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Self-Care Technologies and Collaboration

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The self-management of a chronic condition is a collaborative activity, performed by patients and carers. However, to date, self-care technologies have been mostly designed for individual use. This article uses a case study of people living with Parkinson's disease to (a) illustrate how patients and carers collaborate in self-management, (b) discuss the reasons why self-care technology is designed for individual use, and (c) explore the implications of recognizing collaborations for the design of self-care technologies. This work is based on a qualitative study with interviews and observations with people living with Parkinson's. The analysis illustrates how people living with Parkinson's collaborate in self-care to build a good life. In particular, it exemplifies how the complex interplay of actions and of patients and carers enables the different self-care activities to take place. To further integrate self-care technology in everyday life, designers need to consider collaborations when studying the context, conceptualizing a technology, and planning an evaluation.

1. INTRODUCTION

Chronic conditions are medical conditions that have no cure or definitive treatment. Care of people with chronic conditions is focused on creating a good quality of life for as long as possible (Mol, 2008). There are many different chronic conditions, including diabetes, hypertension, dementia, and Parkinson's disease. The latter was the focus of our fieldwork. Chronic conditions can be quite challenging for both patients and carers. Some of the challenges include dealing with symptoms, facing disabilities, understanding and coping with complex medication schemes, and obtaining useful medical advice (Wagner et al., 2001). The condition may also have an emotional impact and force radical lifestyle changes. These challenges encourage patients and carers to self-care, that is, to manage the condition by themselves. Self-care refers to the activities that people living with a chronic condition (patients and carers[1]) undertake to manage the condition outside of institutionalized or professional care and as part of their everyday life. This is in complement to, but different from, the clinical care undertaken by healthcare professionals (Fitzpatrick, 2011; Randell, Wilson, & Fitzpatrick, 2010). It includes activities such as 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, Wright, Sheasby, Turner, & Hainsworth, 2002).

Self-care technology has the potential to improve the day-to-day life of people living with chronic conditions. Previous studies have shown that self-care technology can help patients learn about their condition (Mamykina, Mynatt, Davidson, & Greenblatt, 2008), monitor disease signs and symptoms (Bardram et al., 2013), and explore treatment adaptations (Aarhus, Ballegaard, & Hansen, 2009). Existing technologies have helped patients and carers in a number of ways; however, the design of these has been mostly for individual use (of either patients or carers), neglecting the collaborations that happen in self-care. This focus on individual use, as we later explain, may be the result of embodying one of two strong discourses in the medical domain that see self-care as solely managed by patients, or carers.

In this article we argue that self-care technologies should enable patients and carers to collaborate in self-care, as they do in everyday life. Drawing on our fieldwork with people living with Parkinson's, we present ways in which patients and carers collaboratively achieve their self-care in everyday life. Considering self-care as a collaborative process has important consequences for the ways in which we conceive and design technological solutions. This is illustrated in the implications for design we present in this article.

Our study extends the current understanding of self-care technologies by showing ways in which people living with Parkinson's (patient and carers) collaboratively build self-care and adapt everyday arrangements in order to create a meaningful life. This work is relevant for designers, researchers, and practitioners working with self-care technologies or in the broader of self-care.

2. BACKGROUND: COLLABORATION IN SELF-CARE AND THE INDIVIDUAL FOCUS OF TECHNOLOGY

Healthcare is a highly collaborative field. Collaborations happen at multiple levels and take place in clinics, hospitals, and even the home (Strauss, Fagerhaugh, Suczek, & Wiener,

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[1] In this article we use the word *patient* to identify people who have at least one chronic condition and the word *carer* for those involved in caring for patients outside of an institutionalized setting. We recognize that being a patient or a carer are not the only roles in which people engage, however, we use these terms for clarity and brevity.

1985). In this article, we focus on the collaborations between patients and carers, in the context of self-managing a chronic condition in everyday life. 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 & Strauss, 1984). This division of work is flexible, changing in the face of progression of their condition or the emergence of unexpected life events. Moreover, the collaboration is based on acceptance of the chronic condition and a mutual commitment to its management.

