers some notes about the fieldwork. First, it presents the guide that was used during the first phase of the interviews. Then, it details the quotes used in the third phase of the interviews. Following, it shows an exemplary screenshot of Scrivener™, the analysis software used. To finalise is a picture of a commented draft that was returned by one participant.

B.1   Guide used during Phase 1 of the interviews

This section details the basic interview guide used during the open interview phase. Since the interviews were loosely structured, the questions in this guide did not always appear in this order, and sometimes were divided into more than one interview session. The presented guide covers the overall themes mentioned in the interviews. In some cases, other questions were introduced to investigate specific themes; however, these questions would fit as well under the overall themes of this guide.

Opening questions:

- Tell me a bit about you. Who are you? What do you do?

- Do you still work? If not, what did you do before?

- Do you live by yourself?

- Can you describe a typical day of your life?

- Can you describe your last weekend?

Getting a diagnosis:

- How did you discover you had Parkinson's disease?

- When did the first signs appear?

- When was the condition diagnosed?

- How did the diagnosis make you feel?

- Did the initial diagnosis bring about any change in your daily life?

Learning to live with Parkinson's:

- How did you learn to live with the condition?

- Did anyone advise you? Who? What did they say?

- What is the most important thing to learn if you have Parkinson's?

- What advice would you give to someone that just discovered they had Parkinson's?

Treatment and relationship with doctors:

- Who is involved in the treatment of your conditions? Are you followed in the hospital?

- Can you describe a typical consultation to me?

- How do you prepare for consultations?

- Are the consultations enough for reaching a good quality of life?

- How is the relationship with your doctors? Do they understand you?

Living with the condition:

- How do you manage your condition in the day to day life?

- What are the activities that you have to do because you have Parkinson's?

- What other things in your life are in a specific way because of Parkinson's?

- What is the thing you most miss because of the condition?

Parkinson's and me:

- What is Parkinson's for you?

- What symptoms do you have?

- What medication do you take?

B.2 Quotes used in Phase 3 of the interviews

During the third phase of interviews, I brought up quotes from previous interviews to discuss issues of the condition. These were the quotes used during these interactions:

- *"I make a terrible effort. I make an effort. I walk slowly, but every day I go for a walk."*

- *"This is something that has no cure mate. And adapting to it is even harder."*

- *"If I do things relaxed, without getting nervous, I can do everything. At my speed, I do. But if I get nervous, then..."*

- *"I have forgotten [to raise issues in consultations] and my wife tells me: when you go to the consultation, make some notes so that you don't forget."*

- *"And he sees others that are worse than him. That also helps."*

- *"In the morning and the evening one does not forget. It never fails. But at noon..."*

- *"Doctor: What are you taking now?"*

- *"Maybe it would not be worse, because six months between consultations is a lot of time."*

- *"When I saw that he was sitting like this, putting the hand like this, I would know that he was having a bad moment. (...) I would say: come, come. Let's go for a walk."*

- *"Sometimes it is complicated to understand the disease..."*

- *"In the beginning everything was new... I did not have anyone in the family with Parkinson's. I did not have anyone... not even friends..."*

B.3 Software used in the analysis

The analysis of the fieldwork was supported by the Scrivener™ writing software. With this application, I was able to code fieldwork excerpts, write memos about them, and overall change the coding structure to adapt to the evolution of the codes. In Figure B.1, there is an example of a screenshot of Scrivener while analysing the theme about the interactions between patients and carers and their doctors.
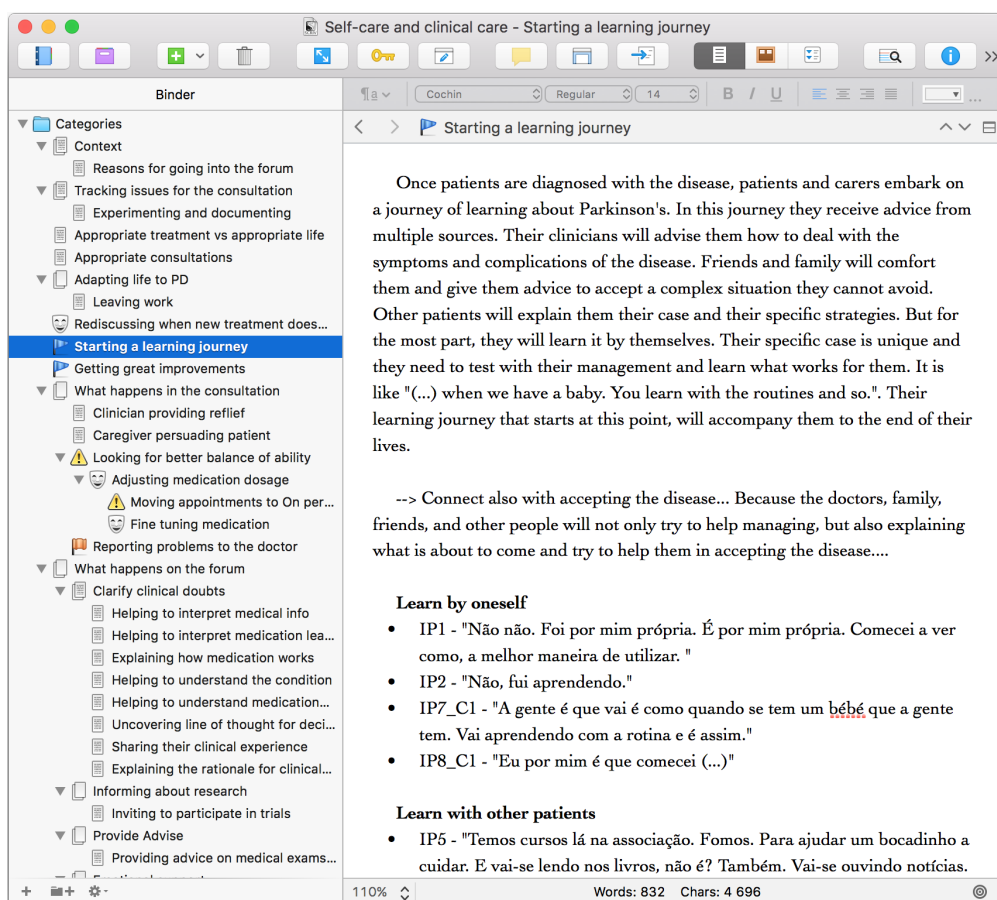
Figure B.1: Scrivener^{TM} software displaying a code, memo, and incidents. This file corresponds to the analysis of the interactions with doctors. On the bottom right, there are some quotes or incidents that were extracted from the interview transcripts. Above the quotes, there is a work-in-progress memo that seeks to make sense of the incidents that are identified underneath. On the left side of the window, there is a bit of the coding tree belonging to this part of the study.

B.4   Comments to initial draft analysing the interviews

After an initial analysis of the interviews, participants were offered an early manuscript to comment on the analysis made about them. This was the first draft of what would become Chapter 4. After reading, patients and carers were informally interviewed to understand their perspective. However, some patients wrote numerous comments and suggestions along the draft better explaining their perspective and stressing their point of view. Figure B.2 is a picture of one page commented by one of the participants.

LIBERTAÇÃO PROLONGADA (24 HORAS)

(e.g. Azilect)³. A medicação é forte na luta contra os sintomas, contudo
perde o efeito passado algumas horas. A medicação é também bastante
sensível. Medicação a menos não reduz os sintomas satisfatoriamente, e
medicação a mais traz efeitos colaterais como movimentos
involuntários. Por esta razão, os pacientes costumam tomar uma
combinação de diferentes comprimidos em momentos específicos do
dia, para manter o efeito da medicação durante o dia.

Com esquemas de medicação tão complexos esta é por vezes esquecida. _TENHO A DOENÇA_
No entanto, é importante distinguir entre dois tipos de esquecimento. O _HÁ 14 ANOS E_
primeiro é o esquecimento ocasional. Nestes casos, pacientes e _NUNCA ME ESQ._
cuidadores por vezes não se conseguem lembrar da medicação a tomar _QUER. SOU_
em alturas que não encaixam bem nas suas atividades, sendo por isso _DISCIPLINADO_
mais fáceis de esquecer. O segundo caso está relacionado com pacientes
que se esquecem da medicação sistematicamente. Encontramos esta
situação em diversos casos nos quais os cuidadores preparam a
medicação e lembram os pacientes na altura de tomá-la.

Para se lembrarem da medicação, pacientes e cuidadores usam diversas
estratégias. Aqui descrevemos três. A primeira consiste em ligar a
lembrança da medicação com as rotinas diárias. É frequente ouvir as
pessoas com Parkinson ou respetivos cuidadores dizerem que colocam
a medicação na mesa da cozinha para não esquecer de a tomar às
refeições, ou na mesa de cabeceira para a tomar antes de dormir.
Embora estas estratégias funcionem em alguns casos, noutros em que a
hora da medicação não esteja alinhada com estas rotinas, é mais
complicado de lembrar. A segunda estratégia está relacionada com o
controlo do tempo. Alguns pacientes ou cuidadores olham
sistematicamente para o relógio para garantir que a medicação é
tomada a horas. A terceira estratégia consiste em usar o alarme do _TELEMÓVEL_
~~telefone~~ para lembrar a medicação. Quando o telefone toca, é hora de
tomar a medicação. Esta estratégia fez com que pacientes e cuidadores
se sentissem aliviados por não terem de se preocupar em lembrar-se
dos medicamentos. É interessante ainda observar que a utilização do
alarme do ~~telefone~~ _TELEMÓVEL_ não pressupõe maior habilidade, da pessoa com
Parkinson ou do cuidador, com o telefone, já que o alarme pode ser
ativado por outros.

Figure B.2: Commented page of initial draft provided to patients and carers. The writing
on top notes that Azilect® is a medication with prolonged release effect. Following on
the right side says that in 14 years with the condition he never forgot a pill, and adds
that he is disciplined. In the bottom the participant replaced phone with mobile phone
as the strategy used for reminding of medication.

APPENDIX C

Ethics information sheets and consent forms

This appendix presents the two documents that were used for gathering informed consent from participants.

The first document (Figure C.1) was used to obtain consent in the interviews. This document follows a consent form template from the Institute for Design and Assessment that includes the information about the study and the consent form in the same page. The document gathers permission for participating in the study, as well as having pictures in presentations and academic articles, and in project web pages.

The second document, used in the observations, was divided into two pages. The first page (Figure C.2) was an information sheet that presented information about the observation. The second page (Figure C.3) was the consent form in itself. This document followed the template of the ethics committee of the hospital where the observation took place.

Both documents were written in Portuguese matching the native language of the participants.

APPENDIX C

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Both documents were written in Portuguese matching the native language of the participants.

Estudo Exploratório "Viver com Parkinson"

O investigador Francisco Nunes está a desenvolver um estudo exploratório intitulado *"Viver com Parkinson"*. Este projeto pretende investigar o contexto em que vivem as pessoas com Parkinson e está integrado no início do doutoramento do investigador.

Pede-se por isso, a sua participação numa entrevista que incidirá sobre a sua experiência com a doença de Parkinson. A entrevista será gravada em formato áudio e levará cerca de 45 minutos.

O investigador compromete-se a garantir confidencialidade e uso exclusivo dos dados recolhidos no presente estudo. Garante ainda que a identificação dos participantes não será tornada pública em nenhuma situação.

A participação neste estudo é voluntária, não havendo lugar ao pagamento de quaisquer contrapartidas. Em qualquer altura, poderá recusar participar neste estudo, sem qualquer tipo de consequências ou prejuízos, bastando para isso contactar o investigador responsável.

Francisco Maria Cruz Nunes
Universidade Técnica de Viena
francisco.nunes@igw.tuwien.ac.at
9196713XX

Consentimento

- Declaro ter lido e compreendido este documento e consinto participar no estudo proposto

    Sim / Não

- Se forem tiradas fotografias, autorizo a utilização das mesmas em apresentações e artigos académicos

    Sim / Não

- Se forem tiradas fotografias, autorizo a utilização das mesmas na página da internet do projeto

    Sim / Não

Nome do participante: _____

Assinatura: _____ Data:__/__/____

Investigador responsável: Francisco Maria Cruz Nunes

Assinatura: _____

Figure C.1: Information sheet and consent form used in the interviews.

INFORMAÇÃO AO PARTICIPANTE

O investigador Francisco Nunes e a Dra. Carolina Garrett estão a desenvolver um estudo intitulado *"Estudo exploratório de observação em contexto de consulta de acompanhamento da doença de Parkinson".* Este projeto pretende explorar o tratamento e o contexto de vida das pessoas com Parkinson e está integrado no doutoramento do investigador Francisco Nunes.

Pedimos a sua colaboração durante a consulta, que com a sua autorização, será gravada em formato áudio pelo investigador Francisco Nunes.

Esta investigação não apresenta quais riscos para o participante.

Os investigadores comprometem-se a garantir confidencialidade e uso exclusivo dos dados recolhidos no presente estudo. Garantem ainda que a identificação dos participantes não será tornada pública em nenhuma situação.

A participação neste estudo é voluntária, não havendo lugar ao pagamento de quaisquer contrapartidas. Em qualquer altura, poderá recusar participar neste estudo, sem qualquer tipo de consequências ou prejuízos, bastando para isso contactar o investigador responsável.

É ainda importante referir que este estudo foi aprovado pela Comissão de Ética para a Saúde do Centro Hospitalar de S. João – EPE.

Obrigado pela sua atenção.

Investigador responsável: Francisco Nunes
Instituição: Universidade Técnica de Viena
Telefone: 9196713XX
e-mail: francisco.nunes@igw.tuwien.ac.at

Figure C.2: Information sheet used in the observations.

DECLARAÇÃO DE CONSENTIMENTO

Considerando a "Declaração de Helsínquia" da Associação Médica Mundial
(Helsínquia 1964; Tóquio 1975; Veneza 1983; Hong Kong 1989; Somerset West 1996 e Edimburgo 2000)

"Estudo exploratório de observação em contexto de consulta de acompanhamento da doença de Parkinson

Eu, abaixo-assinado, (nome completo) -- --, declaro tendo compreendido a explicação que me foi fornecida acerca da investigação que se tenciona realizar. Foi-me ainda dada oportunidade de fazer as perguntas que julguei necessárias, e de todas obtive resposta satisfatória. Declaro ainda não ter participado em nenhum outro projeto de investigação durante esta consulta,

Tomei conhecimento de que, de acordo com as recomendações da Declaração de Helsínquia, a informação ou explicação que me foi prestada versou os objectivos, os métodos, os benefícios previstos, os riscos potenciais e o eventual desconforto. Além disso, foi-me afirmado que tenho o direito de recusar a todo o tempo a minha participação no estudo, sem que isso possa ter como efeito qualquer prejuízo na assistência que me é prestada.

Por estas razões, consinto que seja aplicado o método proposto pelo investigador.

Data: _____ / _____ / 2014

Assinatura do participante: _____

O Investigador responsável:

Nome: Francisco Maria Cruz Nunes

Assinatura: _____

Contacto: 9196713 ou francisco.nunes@igw.tuwien.ac.at

Figure C.3: Consent form used in the observations.

Description of mentioned self-care technologies

This appendix quickly describes the self-care technologies mentioned in this thesis. For each technology, Table D.1 documents: i) the name of the prototype or product; ii) the scientific reference or website of the application; and iii) a quick explanation of the technology components and how these are used. Some of the descriptions were imported from Nunes et al. (2015), while the largest part were added or rewritten. The descriptions offered in this appendix can be used as a reference sheet to get a glimpse of each technology while reading the thesis; or as an overview of the technologies that were considered in the analysis.

Name	Source	Condition	Technology and setting
ADMS	Toscos et al. (2012)	Diabetes	Children use blood glucose meter that sends measurements to the web and can be checked by their parents
AssistingIn-sulin*	Preuveneers and Berbers (2008)	Diabetes	Patients use a smartphone application that recommends insulin dosages based on the prediction of energy spending related with the location with predicted activity
AsthmaProbes*	Yun et al. (2010)	Asthma	Patients and carers use the Salud! system, desktop widget, peak flow meter, and indoor air quality sensor

Table D.1: Self-care technologies mentioned in the thesis. The * denotes fictional names because the studies did not name the technologies.

Name	Source	Condition	Technology
Beats Medical	https://itun.es/i6Yk7tQ	Parkinson's	Patients use an iOS application to remember about medication, as well as for exercising their fine motor skills, walking, and speech
Boundary-Work*	Aarhus and Ballegaard (2010)	Diabetes or cardiovascular	Patients use common blood glucose meters, blood-pressure monitors, and INR meters
BP@Home	Kusk et al. (2013)	Hypertension	Patients use a tablet and blood-pressure monitor (with noise and movement sensors) that sends measurements to the patient record
Caring~Web	Keaton et al. (2004)	Stroke (survivors)	Carers of persons that survived stroke send questions to a nurse on a Web platform, or to a mailing list of carers moderated by a nurse
CHAP	Mamykina et al. (2006)	Diabetes	Patients wore a watch that regularly measures blood glucose. They also reported activities, meals, and emotions with a desktop application
CKDManagement*	Sota et al. (2011)	Chronic kidney disease	Patients use the smartphone to visualise their blood tests and self-report symptoms
COPD-Therapy*	Taylor et al. (2011)	COPD	Patients attend physiotherapy sessions with a TV, set-top box, and webcam. Doctors use a desktop interface to broadcast instructions and accompany the patients' exercise
COPDTrainer	Spina et al. (2013)	COPD	Patients exercise while wearing a smartphone for example, on their wrist to get feedback
Cueing Swallowing*	McNaney et al. (2011)	Parkinson's	Patients wear a wrist device that vibrates at regular intervals to remind the patient to swallow saliva

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
CuPiD	Casamas-sima et al. (2013)	Parkinson's	Patients receive vocal feedback from their smartphone to improve posture and gait, based on data from wearable inertial sensors (shoes, lower trunk)
DAF Professional	https://itun.es/i6Ym4LZ	Parkinson's	Patients use iOS application that reproduces their voice after a short delay. The application enables the configuration of the delay, pitch, volume, and noise, and the idea is to help improve speech
DailyAppro-priation*	Storni (2010)	Diabetes, hypertension	Patients used common blood-pressure monitor or glucose meters
DialysisMa-chine*	Kilbourn (2010)	Chronic kidney disease	Patients use common dialysis machine
eDiary	Aarhus et al. (2009)	Diabetes T1	Patients use web application and smartphone to monitor condition. Doctors use the web application
Emotion-Mingle	Fuentes et al. (2014)	Cancer (survivors)	Mothers of children with cancer use a small display to check the status of other carers in their network to avoid isolation and distribute the care burden
eREHAB	Theodoros et al. (2006)	Parkinson's	Patients use a computer, headset microphone, and two webcams to engage in speech therapy sessions over the Internet. The doctor on the other end can send prompts and control the webcams
Food Quiz	Glasemann et al. (2010)	Diabetes T1	Patients play a smartphone game to learn counting carbohydrates
FOG cueing*	Bächlin et al. (2010)	Parkinson's	Patients wear tiny computer and inertial sensors to detect freezing of gait and automatically start auditory cueing in the earphones to improve walking

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
GaitAssist	Mazilu et al. (2014)	Parkinson's	Patients use a smartphone that triggers cueing feedback when freezing of gait (FOG) is detected by wearable inertial sensors. Exercises for reducing FOG are also supported
GoLearning-Bus	https://itun.es/i6Yb3Tj	Parkinson's	Patients use iOS application to learn about medical aspects of Parkinson's. The application includes information on symptoms, diagnosis, treatment, and presents some quizzes to assess what was learned
HeartPa-tients*	Grönvall and Verdezoto (2013)	Atherosclero-sis, hypertension	Patients use scales, blood-pressure monitors, pulse, and ECG devices. They enter the collected data into an online form that shares it with doctors, who analyse it and provide feedback to the patient.
HIVForum*	(Mo and Coulson, 2010)	HIV/AIDS	Patients use an online support group to share their health and life concerns
ICT-BTMS	Pinsker et al. (2008)	Diabetes	Patients enter measurements on smartphone application which uploads them to the web. Doctors use this data for analysis of evolution
iParkinsons	https://itun.es/i6YV5ZB	Parkinson's	Patients use iOS application that reproduces their voice after a short delay, with a slightly changed pitch, or together with background noise, as a way to help improve speech
Jaw Drop Toolkit	https://itun.es/i6YP5sg	Parkinson's	Patients play serious games to train voice and swallowing. While the game is played on an iPhone or iPad, doctors are expected to define the parameters of the training and evaluate the progress

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
Jog Falls	Nachman et al. (2010)	Diabetes T2	Patients wear sensors and use a smartphone application to track activities and food intake. Doctors monitor evolution in web application
Kinesia	Mera et al. (2012)	Parkinson's	Patients wear inertial sensors (in the wrist and finger) while performing specific movements in front of a desktop computer for reporting movement symptoms to doctors
LApp	McNaney et al. (2015)	Parkinson's	Patients wear a Google Glass device that monitors their speech level against a pre-defined level and cues them to speak louder when they go under that level
MAHI	Mamykina et al. (2008)	Diabetes	Patients use glucose meters, connected to a smartphone, to upload measurements to a web application, shared with an educator
mobileWAY	Jordan et al. (2013)	Dementia	Carers use mobile application to inform patients where they are at each moment. Patients receive information on a TV screen
MONARCA	Bardram et al. (2013)	Bipolar disease	Patients monitor condition with a smartphone or web application. Doctors track evolution and emergencies on web application
Montfort iTug	https://itun.es/i6Yk7ng	Parkinson's	Patients use an iOS device to track movement while performing the Timed Up and Go neurological assessment test. The data collected can be visualised in the device and is expected to be sent to doctors for further analysis