Our fieldwork with people living with Parkinson's disease[2] aligns with previous work as per Corbin and Strauss (1984), showing self-care as a highly collaborative endeavor. Patients and carers living with Parkinson's act together, for example, to ensure that the ill body moves to its best, that the condition is well accepted, and that the day-to-day life fulfills expectations and aspirations. However, even though the self-care of Parkinson's is highly collaborative, existing self-management technologies are largely individual and designed for patients. The orientation for individual use can be observed in three ways. First, *technologies present themselves as being designed for patients.* In most cases, web pages, manuals, and research articles make explicit the expected users of a specific technology. In the case of Parkinson's, technologies tend to be designed for patients (see, e.g., GaitAssist,[3] REMPARK,[4] SCRUMP[5]). Second, most *technologies are designed to be stand-alone,* not communicating with other devices or systems. As a consequence of this, collaborations tend to be reduced to physically sharing the device with others (see, e.g., PD Life,[6] Parkinson's Diary[7]). Third, the *methods chosen in many studies tend to focus on patients only.* Carers tend not to be included in the conceptualisation, design, and or evaluation of self-care technologies (see, e.g., Cueing Swallowing,[8] Lapp,[9] Voice Game[10]).

The argument about individual self-care technologies also holds for other chronic conditions. There are multiple examples of technologies that seem to have been designed for patients to use in isolation from (informal) carers (see, e.g., blood pressure monitors,[11] blood glucose meters,[12] BP@Home,[13] COPDTrainer,[14] eDiary,[15] Food Quiz,[16] myRecord,[17] MONARCA,[18] RemoteLogCam,[19] MAHI,[20] TiY[21]). We also find numerous examples of technologies for carers that do not account for collaborations with patients (see, e.g., CareNet Display,[22] Caring∼Web,[23] EmotionMingle,[24] Portal Monitor,[25] telehealth videophones for carers,[26] TOPIC,[27] @Hand[28]). Collaborations in self-care technologies are usually restricted to connecting patients with their clinicians (see, e.g., eDiary, myRecord, MONARCA, REMPARK), or with other patients, for example, in web forums.[29] Rarely do we find technology that has focused on helping patients and carers self-manage their condition together (see, e.g., mobileWAY,[30] and the design probes by Wallace et al., 2013). Technologies for children with chronic conditions are one exception in which finding collaboration is common (see, e.g., ADMS,[31] and the technology probes in Yun, Jeong, Lee, Arriaga, & Abowd, 2010), acknowledging the impossibility of parents to control every detail of the condition, and the ability of children to start taking more active roles in their condition.

The focus on technologies for individuals is probably the result of embodying one of two discourses in the medical

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[2] Parkinson's disease is a progressive degenerative neurological condition, characterized by a number of motor symptoms, such as tremor, slowness of movement, rigidity, and gait impairment, as well as nonmotor symptoms, like depression, pain and sleep disturbances (Marsden, 1994; Massano & Bhatia, 2012).

[3] GaitAssist is described in Mazilu et al. (2014).

[4] REMPARK is described in de Barros, Cevada, Bayés, Alcaine, and Mestre (2013).

[5] SCRUMP is described in McNaney, Balaam, et al. (2015).

[6] PD Life is an iOS application available at https://itunes.apple.com/gb/app/pd-life/id430413808.

[7] Parkinson's Diary is an Android or iOS application available at https://play.google.com/store/apps/details?id=com.fiec.pd_v1 or https://itunes.apple.com/gb/app/parkinsons-diary/id720019439.

[8] Cueing Swallowing (fictional name, as the study does not name the prototype) is described in McNaney et al. (2011).

[9] LApp is described in McNaney, Poliakov, et al. (2015).

[10] Voice Game (fictional name, as the study does not name the prototype) is described in Krause, Smeddinck, and Meyer (2013).

[11] Blood pressure monitors are discussed in Grönvall and Verdezoto (2013) and Storni (2010).

[12] Blood glucose meters are discussed in Aarhus and Ballegaard (2010) and Storni (2010).

[13] BP@Home is described in Kusk et al. (2013).

[14] COPDTrainer is described in Spina, Huang, Vaes, Spruit, and Amft (2013).

[15] eDiary is described in Aarhus et al. (2009).

[16] Food Quiz is described in Glasemann, Kanstrup, and Ryberg (2010).

[17] myRecord is described in Andersen, Bjørn, Kensing, and Moll (2011).

[18] MONARCA is described in Bardram et al. (2013).

[19] RemoteLogCam is described in Güldenpfennig & Fitzpatrick, (2013).

[20] MAHI is described in Mamykina et al. (2008).

[21] TiY is described in Storni (2011).

[22] CareNet Display is described in Consolvo et al. (2004).

[23] Caring∼Web is described in Keaton et al. (2004).

[24] EmotionMingle is described in Fuentes, Hernandez, Escobedo, Herskovic, and Tentori (2014).

[25] Portal Monitor is described in Duncan, Camp, and Hazelwood (2009).

[26] Telehealth videophones for carers are discussed in Buckley, Tran, and Prandoni (2004).

[27] TOPIC is described in Breskovic, De Carvalho, Schinkinger, and Tellioğlu (2013).

[28] @Hand is described in Taylor, Wilson, and Agamanolis (2009).

[29] Web forums are discussed in Mo and Coulson (2010) and Newman, Lauterbach, Munson, Resnick, and Morris (2011).

[30] mobileWAY is described in Jordan, Silva, Nunes, and Oliveira (2013).

[31] ADMS is described in Toscos, Connelly, and Rogers (2012).

domain that inadvertently characterize self-care as solely managed either by patients or by carers. These discourses seem to be well accepted in the medical area, turning attention away from more collaborative approaches to self-care. The first discourse puts patients in the center of the analysis and assumes they do all the self-care. The second discourse focuses on carers and supposes they are in charge of individually managing care. These discourses are presented in the next subsections. We do not aim to be comprehensive in covering the literature, but rather illustrate these different narratives.

2.1. Care as a Patient's Endeavor

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 of self-management in the medical literature as with 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, p. 178)

Here, patients are individually managing their conditions. They are the ones observing the condition, addressing the symptoms, managing their behavior, and adjusting their emotional responses to the condition. The collaboration of carers is absent from the definition. Sometimes we are told that self-care is not an individual activity, in recognition of the influence of other patients (Pols, 2014), clinicians (Unruh & Pratt, 2008), or technologies (Pols, 2012), but carers are not included. Carers are thought to provide only support. A similar narrative can be found in medical literature on chronic conditions (e.g., Wagner et al., 2001), patient education (e.g., Worth, 1997), and sociology of health (e.g., Clark et al., 1991), usually connected with the study of conditions including heart disease, asthma, chronic obstructive pulmonary disease, diabetes, or Parkinson's.

This discourse emerged in the United States for good reasons, as part of a trend to question established authority (Shoor & Lorig, 2002). In this specific case, the authority of the doctor in the doctor–patient relationship. Clinicians 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.

This narrative also permeated policy documents and actions. The "Chronic Disease Self-Management Program" from the USA and "Expert Patients Program" from the UK are examples of such (Vadiee, 2012). Underlying these political actions are usually efforts to reduce costs of healthcare systems; however, the message conveyed to the public is usually about emancipation, empowerment, control, and choice (Mol, 2008; Storni, 2010). In these programs, the reference to carers is scarce, and often simply related with providing social contact or support (e.g., World Health Organization, 1983).

2.2. Care as a Carer's Endeavor

The second discourse considers 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 of care in the literature, 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 & Plantenga, 2004, p. 86)

Here, care is provided pro bono to relatives, in our 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. In addition, literature also focuses on the issues or the burden of providing care (e.g., Pinto, Holanda, Medeiros, Mota, & Pereira, 2007).

We can find this narrative in medical studies about chronic conditions (e.g., Brouwer et al., 2004; Given, Given, & Kozachik, 2001), sociology of aging (e.g., Fine & Glendinning, 2005), and even other areas, such as economics (e.g., Bettio & Plantenga, 2004). The contexts that have been studied include dementia, cancer, and stroke.

This discourse on care[32] also emerged for good reasons, as a contribution of feminist academics who tried to make unpaid work by women become more visible and understood (Fine & Glendinning, 2005). Their agenda had not only research aims but also activist aspirations to influence political decision making, which might be one of the reasons why this literature spanned so many different areas.

2.3. Why Is There a Separation?

One could argue that these two discourses come from the conditions that are studied. According to this argument, researchers who studied self-care of very independent patients focused on patients, and the others focused on carers where patients were more dependent and so foregrounded the carer role. It is probably part of the reason, but we see a number of conditions appearing in both discourses (e.g., diabetes; Langa

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[32] Care in this part of the literature is, many times, defined broadly encompassing health-related tasks, as well as other tasks of home work.

et al., 2002; Mol, 2009), cancer (Given et al, 2001; Unruh & Pratt, 2008), and chronic obstructive pulmonary disease (Pinto, Holanda, Medeiros, Mota, & Pereira 2007; Pols, 2012). A more likely explanation is that researchers from both sides were trying to call attention to specific aspects in self-care. In the literature centered on patients, the focus was on making patients independent from the control of their doctor. In the carers' literature, the focus was showing the work of women providing care, so the focus was on the carers.

These separate discourses are also reflected in the technologies designed to support self-care, which gives an idea that collaboration is not taking place. These discourses have their importance in calling attention to important aspects of self-care, but if we focus on only one part of self-management, we are not really able to see the complete picture. For this reason, if technology aims to fit everyday life, it is important to understand the collaborations and mutual adaptations of patients and carers in their self-care and the implications of these different types of technology support.