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
Motor-Cognitive VR*	Killane et al. (2015)	Parkinson's	Patients go through a virtual reality maze by stepping on a balance board and operating a Wiimote. At the same time, they perform the stroop test, to improve dual task capacity
myHealth-Pal	https://itun.es/i6SC9mf	Parkinson's	Patients use an iOS application to track and measure symptoms, and remind medication. The application can send data remotely to the doctor
myRecord	Andersen et al. (2011)	Cardiac arrhythmias	Patients use a web application for writing comments on the readings from their implantable device (ICD), exchange messages with doctors, and maintain an updated medication list
OneRing	https://itun.es/i6YV7Sj	Parkinson's	Patients wear a ring with movement sensors to monitor the status of the condition throughout the day. Collected data is sent to an iOS device that processes it, displays a visualisation of the day, and emails the data to the doctor to help improve treatment
ONESELF	Camerini et al. (2011)	Fibromyal-gia	The patient uses a web application for mimicking exercises, personalised to current issues
Parkinson's Central	https://itun.es/i6YP5QM	Parkinson's	Patients or carers use an iOS application to access information about symptoms, treatments, doctor visits, living well, and research, provided by the National Parkinson's Foundation
Parkinson's Diary	https://itun.es/i6SQ752	Parkinson's	Patients or carers use an iOS (or Android) application to track activities, feelings, and symptoms

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
Parkinson's Speech Aid	https://itun.es/i6YV6CL	Parkinson's	Patients use iOS application that reproduces their voice with a slight delay and pitch change for helping them improve speech. Headphones and microphone are required
Patient Innovation	Habicht et al. (2013)	Multiple chronic conditions	Patients or carers use an online community for sharing innovative technologies and strategies for dealing with issues of their conditions
Patients-LikeMe	Frost and Massagli (2008)	Multiple chronic conditions	Patients or carers use an online community for finding treatments used by similar patients. They can also use messages, online forums, or other tools for discussions with peers. People can also export their symptoms for discussions with doctors
PDApp	Serrano et al. (2014)	Parkinson's	Patients use an Android smartphone and inertial sensors to: i) automatically report symptoms to doctors; ii) record events to be analysed; and iii) receive medication reminders
pd-FIT	https://itun.es/i6Yb3jr	Parkinson's	Patients use an iOS application, together with a heart rate monitor and a cadence sensor, to perform exercise protocols and track evolution over time
PD Headline News	https://itun.es/i6Ym3Ky	Parkinson's	Patients use an iOS application to access the latest news about Parkinson's
PD Life	https://itun.es/i6SQ2Z2	Parkinson's	Patients or carers use an iOS application to track symptoms and receive reminders for their medication

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
PD Me	https://itun.es/i6YV2xf	Parkinson's	Patients use an iOS application to log symptoms or to measure balance. The resulting data can be visualised in plots
PD Me Tools	https://itun.es/i6YV2rB	Parkinson's	Patients use small games in iOS application to assess their cognitive function. The data collected can be visualised enabling the comparison between different episodes
PD Monitor & Commentary	https://itun.es/i6YV3fd	Parkinson's	Patients use iOS application to access a newsletter that summarises and explains recent research on Parkinson's
PDmove	https://itun.es/i6YV7fZ	Parkinson's	Patients play short games that enable them to exercise and track their fine motor skills. Doctors can use the collected data to adjust treatment
PersuasiveSens*	Chatterjee et al. (2012)	Diabetes T2	Patients receive weekly SMS and emails with recommendations based on their activities, tracked using home and wearable sensors
REMPARK	de Barros et al. (2013)	Parkinson's	The patient uses sensors that track symptoms and report them to doctors. REMPARK also includes medication reminders, calendar, and auditory cueing
RemoteLogCam	Güldenpfennig and Fitzpatrick (2013)	Cerebral palsy	Patients wear glove that detect spasms, providing haptic feedback and taking a picture with the smartphone for later reflection
RemoteReminiscence*	Yasuda et al. (2009)	Dementia	Patients attend reminiscence sessions with talking partners (of their social circle), and receive reminders, from a desktop application. Carers provide content for sessions

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
Report-Asthma*	Craven et al. (2013)	Asthma	Patients use an Android smartphone with sensors (oximeter, respiration flow, pulse) to report the disease state
Rides For Parkinson's	https://itun.es/i6YV6cJ	Parkinson's	Patients use iOS application to connect with volunteer drivers who might be willing to give them a ride
SCRUMP	Galna et al. (2014)	Parkinson's	Patients play specifically developed exercise games for balance and postural control. Game is projected onto a wall and movements tracked with the Microsoft Kinect
SMS reminders*	Keränen and Liikkanen (2013)	Parkinson's	Patients receive SMS messages reminding them to take the medication for Parkinson's
SPARK	Sharma et al. (2014)	Parkinson's	Patients use an Android smartphone and Pebble smartwatch to detect tremors, issues in speech, as well as self-report symptoms to doctors
Speak Better	https://itun.es/i6YV7pH	Parkinson's	Patients use an iOS application that displays text passages and visual cues to help set the pace of the reading and as a result of speech. Speech therapists are expected to guide the use of the application
SpeechOme-ter	Pervaiz and Patel (2014)	Parkinson's	Patients wear a Google Glass device that monitors their speech level and feedbacks them to speak louder when they approach the level of environment noise (as measured by the smartphone)
Speech Pacesetter	https://itun.es/i6YP548	Parkinson's	Patients use iOS application that displays text as well as visual cues to help set the pace of the reading. The idea is to help train the pace of the speech

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
Speech Tool	https://itun.es/i6YP5sG	Parkinson's	Patients use an iOS application that enables them to measure how loud they are. Patients can also train to achieve a specific speech volume
StudyMyTremor	https://itun.es/i6YV2m5	Parkinson's	Patients use an iOS application that enables them to measure their current tremor. The idea is to quantify tremor at different points and thus enable comparisons
Support-Team	Barish et al. (2014)	Post-Traumatic Stress Disorder	Patients and carers use smartphone application to self-report and answer questionnaires that are sent to doctors. Carers also answer questionnaires about them and the patient
Swallow Prompt	https://itun.es/i6YV2wW	Parkinson's	Patients use an iOS application that makes the smartphone vibrate at regular intervals to remind the patient to swallow saliva
Telehealth video-phones*	Buckley et al. (2004)	Stroke (survivors)	Carers of people who survived stroke use videophones to communicate with nurses regarding their self-care
Telephone CBT*	Dobkin et al. (2011)	Parkinson's	Patients with depression use the telephone to engage in remote individual cognitive behavioural therapy. Carers also engaged in the same therapy separately from the patients
TiY	Storni (2011)	Diabetes T1	Patients use an iPhone application to track parameters of their choice and identify patterns
TLC-Depression	Farzanfar et al. (2007)	Unipolar depression	Patients reports symptoms to telephony system, and use pillbox that monitors intake. Doctors receive alerting e-mails

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
TR_Meter	https://itun.es/i6YV7Kn	Parkinson's	Patients use an iOS application that enables them to measure their current tremor. The idea is to quantify and compare tremor at different points
VideoCare	Czaja et al. (2014)	Dementia	Carers use a Cisco videophone to communicate with a support group and to receive individual self-care advice from a nurse
Video Consultations*	Dorsey et al. (2010)	Parkinson's	Patients use laptop, webcam, microphone, and Polycom videoconference software, to attend remote consultations with a neurologist. Nurses are collocated with patients to help in the movement assessment and setting up the software
Video Recordings*	Marzinzik et al. (2012)	Parkinson's	Patients record videos of specific activities, such as finger tapping, or raising from a chair, using a computer and a camera, three times a day. After recording the videos, patients self-report their motor state and note their complaints. Doctors receive this information over the Internet and use it to adjust the patient's treatment. The resulting medication schedule is printed every morning in a printer at the patient's home
Virtual Consultations*	Samii et al. (2006)	Parkinson's	Patients use videoconference software to engage in remote consultations with a neurologist. Doctors control the webcam of patients and access their patient record. Together with the patient, there is a nurse or the primary care physician, and most of the times, a carer

(Table D.1 – continued from previous page)

Name	Source	Condition	Technology
Virtual Housecalls*	Dorsey et al. (2013)	Parkinson's	Patients use the videoconference software called Vidyo on their computer to engage in remote consultations with a neurologist
Voice Analyst	https://itun.es/i6YP27y	Parkinson's	Patients use an iOS application that analyses the pitch and volume of their voice in detail. Speech therapists are expected to guide the use of the application
Voice Game	Krause et al. (2013)	Parkinson's	Patients play a game by making loud voice sounds in front of a microphone. The game is projected to the wall
Wii Fit*	Pompeu et al. (2012)	Parkinson's	Patients play with the standard Wii Fit for motor and cognitive training
Wii with balance board*	Esculier et al. (2012)	Parkinson's	Patients play with Wii Fit (with balance board) and Wii Sports games on the Nintendo Wii to improve balance and mobility
WuppDi!	Assad et al. (2011)	Parkinson's	Patients play specifically developed exercise games for training motor skills. The movements are tracked using the PlayStation Eye camera and the game is projected on the wall
@Hand	Taylor et al. (2009)	Undefined long-term condition	Carers use application to monitor the evolution of vital signs and mood of the patient, as well as their own mood. Patients may be the ones tracking their data, and the overall objective is to enable better self-care. Concerning values are sent to doctors
@Point of Care	https://itun.es/i6Yk7fv	Parkinson's	Patients use iOS application to track medication, treatments, symptoms, and side-effects. Some data can be plotted in the device. Doctors are expected to co-analyse the data with patients in consultations

(Table D.1 – continued from previous page)

Bibliography

Aarhus, R. and Ballegaard, S. A. (2010). Negotiating boundaries: Managing disease at home. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '10, pages 1223–1232. ACM.

Aarhus, R., Ballegaard, S. A., and Hansen, T. R. (2009). The eDiary: Bridging home and hospital through healthcare technology. In *Proceedings of ECSCW 2009*, pages 63–83. Springer.

Abowd, G. D., Hayes, G. R., Kientz, J. A., Mamykina, L., and Mynatt, E. D. (2006). Challenges and opportunities for collaboration technologies for chronic care management. In *Proceedings of the The Human-Computer Interaction Consortium (HCIC 2006)*, pages 1–13.

Achey, M., Aldred, J. L., Aljehani, N., Bloem, B. R., Biglan, K. M., Chan, P., Cubo, E., Ray Dorsey, E., Goetz, C. G., Guttman, M., Hassan, A., Khandhar, S. M., Mari, Z., Spindler, M., Tanner, C. M., van den Haak, P., Walker, R., Wilkinson, J. R., on behalf of the International Parkinson, and Force, M. D. S. T. T. (2014). The past, present, and future of telemedicine for Parkinson's disease. *Movement Disorders*, 29(7):871–883.

ACM (1992). ACM code of ethics and professional conduct. http://www.acm.org/about/code-of-ethics.

Ahlskog, J. E. (2011). Does vigorous exercise have a neuroprotective effect in parkinson disease? *Neurology*, 77(3):288–294.

Akrich, M. (1992). The de-scription of technical objects. In Bijker, W. E. and Law, J., editors, *Shaping Technology/Building Society*, chapter 7, pages 205–224. The MIT Press.

Andersen, T., Bjørn, P., Kensing, F., and Moll, J. (2011). Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents. *International Journal of Medical Informatics*, 80(8):e112 – e126.

Anderson, R. M. and Funnell, M. M. (2000). Compliance and adherence are dysfunctional concepts in diabetes care. *The Diabetes Educator*, 26(4):597–604.

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K. A., and Straus, S. E. (2011). Personal health records: A scoping review. *Journal of the American Medical Informatics Association*, 18(4):515–522.

Arksey, H. (1994). Expert and lay participation in the construction of medical knowledge. *Sociology of Health & Illness*, 16(4):448–468.

Assad, O., Hermann, R., Lilla, D., Mellies, B., Meyer, R., Shevach, L., Siegel, S., Springer, M., Tiemkeo, S., Voges, J., Wieferich, J., Herrlich, M., Krause, M., and Malaka, R. (2011). Motion-based games for Parkinson's disease patients. In *Proceedings of the 10th International Conference on Entertainment Computing*, ICEC'11, pages 47–58. Springer-Verlag.

Attard, A. and Coulson, N. S. (2012). A thematic analysis of patient communication in Parkinson's disease online support group discussion forums. *Computers in Human Behavior*, 28(2):500–506.

Bächlin, M., Plotnik, M., Roggen, D., Maidan, I., Hausdorff, J., Giladi, N., and Troster, G. (2010). Wearable assistant for Parkinson's disease patients with the freezing of gait symptom. *IEEE Transactions on Information Technology in Biomedicine*, 14(2):436–446.

Ballegaard, S. A., Hansen, T. R., and Kyng, M. (2008). Healthcare in everyday life: Designing healthcare services for daily life. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '08, pages 1807–1816. ACM.

Bardram, J. E., Frost, M., Szántó, K., Faurholt-Jepsen, M., Vinberg, M., and Kessing, L. V. (2013). Designing mobile health technology for bipolar disorder: A field trial of the Monarca system. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '13, pages 2627–2636. ACM.

Barish, G., Lester, P., Saltzman, W. R., and Elbogen, E. (2014). Beyond sensors: Reading patients through caregivers and context. In *Proceedings of the 2014 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct Publication*, UbiComp '14 Adjunct, pages 1273–1277. ACM.

Barlow, J., Singh, D., Bayer, S., and Curry, R. (2007). A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions. *Journal of Telemedicine and Telecare*, 13(4):172–179.

Barlow, J., Wright, C., Sheasby, J., Turner, A., and Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling*, 48(2):177 – 187.

Ben-Shlomo, Y. and Kuh, D. (2002). A life course approach to chronic disease epidemiology: Conceptual models, empirical challenges and interdisciplinary perspectives. *International Journal of Epidemiology*, 31(2):285–293.

Bensink, M., Hailey, D., and Wootton, R. (2006). A systematic review of successes and failures in home telehealth: Preliminary results. *Journal of Telemedicine and Telecare*, 12:8–16.

Berardelli, A., Rothwell, J. C., Thompson, P. D., and Hallett, M. (2001). Pathophysiology of bradykinesia in Parkinson's disease. *Brain*, 124(11):2131–2146.

Berwick, D. M. (2009). What 'patient-centered' should mean: Confessions of an extremist. *Health Affairs*, 28(4):w555–w565.

Bettio, F. and Plantenga, J. (2004). Comparing care regimes in europe. *Feminist Economics*, 10(1):85–113.

Bodenheimer, T., Lorig, K., Holman, H., and Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *JAMA*, 288(19):2469–2475.

Bonnet, A. M., Jutras, M. F., Czernecki, V., Corvol, J. C., and Vidailhet, M. (2012). Non-motor symptoms in Parkinson's disease in 2012: Relevant clinical aspects. *Parkinson's Disease*, 2012.

Borkman, T. (1976). Experiential knowledge: A new concept for the analysis of self-help groups. *The Social Service Review*, pages 445–456.

Bramley, N. and Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology & Health*, 20(2):223–235.

Brouwer, W. B. F., van Exel, N. J. A., van de Berg, B., Dinant, H. J., Koopmanschap, M. A., and van den Bos, G. A. M. (2004). Burden of caregiving: Evidence of objective burden, subjective burden, and quality of life impacts on informal caregivers of patients with rheumatoid arthritis. *Arthritis Care & Research*, 51(4):570–577.

Bruckman, A. (2006). Teaching students to study online communities ethically. *Journal of Information Ethics*, Fall:82–95.

Buckley, K. M., Tran, B. Q., and Prandoni, C. M. (2004). Receptiveness, use and acceptance of telehealth by caregivers of stroke patients in the home. *Online journal of Issues in Nursing*, 9(3).

Buetow, S., Henshaw, J., Bryant, L., and O'Sullivan, D. (2010). Medication timing errors for Parkinson's disease: Perspectives held by caregivers and people with Parkinson's in New Zealand. *Parkinson's Disease*, 2010.

Cahill, J. (1998). Patient participation – a review of the literature. *Journal of Clinical Nursing*, 7(2):119–128.

Camerini, L., Giacobazzi, M., Boneschi, M., Schulz, P. J., and Rubinelli, S. (2011). Design and implementation of a web-based tailored gymnasium to enhance self-management of fibromyalgia. *User Modeling and User-Adapted Interaction*, 21(4-5):485–511.

Casamassima, F., Ferrari, A., Milosevic, B., Rocchi, L., and Farella, E. (2013). Wearable audio-feedback system for gait rehabilitation in subjects with Parkinson's disease. In *Proceedings of the 2013 ACM Conference on Pervasive and Ubiquitous Computing Adjunct Publication*, UbiComp '13 Adjunct, pages 275–278. ACM.

Chandak, A. and Joshi, A. (2015). Self-management of hypertension using technology enabled interventions in primary care settings. *Technology and Health Care*, 23(2):119–128.

Charlton, G. S. and Barrow, C. J. (2002). Coping and self-help group membership in Parkinson's disease: An exploratory qualitative study. *Health & Social Care in the Community*, 10(6):472–478.

Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. Rutgers University Press.

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Sage Publications Ltd.

Chatterjee, S., Byun, J., Pottathil, A., Moore, M. N., Dutta, K., and Xie, H. Q. (2012). Persuasive sensing: A novel in-home monitoring technology to assist elderly adult diabetic patients. In Bang, M. and Ragnemalm, E., editors, *Persuasive Technology. Design for Health and Safety*, volume 7284 of *Lecture Notes in Computer Science*, pages 31–42. Springer.

Chen, Y., Ngo, V., and Park, S. Y. (2013). Caring for caregivers: Designing for integrality. In *Proceedings of the 2013 Conference on Computer Supported Cooperative Work*, CSCW '13, pages 91–102. ACM.

Chiong-Rivero, H., Ryan, G. W., Flippen, C., Bordelon, Y., Szumski, N. R., Zesiewicz, T. A., Vassar, S., Weidmer, B., García, R. E., Bradley, M., and Vickrey, B. G. (2011). Patients' and caregivers' experiences of the impact of Parkinson's disease on health status. *Patient Related Outcome Measures*, 2011(2):57–70.

Cicutto, L., Brooks, D., and Henderson, K. (2004). Self-care issues from the perspective of individuals with chronic obstructive pulmonary disease. *Patient Education and Counseling*, 55(2):168 – 176.

Clark, N. M., Becker, M. H., Janz, N. K., Lorig, K., Rakowski, W., and Anderson, L. (1991). Self-management of chronic disease by older adults: A review and questions for research. *Journal of Aging and Health*, 3(1):3–27.

Clark, N. M., Nothwehr, F., Gong, M., Evans, D., Maiman, L. A., Hurwitz, M. E., Roloff, D., and Mellins, R. B. (1995). Physician-patient partnership in managing chronic illness. *Academic Medicine*, 70.

Conrad, P. (1985). The meaning of medications: Another look at compliance. *Social Science & Medicine*, 20(1):29 – 37.

194

Cools, R. (2006). Dopaminergic modulation of cognitive function-implications for L-DOPA treatment in Parkinson's disease. *Neuroscience & Biobehavioral Reviews*, 30(1):1 – 23.

Corbin, J. and Strauss, A. (1984). Collaboration: Couples working together to manage chronic illness. *Image: the Journal of Nursing Scholarship*, 16(4):109–115.

Corbin, J. M. and Strauss, A. (1988). *Unending Work and Care: Managing Chronic Illness at Home.* Jossey-Bass.

Craven, M. P., Selvarajah, K., Miles, R., Schnädelbach, H., Massey, A., Vedhara, K., Raine-Fenning, N., and Crowe, J. (2013). User requirements for the development of smartphone self-reporting applications in healthcare. In Kurosu, M., editor, *Human-Computer Interaction. Applications and Services*, volume 8005 of *Lecture Notes in Computer Science*, pages 36–45. Springer Berlin Heidelberg.

Cruz, J., Brooks, D., and Marques, A. (2014). Home telemonitoring effectiveness in COPD: A systematic review. *International Journal of Clinical Practice*, 68(3):369–378.

Czaja, S. J., Schulz, R., Perdomo, D., and Nair, S. N. (2014). The feasibility and efficacy of technology-based support groups among family caregivers of persons with dementia. In *Proceedings of the 14th International Conference, ICCHP 2014*, pages 455–458. Springer.

Daley, D., Deane, K., Hill, R., Myint, P., and Gray, R. (2015). Qualitative evaluation of adherence therapy in Parkinson's disease: A multidirectional model. *Patient Preference and Adherence*, pages 989–998.

Dalgaard, L., Grönvall, E., and Verdezoto, N. (2013). Accounting for medication particularities: Designing for everyday medication management. In *Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare, PervasiveHealth 2013*, pages 137–144.