3. METHODS

This work emerged from a qualitative study based on interviews and observations with people living with Parkinson's. We were studying the everyday practices of people living with the condition and were surprised to observe numerous collaborations taking place between patients and carers. We followed this lead further, and it became a strong theme in our grounded theory analysis.

During our study, we interviewed nine patients and eight carers.[33] The interviews were semistructured and iteratively modified as the analysis progressed. The participants[34] were recruited through a local chapter of the Portuguese Association of Parkinson's Patients in an urban town. They had very diverse backgrounds but joined each other every week for two physiotherapy sessions. All patients were older than 60 and retired either because of the disease or soon before it was diagnosed. All interviewed carers but one were retired and had a very active role in the self-care of the condition. In most cases participants were interviewed in the association's premises, but we also visited two in their homes. The interviews were audio-recorded, totaling 14 hr.

The interviews were enriched by observations at an outpatient neurology clinic of a central hospital, which enabled us to further test our emerging theories and reshape the analysis to fit the situations of these new participants.[35] The observation was held in two moments: in the waiting room and in the medical consultation room. In the waiting room, we did participant observation. We met the patients and carers, informed them about the study, obtained consent to observe the medical consultation, and asked some questions about their everyday life and the disease. Their answers were captured by field notes. In the consultation room, we used nonparticipant observation. In total we participated in 12 appointments[36] with patients in very diverse phases of the disease, from patients diagnosed months before to patients living with the disease for more than 15 years. The patients were usually accompanied. Only one person came by himself to the appointment, whereas the others were accompanied by their adult children (six), partners (four), or by a sister (one). The carers actively participated in the appointment. The conversations in the consultation were audio-recorded, totaling about 5 hr.

The participants in the study were presented with the objectives of the study and volunteered to participate. In the case of interviews, participants provided consent for their participation. In the case of observations, we received permission from the ethical committee of the institution where we conducted the study, which was approved without further change requests. We also had written consent given by the patient, or the carer, when writing was an issue. There were two exceptions, in which patients preferred to give only verbal consent.

The audio recorded during the interviews and observations was transcribed and analyzed for common themes using grounded theory (Charmaz, 2006). The analysis occurred concurrently with the interviews and observations, shaping how the fieldwork evolved. As the fieldwork progressed, codes were added, renamed, removed, or rearranged to match the categories suggested by the participants' accounts as they were added. The coding process was supported by Scrivener[37] and was performed by the first author and discussed with the second. Parallel to coding, memos were also written. Furthermore, the quotes used in this article were translated from Portuguese to English and verified by native speakers of both languages.

In approaching this study, we used a constructivist lens. As researchers, we are deeply involved in the research we do. We choose problems to explain and methods to apply; we derive conclusions from our (own) observation and reflection. Having this in mind, in this work we did not attempt to remove ourselves from the study; rather we consider ourselves (researchers) to be a determinant part of the conclusions made. To ensure the conclusions portrayed the self-care practices of our population, we confronted multiple perspectives involved in care and compared each new case with all others. The conclusions of the work are also situated. They are the result of an iterative interpretation shaped by the particular population we interviewed and observed, the literature we reviewed, and our previous experience. For this reason, we do not aim to "generalize" the findings

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[33] We interviewed a carer recently widowed. The remaining carers were related to patients who were also interviewed.

[34] Participants from the interviews are named according to a specific template. IP1 refers to the interviewed Patient 1, whereas IP2_C1 refers to the first carer of Patient 2.

[35] The participants of the observation sessions were different from the ones in the interviews. There is one exception in which one interviewed patient attended the medical consultation on one day we were making observations.

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

[37] Scrivener is a writing software, available at http://www.literatureandlatte.com/scrivener.php

beyond this context. We believe that our analysis unveils relevant ideas about self-care, but the application of these findings to other groups is to be explored by future work.

4. SELF-CARE AS A COLLABORATION

In this section we unpack the self-care work for people living with Parkinson's. Using examples from our fieldwork, we show the complexity and diversity of the self-care work patients and carers are engaged in, as well as how collaborations take place during this process. We do not aim to be thorough in our description of how these people self-manage, but rather we provide an overview of how their self-care can be seen as collaborative.

4.1. Collaborating to Achieve Care

Patients and carers collaborate in every care activity that can be considered to be part of self-care (Figure 1). Barlow et al. (2002) argued that self-care usually entails four main activities: acting on symptoms, managing treatment, dealing with psychological and physical consequences, and performing lifestyle changes. Our analysis shows that patients and carers collaborate in all such activities listed by Barlow and colleagues. In the next sections we visit each of these activities demonstrating how patients and carers are collaborating to achieve them.

Acting on symptoms: At medical consultations. In a progressive disease like Parkinson's, the symptoms are likely to remain the same for some months or years, but every couple of months, patients visit their specialist doctor to reanalyze their situation or make changes to treatment. In the meanwhile, fluctuations are likely to occur, for a variety of reasons.

We argue that patients and carers act on symptoms in two situations in particular when having medical consultations and when experiencing fluctuations. In the medical consultations, they collaborate with the doctor to address recent changes, and when having fluctuations, they try to act to reduce the symptoms to their "normal" state.

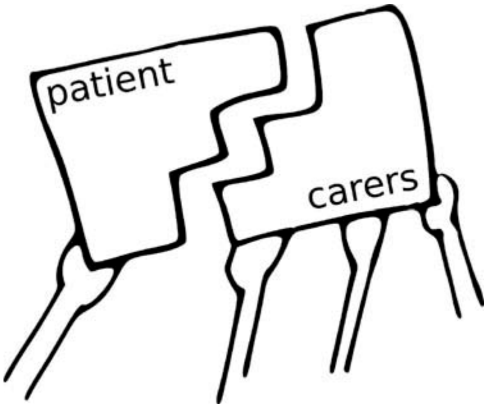

FIG. 1. Self-care is collaboratively built by the patient and carers in their everyday life.

FIG. 2. During consultations, patients and carers discuss with the clinician their disease state and their current 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.

Medical consultations are separated by a couple of months depending on the stability of the disease evolution. During the consultation, people living with Parkinson's comment on their everyday lives and activities that have became harder since the last appointment. The clinicians, typically neurologists, listen to them, analyze the movement of the patient, and provide treatment adjustment suggestions based on their experience with other patients (Figure 2). Both patients and carers participate in the discussions.[38] They verbalize what they feel or observe and try to discuss things that seem weird to them. Patients and carers have different perspectives. Whereas patients feel the symptoms in their body, carers can only observe the external signs of symptoms.

> OP1: "I think I [my body] did not like missing the Pramipexole [medication] . . ."
> OP_Cl: "I think that in those days that she had the reduced dose of Pramipexole, she was shaking more . . . "

The patient felt worse, in general, because as the medication was not enough, her overall symptoms became stronger. To the carer, however, this was experienced as an observable change, noticing a more evident tremor. This shows the different perspectives they bring to the consultation. However, their individual contributions are not as important as the gathering together of the different perspectives. It is the discussion across these perspectives during the appointment about what is challenging and what could be adjusted that leads to appropriate treatment changes.

Acting on symptoms: When fluctuations happen. The other case in which we see a direct action on the symptoms is when there are fluctuations. Fluctuations are moments in which

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[38] It is not common to find patients who go to the appointments by themselves. In the group of people we interviewed and observed, only two (out of 22) went alone to the doctor.

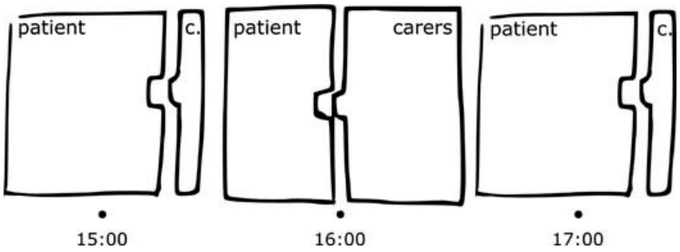

FIG. 3. Fluctuations are likely to require adjustments in self-care, as patients will have their abilities restricted.

patients have stronger symptoms (Figure 3). There are a number of factors that can cause such fluctuations; these include medication wearing off, a change to cold weather, or becoming worried about different situations.

> OP5: "If I do things in a relaxed way, without getting nervous, I can do everything. At my speed, I can do it. But if I get nervous, then . . . "

If patients are able to become calmer, then they find that their activities will start being easier. To become calmer, however, patients may need to do some distracting activity, usually related with movement. Sometimes, patients do not realize they are worrying too much, or overthinking an issue. At these times, carers are likely to collaborate with them to help them calm down. Some of the carers are very active in this. One carer told us that she would ask her husband to perform some housework when she saw that he was becoming like this, so that he would distract himself and move a bit. Another carer would get ready to go for a walk and then ask her husband to join her. Others were more subtle, not showing that they noticed the fluctuation but keeping an eye on how it evolved to see if they should act in some way.

In addressing fluctuations, one could think that carers lead, because they proactively motivate, and sometimes push, patients to exercise. However, this analysis strips self-care from an important component, which is that patients actually benefit from the exercise. If the carer was not able to motivate the patient to exercise, self-care might not happen. So collaboration in this case is in the ability of the carer and the patient to coordinate their actions and reactions that make exercise happen, and therefore address a negative symptom, thus creating a better life for the both of them.