Danholt, P. and Langstrup, H. (2012). Medication as infrastructure: Decentring self-care. *Culture Unbound*, 4:513–532.

de Barros, A. C., Cevada, J. a., Bayés, A., Alcaine, S., and Mestre, B. (2013). User-centred design of a mobile self-management solution for Parkinson's disease. In *Proceedings of the 12th International Conference on Mobile and Ubiquitous Multimedia*, MUM '13, pages 23:1–23:10. ACM.

de la Guía, E., Lozano, M. D., and Penichet, V. R. (2013). Cognitive rehabilitation based on collaborative and tangible computer games. In *Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare*, pages 389–392. ICST (Institute for Computer Sciences, Social-Informatics and Telecommunications Engineering).

de Lau, L. M. and Breteler, M. M. (2006). Epidemiology of Parkinson's disease. *The Lancet Neurology*, 5(6):525–535.

DelliFraine, J. L. and Dansky, K. H. (2008). Home-based telehealth: A review and meta-analysis. *Journal of Telemedicine and Telecare*, 14(2):62–66.

Dobkin, R. D., Menza, M., Allen, L. A., Tiu, J., Friedman, J., Bienfait, K. L., Gara, M. A., and Mark, M. H. (2011). Telephone-based cognitive-behavioral therapy for depression in Parkinson disease. *Journal of Geriatric Psychiatry and Neurology*, 24(4):206–214.

Dontje, M. L., de Greef, M. H. G., Speelman, A. D., van Nimwegen, M., Krijnen, W. P., Stolk, R. P., Kamsma, Y. P. T., Bloem, B. R., Munneke, M., and van der Schans, C. P. (2013). Quantifying daily physical activity and determinants in sedentary patients with Parkinson's disease. *Parkinsonism & Related Disorders*, 19(10):878–882.

Dorsey, E. R., Deuel, L. M., Voss, T. S., Finnigan, K., George, B. P., Eason, S., Miller, D., Reminick, J. I., Appler, A., Polanowicz, J., Viti, L., Smith, S., Joseph, A., and Biglan, K. M. (2010). Increasing access to specialty care: A pilot, randomized controlled trial of telemedicine for Parkinson's disease. *Movement Disorders*, 25(11):1652–1659.

Dorsey, E. R., Venkataraman, V., Grana, M. J., Bull, M. T., George, B. P., Boyd, C. M., Beck, C. A., Rajan, B., Seidmann, A., and Biglan, K. M. (2013). Randomized controlled clinical trial of "virtual house calls" for parkinson disease. *JAMA Neurology*, 70(5):565–570.

Dourish, P. (2003). The appropriation of interactive technologies: Some lessons from placeless documents. *Comput. Supported Coop. Work*, 12(4):465–490.

Dourish, P. (2006). Implications for design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '06, pages 541–550. ACM.

Dourish, P. (2007). Responsibilities and implications: Further thoughts on ethnography and design. In *Proceedings of the 2007 Conference on Designing for User eXperiences*, DUX '07, pages 25:2–25:16. ACM.

Dourish, P., Graham, C., Randall, D., and Rouncefield, M. (2010). Theme issue on social interaction and mundane technologies. *Personal and Ubiquitous Computing*, 14(3):171–180.

Drey, N., Mckeown, E., Kelly, D., and Gould, D. (2012). Adherence to antiparkinsonian medication: An in-depth qualitative study. *International Journal of Nursing Studies*, 49(7):863–871.

Edwards, M., Quinn, N., and Bhatia, K. (2008). *Parkinson's Disease and Other Movement Disorders (Oxford Specialist Handbooks in Neurology) with DVD*. Oxford University Press, USA.

196

Eisenberg, L. (1977). Disease and illness distinctions between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry*, 1(1):9–23.

Ekeland, A. G., Bowes, A., and Flottorp, S. (2011). Effectiveness of telemedicine: A systematic review of reviews. *International Journal of Medical Informatics*, 79:736–771.

EPDA (2011). Life with Parkinson's. Technical report, European Parkinson's Disease Association (EPDA). http://www.epda.eu.com/en/resources/life-with-parkinsons/.

Epstein, R. M., Alper, B. S., and Quill, T. E. (2004). Communicating evidence for participatory decision making. *JAMA*, 291(19):2359–2366.

Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology & Human Values*, 20(4):408–437.

Esculier, J.-F., Vaudrin, J., Bériault, P., Gagnon, K., and Tremblay, L. E. (2012). Home-based balance training programme using Wii Fit with balance board for Parkinsons's disease: A pilot study. *Journal of Rehabilitation Medicine*, 44:144–150.

European Commission (2012). The 2012 ageing report: Economic and budgetary projections for the EU27 member states (2010-2060). Technical report, European Commission, European Commission (DG ECFIN) and the Economic Policy Committee (AWG). http://dx.doi.org/10.2765/19991.

Farzanfar, R., Frishkopf, S., Friedman, R., and Ludena, K. (2007). Evaluating an automated mental health care system: Making meaning of human-computer interaction. *Computers in Human Behavior*, 23(3):1167 – 1182.

Febretti, A., Lopez, K. D., Stifter, J., Johnson, A. E., Keenan, G., and Wilkie, D. (2014). Evaluating a clinical decision support interface for end-of-life nurse care. In *Proceedings of the Extended Abstracts of the 32Nd Annual ACM Conference on Human Factors in Computing Systems*, CHI EA '14, pages 1633–1638. ACM.

Fine, M. and Glendinning, C. (2005). Dependence, independence or inter-dependence? revisiting the concepts of 'care' and 'dependency'. *Ageing and Society*, 25:601–621.

Fitzpatrick, G. (2011). New challenges for health IT - Design fit for life. In *Proceedings of the Conference on Design 4 Health 2011*, pages 121–135.

Fitzpatrick, G. and Ellingsen, G. (2013). A review of 25 years of CSCW research in healthcare: Contributions, challenges and future agendas. *Computer Supported Cooperative Work (CSCW)*, 22(4-6):609–665.

Forsyth, G. L., Delaney, K. D., and Gresham, M. L. (1984). Vying for a winning position: Management style of the chronically ill. *Research in Nursing & Health*, 7(3):181–188.

Frauenberger, C., Rauhala, M., and Fitzpatrick, G. (2017). In-Action Ethics. *Interacting with Computers*, 29(2):220.

Frost, H. J. and Massagli, P. M. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another's data. *Journal of Medical Internet Research*, 10(3):e15.

Fuentes, C., Hernandez, C., Escobedo, L., Herskovic, V., and Tentori, M. (2014). Promoting self-reflection of social isolation through persuasive mobile technologies: The case of mother caregivers of children with cancer. *International Journal of Human-Computer Interaction*, 30(10):802–814.

Funnell, M. and Anderson, R. M. (2000). The problem with compliance in diabetes. *JAMA*, 284(13):1709.

Gago, M., an José Luís Quental Mota Vieira, J. F., Rosas, M. J., Simões, R., Guedes, L. C., Outeiro, T. F., Carneiro, G., Neutel, D., Rosa, M. M., Mendes, A., Marques, N., Domingos, J., Batista, M. F. A., and Pereira, A. G. D. (2014). Manual para pessoas com parkinson [Manual for people with Parkinson's]. www.cnscampus.com/uploads/files/Manual_para_Pessoas_com_Parkinson.pdf.

Gallagher, D. A., Lees, A. J., and Schrag, A. (2010). What are the most important nonmotor symptoms in patients with Parkinson's disease and are we missing them? *Movement Disorders*, 25(15):2493–2500.

Galna, B., Jackson, D., Schofield, G., McNaney, R., Webster, M., Barry, G., Mhiripiri, D., Balaam, M., Olivier, P., and Rochester, L. (2014). Retraining function in people with Parkinson's disease using the microsoft kinect: Game design and pilot testing. *Journal of NeuroEngineering and Rehabilitation*, 11(1):1–12.

Garcia, A. C., Standlee, A. I., Bechkoff, J., and Cui, Y. (2009). Ethnographic approaches to the internet and computer-mediated communication. *Journal of Contemporary Ethnography*, 38(1):52–84.

Gentles, S. J., Lokker, C., and McKibbon, K. A. (2010). Health information technology to facilitate communication involving health care providers, caregivers, and pediatric patients: A scoping review. *Journal of Medical Internet Research*, 12(2):e22.

Gibson, G. (2013). *Men's experiences of living with Parkinson's Disease*. PhD thesis, University of Liverpool.

Gibson, G. (2016). 'Signposts on the journey'; Medication adherence and the lived body in men with Parkinson's disease. *Social Science & Medicine*, 152:27–34.

Given, B. A., Given, C. W., and Kozachik, S. (2001). Family support in advanced cancer. *CA: A Cancer Journal for Clinicians*, 51(4):213–231.

Glasemann, M., Kanstrup, A. M., and Ryberg, T. (2010). Making chocolate-covered broccoli: Designing a mobile learning game about food for young people with diabetes. In *Proceedings of the 8th ACM Conference on Designing Interactive Systems*, DIS '10, pages 262–271. ACM.

Glaser, B. G. (1992). *Basics of grounded theory analysis*. Sociology Press.

Glaser, B. G. and Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Glasgow, R. E. and Anderson, R. M. (1999). In diabetes care, moving from compliance to adherence is not enough. Something entirely different is needed. *Diabetes Care*, 22(12):2090–2092.

Godinho, C., Domingos, J., Cunha, G., Santos, A. T., Fernandes, R. M., Abreu, D., Gonçalves, N., Matthews, H., Isaacs, T., Duffen, J., Al-Jawad, A., Larsen, F., Serrano, A., Weber, P., Thoms, A., Sollinger, S., Graessner, H., Maetzler, W., and Ferreira, J. J. (2016). A systematic review of the characteristics and validity of monitoring technologies to assess Parkinson's disease. *Journal of NeuroEngineering and Rehabilitation*, 13(1):24.

Godolphin, W. (2009). Shared decision-making. *Healthcare Quarterly*, 12(Sp):e186–e190.

Goffman, E. (1963). *Stigma: Notes on The Management of Spoiled Identity*. Prentice Hall, 1st edition.

Goodman, N. and Elgin, C. (1988). *Reconceptions in Philosophy and Other Arts and Sciences*. Hackett Readings in Philosophy. Hackett Publishing Company.

Goodwin, V. A., Richards, S. H., Taylor, R. S., Taylor, A. H., and Campbell, J. L. (2008). The effectiveness of exercise interventions for people with Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders*, 23(5):631–640.

Gorst, S. L., Armitage, C. J., Brownsell, S., and Hawley, M. S. (2014). Home telehealth uptake and continued use among heart failure and chronic obstructive pulmonary disease patients: A systematic review. *Annals of Behavioral Medicine*, 48(3):323–336.

Grönvall, E. and Verdezoto, N. (2013). Beyond self-monitoring: Understanding non-functional aspects of home-based healthcare technology. In *Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, UbiComp '13, pages 587–596. ACM.