Managing treatment. Medication usually consists of a number of different pills to be taken at different times during the day. The medication is strong in counteracting the disease symptoms but wears off after some hours, so patients usually take a mixture of different pills at specific moments of the day to keep the effect of the medication lasting the whole day.

Our participants had distinct ways of dealing with medication, but they 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 reminding them about the medication, but only through occasional reminders and more in a support role. In the second situation, carers had a greater participation. Patients were still the ones who were taking care of medication, but carers needed to remind them often, as otherwise they would forget it. 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. It is interesting that, 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.

Reminding about medication can happen in quite different ways, but it seems that patients and carers collaborate in all of them. Either through occasional reminders or more systematic actions, the interplay of their actions ensures that the medication is taken on time so that the symptoms are well controlled and the impact of the symptoms on their life minimized.

Managing physical consequences. Parkinson's also affects the ability of patients to move around easily, particularly because of balance issues and gait impairments. This means that the progression, or fluctuations, of the disease are likely to disable patients from performing some activities with more autonomy. When that happens, carers are likely to participate more. To illustrate these collaborative adaptations, we start with an example in which the carer works together with the patient to enable her to cook.

> 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 . . . "

The carer is enabling adaptation to the physical disability. An activity that is not possible to perform autonomously without risk can now be performed with his help. The fine motor issues of the disease and the gait problems are compensated for by the carer's modest cooking abilities and his attention to preventing a fall.

The adaptation to the physical consequences is not always achieved with patients and carers working together; sometimes the carer replaces the patient in performing an activity.

> IP3: "Sometimes at noon after eating I have to lay down for a little while. Only after that I feel better in my head. And many times when I wake up, my husband has already done the dishes for me."

This excerpt documents how the patient and carer adapted to the fatigue symptom of the disease. On the days when the patient does not feel well, the carer takes over the activity of doing the dishes.

These adaptations mirror the mundane yet critical ways in which patients and carers collaborate to manage the physical consequences of the condition. When analyzed out of context, cooking or doing the dishes may seem like individual actions that carers do. However, when considered in the context of self-care, these activities become deliberate actions to adapt to and manage the consequences of living with the condition. The physical consequences of the disease challenge both patients and carers, motivating them to find creative ways, adapted to the context at hand, to achieve the day-to-day life they want to have.

Managing psychological consequences. Parkinson's entails both physical and psychological consequences. In particular, many people find it hard to accept their current situation and the future. Still, most patients and carers we met showed a great acceptance of their situation. They lived with their current situation, day to day, without excessively thinking about the condition. They did not focus so much on what they could not do but rather valued what they could do. Because accepting the condition is so hard, patients and carers continually need to reframe and reassert their acceptance at different times. They tell each other regularly how they can still manage to do many activities and comment on how much better off they are than other people they know. They even go on to acknowledge that the disease they live with is not the worst one.

> IP5_C1: "It is not the worse for sure because Alzheimer's is much worse, isn't it?"

Besides accepting their current situation, patients and carers have to prepare themselves for the future disease state. Having a progressive disorder means that they are likely to experience stronger symptoms, as well as greater disability and loss. In most cases, people living with Parkinson's confront their future directly. They recognize that their disease is there to stay for the duration of their lives but try to avoid worrying about it too much. There is also an expression of hope that is brought in the conversation when patients and carers speak about the future. On one hand, they hope for the medication to have a good effect on them for a long time. On the other hand, they hope for a cure.

> IP10_C1: "It is a disease they have not worked out how to cure yet. This [science] is very advanced, but they haven't reached it yet. But maybe it comes. She [the patient] is still very young."

Accepting the future, similar to accepting their current situation, is a challenge. To achieve it, patients and carers continually reframe and reaffirm their acceptance and assert their willingness to deal with the condition, and their hope for a cure. They do so not individually but interactively, influencing each other's points of view to facilitate joint acceptance.

Performing lifestyle changes. Parkinson's can be responsible for a number of lifestyle changes. We already mentioned some of these when referring to the management of physical consequences. Here we refer to the example of leaving work.

The need to stop paid work is a common lifestyle change caused by having Parkinson's. When the body no longer responds adequately, continuing work can even be dangerous. However, although leaving work might be positive for health, it is likely to be a hard change to make and accept for both patients and carers. To illustrate this complexity, we focus on an excerpt of an interview with a carer who refers to how she left work soon after her husband.

> 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 also very hard for the patient. He stopped taking the medication and lost hope somehow. Facing such a situation, the carer decided to leave the business they both owned quickly to help in the care of her husband. She started giving the medication on time and took action to reinstill 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.

4.2. Dividing Self-Care Activities

Having seen that patients and carers collaborate in the different parts of self-care it is reasonable to ask how they divide the activities between them. There does not seem to be a clear answer to this question but rather a set of factors that influence the way they distribute care activities.

Personalities play an important role. If the patient is not very motivated, carers might take the lead in more care activities. On the contrary, it is also possible to find patients who want to do the most they can by themselves so that they do not feel dependent on others.

It also has to do with what is practical for them. Parkinson's makes patients move more slowly, and that can be difficult at times. At the same time, some activities the patients did previously might have become impractical because they now take too long, make patients very tired, or can hurt someone. So out of practicality, these activities become shared.

Although personality traits and practicality influence the division of tasks, there are other factors that might motivate an adjustment. In this section, we discuss the adaptation required by disease progression and fluctuations.

Adapting to progression. The division of self-care is not static and gets shuffled around and challenged by the unpredictable progression of the disease. The progression can impact self-care in multiple ways. There can be consequences of losing gross or fine motor skills, or losing short-term memory, as well as other consequences. In early phases of the disease, patients are more likely to perform a larger share of self-care activities than closer to more advanced phases (Figure 4). To illustrate adjustments in the division of self-care, we present an example caused by memory loss.

> IP10_C1: "I didn't have to be concerned about it [reminding medication], now I have to, because . . . Did you take it? Oh, I forgot. Now she starts [to forget] . . . But, there are so many [tablets],

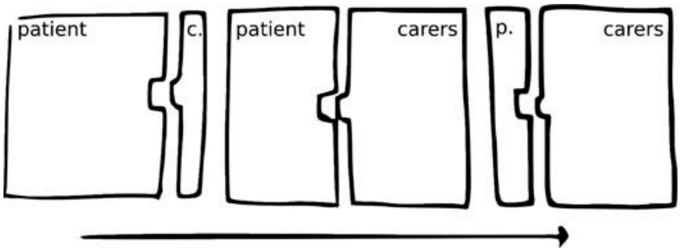

FIG. 4. As the disease progresses carers are likely to take more parts of self-care from the patients, but the collaborations remain.

> aren't there? At noon she has to take one, and I ask her and she forgot. It was not usual, 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 they quickly integrated it into their everyday life. This does not mean that the change was easy. We see, for example, that the carer justifies the forgetfulness with the fact that the patient takes many pills. However, this does not seem to be a logical explanation, considering she could manage medication for years before with success. What seems more likely is that the carer is trying to help his wife accept more easily that the disease is worsening. Realizing one is losing abilities is not easy, so the carer actively contributes to a reframed acceptance of the condition by arguing that it is something that could have happened to everyone.

Adaptations to the division of self-care seem to be carefully thought out by carers. In particular, they need to find a balance between encouraging autonomy and encouraging acceptance while trying to redefine and maintain a quality of life. Encouraging autonomy helps keep patients motivated to pursue with their self-care, ignoring some issues they might have. Encouraging acceptance helps patients adapt to the progression of the condition but also makes them understand that they are no longer able to do some things. Getting this balance right is not easy but seems 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."

Patients are also reluctant to start depending more on others, even for small things. Buttoning a shirt by oneself, for example, is very important to IP2, even if it takes him three times as long as it used to take. The more patients insist, the more they will be able to do in the future, so they don't want to stop doing anything they can.

> 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 are likely to happen as a result of the disease progression. These changes are likely to be well thought out in order not to constrain patients from doing what they still can. Furthermore, the adaptation of self-care work division is accompanied by emotion management, ensuring the patient does not become demotivated in losing abilities.

Adapting to the current disease state. The problem is not only that the disease progresses but also that its state is highly variable. This differs from other chronic conditions that have more stable disease phases and more predictable linear progressions. In Parkinson's, people might have the disease under control on some days and experience difficulties in managing it on other days. When troubling moments come, the division of self-care is likely to be adjusted, sometimes through new self-care activities. This means that both patients, and carers in particular, are engaged in ongoing monitoring of the situation to determine if and how they need to adapt or act at any point in time.

Let's look at one example of how adjustments in self-care division take place. IP8_C1 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 so that she was available to walk with him. IP8_C1 did not want to tell her husband when to exercise, but always tried to motivate him and create the conditions that would make exercising easier. Thus, her role in exercise was that of an enabler. This division of self-care was kept for some time, but when stronger symptoms came, they had to adjust.

> 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."

In these specific situations, IP8_C1's role in exercise was changed. She became an even greater source of motivation, and the one responsible for recognizing the need and choosing when to exercise. The trigger for changing the division 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 practical situated response to a bad moment.