Grosset, K. A., Bone, I., and Grosset, D. G. (2005). Suboptimal medication adherence in Parkinson's disease. *Movement Disorders*, 20(11):1502–1507.

Grosset, K. A. and Grosset, D. G. (2007). Effect of educational intervention on medication timing in Parkinson's disease: A randomized controlled trial. *BMC Neurology*, 7(1):1–6.

Guba, E. G. and Lincoln, Y. S. (1989). *Fourth Generation Evaluation*. Sage Publications.

Güldenpfennig, F. and Fitzpatrick, G. (2013). A monitoring device as assistive lifestyle technology: Combining functional needs with pleasure. In *Proceedings of the 4th Augmented Human International Conference*, AH '13, pages 190–193. ACM.

Haahr, A., Kirkevold, M., Hall, E. O., and Østergaard, K. (2011). Living with advanced Parkinson's disease: A constant struggle with unpredictability. *Journal of Advanced Nursing*, 67(2):408–417.

Habicht, H., Oliveira, P., and Shcherbatiuk, V. (2013). User innovators: When patients set out to help themselves and end up helping many. *Die Unternehmung*, 66(3):277–294.

Haehner, A., Hummel, T., and Reichmann, H. (2011). Olfactory loss in Parkinson's disease. *Parkinson's Disease*, 2011.

Hamilton, D. W. (2014). Shared decision making asks patients to share their aims and values for treatment. *BMJ*, 348.

Hardisty, A. R., Peirce, S. C., Preece, A., Bolton, C. E., Conley, E. C., Gray, W. A., Rana, O. F., Yousef, Z., and Elwyn, G. (2011). Bridging two translation gaps: A new informatics research agenda for telemonitoring of chronic disease. *International Journal of Medical Informatics*, 80(10):734–744.

Hartzler, A. and Pratt, W. (2011). Managing the personal side of health: How patient expertise differs from the expertise of clinicians. *Journal of Medical Internet Research*, 13(3):e62.

Heath, C. and Luff, P. (1991). Collaborative activity and technological design: Task coordination in London underground control rooms. In Bannon, L., Robinson, M., and Schmidt, K., editors, *Proceedings of the Second European Conference on Computer-Supported Cooperative Work ECSCW '91*, pages 65–80. Springer Netherlands.

Holman, H. and Lorig, K. (2000). Patients as partners in managing chronic disease. *BMJ*, 320(7234):526–527.

Huang, V. W., Reich, K. M., and Fedorak, R. N. (2014). Distance management of inflammatory bowel disease: Systematic review and meta-analysis. *World Journal of Gastroenterology: WJG*, 20(3):829–842.

Hughes, J. A., Randall, D., and Shapiro, D. (1992). Faltering from ethnography to design. In *Proceedings of the 1992 ACM Conference on Computer-supported Cooperative Work*, CSCW '92, pages 115–122. ACM.

Huh, J. and Ackerman, M. S. (2012). Collaborative help in chronic disease management: Supporting individualized problems. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work*, CSCW '12, pages 853–862. ACM.

Hutchinson, H., Mackay, W., Westerlund, B., Bederson, B. B., Druin, A., Plaisant, C., Beaudouin-Lafon, M., Conversy, S., Evans, H., Hansen, H., Roussel, N., and Eiderbäck, B. (2003). Technology probes: Inspiring design for and with families. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '03, pages 17–24. ACM.

ISA (2001). Code of ethics. http://www.isa-sociology.org/about/isa_code_of_ethics.htm.

Ishihara, L. S., Cheesbrough, A., Brayne, C., and Schrag, A. (2007). Estimated life expectancy of Parkinson's patients compared with the UK population. *Journal of Neurology, Neurosurgery & Psychiatry*, 78(12):1304–1309.

Jankovic, J. (2008). Parkinson's disease: Clinical features and diagnosis. *Journal of Neurology, Neurosurgery & Psychiatry*, 79(4):368–376.

Jordan, P., Silva, P. A., Nunes, F., and Oliveira, R. (2013). mobileWAY – A system to reduce the feeling of temporary lonesomeness of persons with dementia and to foster inter-caregiver collaboration. In *46th Hawaii International Conference on System Sciences (HICSS)*, pages 2474–2483.

Kaplan, S. M. and Fitzpatrick, G. (1997). Designing support for remote intensive-care telehealth using the Locales framework. In *Proceedings of the 2nd Conference on Designing Interactive Systems: Processes, Practices, Methods, and Techniques*, DIS '97, pages 173–184. ACM.

Kasper, D., Fauci, A., Hauser, S., Longo, D., Jameson, J., and Loscalzo, J. (2015). *Harrison's principles of internal medicine*. Mcgraw-hill, 19 edition.

Keaton, L., Pierce, L., Steiner, V., Lance, K., Masterson, M., Rice, M., and Smith, J. (2004). An e-rehabilitation team helps caregivers deal with stroke. *The Internet Journal of Allied Health Sciences and Practice*, 2(4):17.

Keränen, T. and Liikkanen, S. (2013). Medication reminder service for mobile phones: An open feasibility study in patients with Parkinson's disease. *Telemedicine and e-Health*, 19(11):888–890.

Kilbourn, K. (2010). Weaving the machine. In *Proceedings of the 4th International Conference on Pervasive Computing Technologies for Healthcare, PervasiveHealth 2010*, pages 1–6.

Killane, I., Fearon, C., Newman, L., McDonnell, C., Waechter, S., Sons, K., Lynch, T., and Reilly, R. (2015). Dual motor-cognitive virtual reality training impacts dual-task performance in freezing of gait. *IEEE Journal of Biomedical and Health Informatics*, 19(6):1855–1861.

Kozinets, R. V. (2002). The field behind the screen: Using netnography for marketing research in online communities. *Journal of Marketing Research*, 39(1):61–72.

Krause, M., Smeddinck, J., and Meyer, R. (2013). A digital game to support voice treatment for Parkinson's disease. In *Proceedings of CHI '13 Extended Abstracts on Human Factors in Computing Systems*, CHI EA '13, pages 445–450. ACM.

Kusk, K., Nielsen, D. B., Thylstrup, T., Rasmussen, N. H., Jørvang, J., Pedersen, C. F., and Wagner, S. (2013). Feasibility of using a lightweight context-aware system for facilitating reliable home blood pressure self-measurements. In *Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare, PervasiveHealth 2013*, pages 236–239. ICST.

Langstrup, H. (2008). Making connections through online asthma monitoring. *Chronic Illness*, 4(2):118–126.

Langstrup, H. (2013). Chronic care infrastructures and the home. *Sociology of Health & Illness*, 35(7):1008–1022.

Lau, A. Y., Arguel, A., Dennis, S., Liaw, S.-T., and Coiera, E. (2015). "Why didn't it work?" lessons from a randomized controlled trial of a web-based personally controlled health management system for adults with asthma. *Journal of Medical Internet Research*, 17(12).

Lawn, S. and Schoo, A. (2010). Supporting self-management of chronic health conditions: Common approaches. *Patient Education and Counseling*, 80(2):205 – 211.

Leopold, N. A., Polansky, M., and Hurka, M. R. (2004). Drug adherence in Parkinson's disease. *Movement Disorders*, 19(5):513–517.

Lofland, J., Snow, D. A., Anderson, L., and Lofland, L. H. (2005). *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis*. Wadsworth Publishing, 4th edition.

Lorig, K. (1993). Self-management of chronic illness: A model for the future. *Generations*, 17(3):11–14.

Lowe, P., Powell, J., Griffiths, F., Thorogood, M., and Locock, L. (2009). "Making it all normal": The role of the internet in problematic pregnancy. *Qualitative Health Research*, 19(10):1476–1484.

Lundell, S., Holmner, A., Rehn, B., Nyberg, A., and Wadell, K. (2015). Telehealthcare in COPD: A systematic review and meta-analysis on physical outcomes and dyspnea. *Respiratory Medicine*, 109(1):11 – 26.

Mamykina, L., Mynatt, E., Davidson, P., and Greenblatt, D. (2008). MAHI: Investigation of social scaffolding for reflective thinking in diabetes management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '08, pages 477–486. ACM.

Mamykina, L., Mynatt, E. D., and Kaufman, D. R. (2006). Investigating health management practices of individuals with diabetes. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '06, pages 927–936. ACM.

Mamykina, L., Nakikj, D., and Elhadad, N. (2015). Collective sensemaking in online health forums. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, CHI '15, pages 3217–3226. ACM.

Marr, J. (1991). The experience of living with Parkinson's disease. *Journal of Neuroscience Nursing*, 23(5):325–329.

Marsden, C. D. (1994). Parkinson's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 57(6):672–681.

Martin, S. C. (2012). *Couples coping with Parkinson's disease: Implications for the patient, partner, and relationship.* PhD thesis, University of Illinois at Urbana-Champaign.

Marzinzik, F., Wahl, M., Doletschek, C. M., Jugel, C., Rewitzer, C., and Klostermann, F. (2012). Evaluation of a telemedical care programme for patients with Parkinson's disease. *Journal of Telemedicine and Telecare*, 18(6):322–327.

Massano, J. and Bhatia, K. P. (2012). Clinical approach to Parkinson's disease: Features, diagnosis, and principles of management. *Cold Spring Harbor Perspectives in Medicine*, 2(6):1–15.

Masten, D. L. and Plowman, T. M. (2003). Digital ethnography: The next wave in understanding the consumer experience. *Design Management Journal (Former Series)*, 14(2):75–81.

Maturana, H. (1988). Ontology of Observing: The Biological Foundations of Self Consciousness and the Physical Domain of Existence. In *Conference workbook: Texts in cybernetics*. Retrieved January 2014 from http://ada.evergreen.edu/~arunc/texts/cybernetics/oo/old/oo.pdf.

Maturana, H. and Pörksen, B. (1985). *Del Ser al Hacer [From Being to Doing].* Comunicaciones Noreste ltda.

Maturana, H. and von Foerster, H. (1998). Truth and Trust: Maturana and Von Foerster. American Society for Cybernetics and Change Management Systems, directed by Pille Bunnell, available at: http://youtu.be/Mc6YFUoPWSI.

Maturana, H. R. (1990). *Biologia de la Cognicion y Epistemologia [Biology of cognition and epistemology].* Ediciones Universidad de La Frontera.

Maturana, H. R. and Varela, F. (1992). *The Tree of Knowledge: The Biological Roots of Human Understanding.* Shambhala Publications, revised edition.

May, C. R., Finch, T. L., Cornford, J., Exley, C., Gately, C., Kirk, S., Jenkings, K. N., Osbourne, J., Robinson, A. L., Rogers, A., Wilson, R., and Mair, F. S. (2011). Integrating telecare for chronic disease management in the community: What needs to be done? *BMC Health Services Research*, 11(1):131.

Mazilu, S., Blanke, U., Hardegger, M., Tröster, G., Gazit, E., and Hausdorff, J. M. (2014). GaitAssist: A daily-life support and training system for Parkinson's disease patients with freezing of gait. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '14, pages 2531–2540. ACM.

McLaughlin, D., Hasson, F., Kernohan, W. G., Waldron, M., McLaughlin, M., Cochrane, B., and Chambers, H. (2011). Living and coping with Parkinson's disease: Perceptions of informal carers. *Palliative Medicine*, 25(2):177–182.

McNaney, R., Lindsay, S., Ladha, K., Ladha, C., Schofield, G., Ploetz, T., Hammerla, N., Jackson, D., Walker, R., Miller, N., and Olivier, P. (2011). Cueing swallowing in Parkinson's disease. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '11, pages 619–622. ACM.

McNaney, R., Poliakov, I., Vines, J., Balaam, M., Zhang, P., and Olivier, P. (2015). LApp: A speech loudness application for people with Parkinson's on Google Glass. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, CHI '15, pages 497–500. ACM.

Mentis, H. M., Shewbridge, R., Powell, S., Fishman, P., and Shulman, L. (2015). Being seen: Co-interpreting Parkinson's patient's movement ability in deep brain stimulation programming. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, CHI '15, pages 511–520. ACM.

Mera, T. O., Heldman, D. A., Espay, A. J., Payne, M., and Giuffrida, J. P. (2012). Feasibility of home-based automated Parkinson's disease motor assessment. *Journal of Neuroscience Methods*, 203(1):152 – 156.

Miller, A. D., Mishra, S. R., Kendall, L., Haldar, S., Pollack, A. H., and Pratt, W. (2016). Partners in care: Design considerations for caregivers and patients during a hospital stay. In *Proceedings of the ACM 2016 Conference on Computer Supported Cooperative Work*, CSCW '16. ACM.

Mo, P. K. and Coulson, N. S. (2010). Empowering processes in online support groups among people living with hiv/aids: A comparative analysis of 'lurkers' and 'posters'. *Computers in Human Behavior*, 26(5):1183 – 1193.

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Routledge.

Mol, A. and Law, J. (2004). Embodied action, enacted bodies: The example of hypoglycaemia. *Body & Society*, 10(2-3):43–62.

Mol, A., Moser, I., and Pols, J. (2010). Care: putting practice into theory. In Mol, A., Moser, I., and Pols, J., editors, *Care in Practice: On Tinkering in Clinics, Homes and Farms*, pages 7–25. transcript Verlag, Bielefeld.

Mort, M., Roberts, C., and Callén, B. (2013). Ageing with telecare: Care or coercion in austerity? *Sociology of Health & Illness*, 35(6):799–812.

Munteanu, C., Molyneaux, H., Moncur, W., Romero, M., O'Donnell, S., and Vines, J. (2015). Situational ethics: Re-thinking approaches to formal ethics requirements for Human-Computer Interaction. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*, CHI '15, pages 105–114. ACM.

Nachman, L., Baxi, A., Bhattacharya, S., Darera, V., Deshpande, P., Kodalapura, N., Mageshkumar, V., Rath, S., Shahabdeen, J., and Acharya, R. (2010). Jog falls: A pervasive healthcare platform for diabetes management. In *Proceedings of the 8th International Conference on Pervasive Computing*, Pervasive'10, pages 94–111. Springer-Verlag.

Nakagawa-Kogan, H., Garber, A., Jarrett, M., Egan, K. J., and Hendershot, S. (1988). Self-management of hypertension: Predictors of success in diastolic blood pressure reduction. *Research in Nursing & Health*, 11(2):105–115.

Newman, M. W., Lauterbach, D., Munson, S. A., Resnick, P., and Morris, M. E. (2011). It's not that i don't have problems, i'm just not putting them on facebook: Challenges and opportunities in using online social networks for health. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work*, CSCW '11, pages 341–350. ACM.

Ni, T., Karlson, A. K., and Wigdor, D. (2011). Anatonme: Facilitating doctor-patient communication using a projection-based handheld device. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '11, pages 3333–3342. ACM.

Nielsen, K. D. (2015). Involving patients with e-health: The dialogic dynamics of information filtration work. *Science and Technology Studies*, 28:29–52.

Nunes, F., Andersen, T., and Fitzpatrick, G. (2017). The agency of patients and carers in medical care and self-care technologies for interacting with clinicians. *Health Informatics Journal (in press)*.

Nunes, F. and Fitzpatrick, G. (2015). Self-care technologies and collaboration. *International Journal of Human Computer Interaction*, 31(12):869–881.

Nunes, F., Verdezoto, N., Fitzpatrick, G., Kyng, M., Grönvall, E., and Storni, C. (2015). Self-care technologies in HCI: Trends, tensions, and opportunities. *ACM Transactions on Computer Human Interaction*, 22(6):33:1–33:45.

Nunes, J. A., Ferreira, P., and Queirós, F. (2014). Taking part: Engaging knowledge on health in clinical encounters. *Social Science & Medicine*, 123:194 – 201.

OECD (2015). Health at a glance 2015: OECD indicators. Technical report, OECD. http://10.1787/health_glance-2015-en.

Ong, L., de Haes, J., Hoos, A., and Lammes, F. (1995). Doctor-patient communication: A review of the literature. *Social Science & Medicine*, 40(7):903 – 918.

Oudshoorn, N. (2008). Diagnosis at a distance: The invisible work of patients and healthcare professionals in cardiac telemonitoring technology. *Sociology of Health & Illness*, 30(2):272–288.

Palen, L. and Aaløkke, S. (2006). Of pill boxes and piano benches: "home-made" methods for managing medication. In *Proceedings of the 2006 Conference on Computer Supported Cooperative Work*, CSCW '06, pages 79–88. ACM.

Paré, G., Jaana, M., and Sicotte, C. (2007). Systematic review of home telemonitoring for chronic diseases: The evidence base. *Journal of the American Medical Informatics Association*, 14(3):269–277.

Paré, G., Moqadem, K., Pineau, G., and St-Hilaire, C. (2010). Clinical effects of home telemonitoring in the context of diabetes, asthma, heart failure and hypertension: A systematic review. *Journal of Medical Internet Research*, 12(2):e21.

Parsons, T. (1951). *The Social System*. Routledge.

PDF (2014). Prescription medications. http://www.pdf.org/parkinson_prescription_meds.

Pervaiz, M. and Patel, R. (2014). Speechometer: Heads-up monitoring to improve speech clarity. In *Proceedings of the 16th International ACM SIGACCESS Conference on Computers & Accessibility*, ASSETS '14, pages 319–320. ACM.

Pinder, R. (1990). *The Management of Chronic Illness: Patient and Doctor Perspectives on Parkinson's Disease*. Macmillan Press.

Pinsker, M., Schindler, K., Morak, J., Hayn, D., Kastner, P., Riedl, M., Ludvik, B., and Schreier, G. (2008). Experiences using mobile phones as patient-terminal for telemedical home care and therapy monitoring of patients suffering from chronic diseases. In Miesenberger, K., Klaus, J., Zagler, W., and Karshmer, A., editors, *Computers Helping People with Special Needs*, volume 5105 of *Lecture Notes in Computer Science*, pages 1305–1312. Springer Berlin Heidelberg.

Piras, E. M. and Zanutto, A. (2010). Prescriptions, x-rays and grocery lists. Designing a Personal Health Record to support (the invisible work of) health information management in the household. *Computer Supported Cooperative Work (CSCW)*, 19(6):585–613.

Piras, E. M. and Zanutto, A. (2014). "One day it will be you who tells us doctors what to do!". Exploring the "personal" of PHR in paediatric diabetes management. *Information Technology & People*, 27(4):421–439.

Poewe, W. (2008). Non-motor symptoms in Parkinson's disease. *European Journal of Neurology*, 15:14–20.

Polisena, J., Tran, K., Cimon, K., Hutton, B., McGill, S., Palmer, K., and Scott, R. E. (2010). Home telehealth for chronic obstructive pulmonary disease: A systematic review and meta-analysis. *Journal of Telemedicine and Telecare*, 16(3):120–127.

Pols, J. (2012). *Care at a Distance: On the Closeness of Technology.* Amsterdam University Press.

Pols, J. (2014). Knowing patients: Turning patient knowledge into science. *Science, Technology & Human Values*, 39(1):73–97.

Pompeu, J. E., dos Santos Mendes, F. A., da Silva, K. G., Lobo, A. M., de Paula Oliveira, T., Zomignani, A. P., and Piemonte, M. E. P. (2012). Effect of nintendo Wii^{TM}-based motor and cognitive training on activities of daily living in patients with Parkinson's disease: A randomised clinical trial. *Physiotherapy*, 98(3):196 – 204.

Preece, J. (1999). Empathic communities: Balancing emotional and factual communication. *Interacting with Computers*, 12(1):63 – 77.

Preuveneers, D. and Berbers, Y. (2008). Mobile phones assisting with health self-care: A diabetes case study. In *Proceedings of the 10th International Conference on Human Computer Interaction with Mobile Devices and Services*, MobileHCI '08, pages 177–186. ACM.

Prior, L. (2003). Belief, knowledge and expertise: The emergence of the lay expert in medical sociology. *Sociology of Health & Illness*, 25(3):41–57.

Randell, R., Wilson, S., and Fitzpatrick, G. (2010). Editorial – Evaluating new interactions in health care: Challenges and approaches. *International Journal of Human-Computer Interaction*, 26(5):407–413.

Riegler, A. (2005). Editorial. The Constructivist Challenge. *Constructivist Foundations*, 1:1–8.

Riggare, S. and Unruh, K. T. (2015). Patients organise and train doctors to provide better care. *BMJ*, 351.

Samii, A., Ryan-Dykes, P., Tsukuda, R. A., Zink, C., Franks, R., and Nichol, W. P. (2006). Telemedicine for delivery of health care in Parkinson's disease. *Journal of Telemedicine and Telecare*, 12(1):16–18.

Sandaunet, A.-G. (2008). A space for suffering? Communicating breast cancer in an online self-help context. *Qualitative Health Research*, 18(12):1631–1641.

Sanders, C., Rogers, A., Bowen, R., Bower, P., Hirani, S., Cartwright, M., Fitzpatrick, R., Knapp, M., Barlow, J., Hendy, J., Chrysanthaki, T., Bardsley, M., and Newman, S. P. (2012). Exploring barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial: A qualitative study. *BMC Health Services Research*, 12(1):1–12.

Schaafsma, J. D., Balash, Y., Gurevich, T., Bartels, A. L., Hausdorff, J. M., and Giladi, N. (2003). Characterization of freezing of gait subtypes and the response of each to levodopa in Parkinson's disease. *European Journal of Neurology*, 10(4):391–398.

Schorch, M., Wan, L., Randall, D. W., and Wulf, V. (2016). Designing for those who are overlooked: Insider perspectives on care practices and cooperative work of elderly informal caregivers. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*, CSCW '16, pages 785–797. ACM.

Schrag, A. (2004). Psychiatric aspects of Parkinson's disease. *Journal of Neurology*, 251(7):795–804.

Seale, C. (1999). Quality in qualitative research. *Qualitative Inquiry*, 5(4):465–478.

Seiler, S., Perleth, B., Gasser, T., Ulm, G., Oertel, W., and Ellgring, H. (1992). Partnership and depression in Parkinson's disease. *Behavioural neurology*, 5(2):75–81.

Serrano, J., Thoms, A., and Weber, P. (2014). Patients initiated timeline marking of events in Parkinson's disease: Visualization of time correlation between patients marked events and acquired data from sensors. In Schmorrow, D. and Fidopiastis, C., editors, *Foundations of Augmented Cognition. Advancing Human Performance and Decision-Making through Adaptive Systems*, volume 8534 of *Lecture Notes in Computer Science*, pages 325–334. Springer International Publishing.

Sharma, V., Mankodiya, K., De La Torre, F., Zhang, A., Ryan, N., Ton, T., Gandhi, R., and Jain, S. (2014). Spark: Personalized parkinson disease interventions through synergy between a smartphone and a smartwatch. In Marcus, A., editor, *Design, User Experience, and Usability. User Experience Design for Everyday Life Applications and Services*, volume 8519 of *Lecture Notes in Computer Science*, pages 103–114. Springer International Publishing.

Shoor, S. and Lorig, K. R. (2002). Self-care and the doctor-patient relationship. *Medical Care*, 40(4):II–40–II–44.

Solimeo, S. (2009). *With Shaking Hands: Aging with Parkinson's Disease in America's Heartland*. Rutgers University Press.

Sota, Y., Yamamoto, K., Hirakawa, M., Doi, S., and Yamamoto, Y. (2011). Support of self-management for chronic kidney failure patients. In *Proceedings of the 2011 Visual Information Communication - International Symposium*, VINCI '11, pages 6:1–6:7. ACM.

Speelman, A. D., van de Warrenburg, B. P., van Nimwegen, M., Petzinger, G. M., Munneke, M., and Bloem, B. R. (2011). How might physical activity benefit patients with Parkinson disease? *Nat Rev Neurol*, 7(9):528–534.

Spina, G., Huang, G., Vaes, A., Spruit, M., and Amft, O. (2013). COPDTrainer: A smartphone-based motion rehabilitation training system with real-time acoustic feedback. In *Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, UbiComp '13, pages 597–606. ACM.

Spradley, J. P. (1980). *Participant observation.* Holt, Rinehart and Winston.

Stoessl, A. J. and Rivest, J. (1999). Differential diagnosis of parkinsonism. *Canadian Journal of Neurological Sciences*, 26:S1–S4.

Storni, C. (2010). Multiple forms of appropriation in self-monitoring technology: Reflections on the role of evaluation in future self-care. *International Journal of Human-Computer Interaction*, 26(5):537–561.

Storni, C. (2011). Complexity in an uncertain and cosmopolitan world. Rethinking personal health technology in diabetes with the Tag-it-Yourself. *PsychNology Journal*, 9(2):165–185.

Storni, C. (2014). Diabetes self-care in-the-wild: Design challenges for personal health record systems and self-monitoring technologies. *Information Technology & People*, 27(4):397–420.

Storni, C. (2015a). A manifesto for epistemological empowerment in chronic disease self care. In Bihanic, D., editor, *Empowering Users through Design*, pages 267–279. Springer International Publishing.

Storni, C. (2015b). Patients' lay expertise in chronic self-care: A case study in type 1 diabetes. *Health Expectations*, 18(5):1439–1450.

Storni, C. and Bannon, L. J. (2012). Towards the design of truly patient-centred infrastructures: A socio-technical approach to self-care. In Chilamkurti, N., editor, *Health Informatics: An Adaptive Communication Technology for Future Healthcare.* Nova Science Publishers.

Strauss, A., Fagerhaugh, S., Suczek, B., and Wiener, C. (1985). *Social Organization of Medical Work.* University of Chicago Press.

Strauss, A. L. and Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques.* Sage, 2nd edition.

Suchman, L. (1987). *Plans and situated actions.* Cambridge University Press.

Suchman, L. (2009). Agencies in technology design: Feminist reconfigurations. www.informatik.uni-bremen.de/soteg/gict2009/proceedings/GICT2009_Suchman.pdf.

Taylor, A., Godden, D., Aitken, A., Colligan, J., and Wilson, R. (2011). Delivering group-based services to the home via the internet: Maximising clinical and social benefits. In *Proceedings of the 5th International Conference on Pervasive Computing Technologies for Healthcare, PervasiveHealth 2011*, pages 384–388.

Taylor, A., Wilson, R., and Agamanolis, S. (2009). Supporting carers in their caring role through design. In *Proceedings of CHI '09 Extended Abstracts on Human Factors in Computing Systems*, CHI EA '09, pages 3985–3990. ACM.

Theodoros, D. G., Constantinescu, G., Russell, T. G., Ward, E. C., Wilson, S. J., and Wootton, R. (2006). Treating the speech disorder in Parkinson's disease online. *Journal of Telemedicine and Telecare*, 12(suppl 3):88–91.

Thordardottir, B., Nilsson, M. H., Iwarsson, S., and Haak, M. (2014). "You plan, but you never know" – Participation among people with different levels of severity of Parkinson's disease. *Disability and Rehabilitation*, 36(26):2216–2224.

Toscos, T., Connelly, K., and Rogers, Y. (2012). Best intentions: Health monitoring technology and children. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '12, pages 1431–1440. ACM.

Tröster, A. (2011). Cognitive Impairment - Parkinson's Disease Foundation (PDF). http://www.pdf.org/en/cognitive_impairment_pd.

UK, P. (2014). Apomorphine. https://www.parkinsons.org.uk/sites/default/files/publications/download/english/fs26_apomorphine_0.pdf.

United Nations (2015). World population ageing 2015. Technical report, United Nations, Department of Economic and Social Affairs, Population Division. http://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf.

Unruh, K. T. and Pratt, W. (2008). The invisible work of being a patient and implications for health care: "[the doctor is] my business partner in the most important business in my life, staying alive.". *Ethnographic Praxis in Industry Conference Proceedings*, 2008(1):40–50.

Van Den Eeden, S. K., Tanner, C. M., Bernstein, A. L., Fross, R. D., Leimpeter, A., Bloch, D. A., and Nelson, L. M. (2003). Incidence of Parkinson's disease: Variation by age, gender, and race/ethnicity. *American Journal of Epidemiology*, 157(11):1015–1022.

van der Eijk, M., Faber, M. J., Post, B., Okun, M. S., Schmidt, P., Munneke, M., and Bloem, B. R. (2015). Capturing patients' experiences to change Parkinson's disease care delivery: a multicenter study. *Journal of Neurology*, 262(11):2528–2538.

van der Eijk, M., Faber, M. J., Shamma, S. A., Munneke, M., and Bloem, B. R. (2011). Moving towards patient-centered healthcare for patients with Parkinson's disease. *Parkinsonism & Related Disorders*, 17(5):360–364.

van der Eijk, M., Faber, M. J., Ummels, I., Aarts, J. W. M., Munneke, M., and Bloem, B. R. (2012). Patient-centeredness in PD care: Development and validation of a patient experience questionnaire. *Parkinsonism & Related Disorders*, 18(9):1011–1016.

van Nimwegen, M., Speelman, A. D., Hofman-van Rossum, E. J. M., Overeem, S., Deeg, D. J. H., Borm, G. F., van der Horst, M. H. L., Bloem, B. R., and Munneke, M. (2011). Physical inactivity in Parkinson's disease. *Journal of Neurology*, 258(12):2214–2221.

von Glasersfeld, E. (1991). Knowing without metaphysics: Aspects of the radical constructivist position. In Steier, F., editor, *Research and reflexivity*, pages 12–29. Sage London.

Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., Schaefer, J., and Bonomi, A. (2001). Improving chronic illness care: Translating evidence into action. *Health Affairs*, 20(6):64–78.

Walther, J. B. (2002). Research ethics in internet-enabled research: Human subjects issues and methodological myopia. *Ethics and Information Technology*, 4(3):205–216.

Weintraub, D., Papay, K., and Siderowf, A. (2013). Screening for impulse control symptoms in patients with de novo Parkinson disease: A case-control study. *Neurology*, 80(2):176–180.

Wilson, P. M., Kendall, S., and Brooks, F. (2007). The expert patients programme: A paradox of patient empowerment and medical dominance. *Health & Social Care in the Community*, 15(5):426–438.

Worth, H. (1997). Self management in COPD: One step beyond? *Patient Education and Counseling*, 32, Supplement 1(0):S105 – S109.

Wressle, E., Engstrand, C., and Granérus, A.-K. (2007). Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living. *Australian Occupational Therapy Journal*, 54(2):131–139.

Wu, K., Politis, M., and Piccini, P. (2009). Parkinson disease and impulse control disorders: A review of clinical features, pathophysiology and management. *Postgraduate Medical Journal*, 85(1009):590–596.

Xu, X., Theng, Y.-L., Li, J., and Phat, P. T. (2016). Investigating effects of exergames on exercise intentions among young-old and old-old. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems*, pages 2961–2968. ACM.

Yasuda, K., Kuwahara, N., and Morimoto, K. (2009). Remote reminiscence talking and scheduling prompter for individuals with dementia using video phone. In Stephanidis, C., editor, *Universal Access in Human-Computer Interaction. Addressing Diversity*, volume 5614 of *Lecture Notes in Computer Science*, pages 429–438. Springer Berlin Heidelberg.

Yun, T.-J., Jeong, H. Y., Lee, H. R., Arriaga, R., and Abowd, G. (2010). Assessing asthma management practices through in-home technology probes. In *4th International Conference on Pervasive Computing Technologies for Healthcare, PervasiveHealth 2010*, pages 1–9.

Zahodne, L. B. and Fernandez, H. H. (2008). A review of the pathophysiology and treatment of psychosis in Parkinson's disease. *Drugs & aging*, 25(8):665–682.

Zesiewicz, T. A., Sullivan, K. L., and Hauser, R. A. (2006). Nonmotor symptoms of Parkinson's disease. *Expert Rev Neurother*, 6(12):1811–22.

Zhou, X., Sun, S., and Yang, J. (2014). Sweet home: Understanding diabetes management via a chinese online community. In *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems*, CHI '14, pages 3997–4006. ACM.