Changes in the disease state may also trigger new self-care activities. These activities are especially interesting here because they can embody new self-care work divisions. Let's look at another example. IP5 usually manages the emotions of the disease without great difficulties; however, in some situations, the symptoms are stronger and he gets 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?"

IP5 got very emotional when talking about dying and started to cry. IP5_C1 quickly reacted 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 is interesting because it 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.

It seems important to remember that the division of care work will not be definitive, but a decision that is made along the way and that will have to be continually monitored and negotiated as adverse conditions emerge and need to be accounted for.

4.3. Patients and Carers: Complementary Perspectives

When collaborating in self-care, patients and carers have different perspectives. Carers are in an "outside" position, even if they know the patient very well. They cannot directly feel the condition in their bodies but observe its consequences on the patient's body. If we think about it, being able to observe it also makes them people living with a chronic condition, thus able to develop knowledge about the condition based on what they see (Prior, 2003).

Of interest, the knowledge developed by patients and carers is intertwined not only with the disease but also with values and interests, because people have multiple and diverse interests, goals, characteristics, and personality traits. So the knowledge they develop is not really about the disease, or about patients with these or those symptoms, but rather focused on the very specific case that they live with, that is, for a particular patient, with specific personality traits, and involved in a specific social context and historical background, with a specific and changing experience of the disease.

Patients and carers develop complementary knowledge through an accumulation of "trial and error" experiences with which patients and carers, willing to adjust and adapt, are able to build a life that is meaningful to them.

5. DISCUSSION

This study expands the current understanding of self-care with examples of how people living with Parkinson's collaboratively self-manage their condition. Parkinson's is an example of a chronic condition that brings particular self-care challenges because of its unpredictable fluctuations and nonlinear progression, as compared to other more stable or linearly progressing conditions such as diabetes or hypertension. Our work was motivated by noticing that most self-care technologies had been designed to be used in isolation by patients or carers, even though previous literature as per Corbin and Strauss (1984) documented the existence of collaborations between patients and carers. This is especially interesting in the context of Parkinson's self-care, because a number of different studies have documented everyday activities shifting from patients to carers (Chiong-Rivero et al., 2011; McLaughlin et al., 2011; Wressle, Engstrand, & Granérus, 2007), and yet collaborations were not described. It was as if activities were simply swapped from one actor to another, with no interaction or common work. Our fieldwork shows a different picture, though, in which numerous collaborations and mutual contributions to a joint objective exist in the pursuit of building a life with quality. This joint objective is not static, but constantly redefined and renegotiated in face of the current context.

The reasons for designing self-care technologies in such a way are understandable if we consider that the design for individual use (patient or carer) reflects one of two popular discourses in the policy and medical area, which sees either patients or carers as self-managing in isolation. Drawing on the work of others and our fieldwork, we show specific self-care activities patients and carers do *together* to self-manage their condition.

Self-care is not about managing health or about being a good patient, but rather about living, that is, about adapting and intervening to create a new way of living in response to the experience of the disease at each moment: a way of living that is practical, that considers the condition, respects the personalities and relationships of the ones involved, and is adapted to everyday life. It is about improvising, using the available tools to make choices and reach a good-enough solution. But creating this new way of living is not an individual endeavor. It is something that patients and carers create together in response to the disease symptoms and its overall progression or fluctuation.

Self-care is dynamic. When facing a new situation, patients and carers adapt to integrate the new challenge into their life. Patients and carers will address the challenges of the condition, not because they want to go against it but because having a good life depends on how well they adapt together to this new situation. In Parkinson's, adjustments in the division of self-care are very frequent due to fluctuations. When fluctuations happen, symptoms are likely stronger, but patients cannot effect immediate change as a diabetic can with an insulin shot or a sugar dose. People living with Parkinson's must adjust their self-management to deal with stronger symptoms. In this sense, the patterns of fluctuations of Parkinson's resemble those of bipolar disorder (Bardram et al., 2013). Other conditions might be more stable in their self-management, but as everyday life is unpredictable, adapting and adjusting self-care is likely a common issue that can be greatly improved if patients and carers are working together.

Collaborations in self-care happen independent of the level of autonomy of the Parkinson's patient. When patients are able to perform most of their own care, carers' actions can be more subtle, but as care activities start becoming harder, carers are likely to start having a more active interventionist role. This may contrast with conditions, such as diabetes or hypertension, in which self-management is more or less stable or more slowly progressive in the long term and in which the same technology can be used at early and advanced phases of the condition (e.g., Kusk et al., 2013). However, we would say that collaborations probably also exist in such conditions, as patients and carers living together will work together to adapt to the issues they face as result of their everyday life with the condition.

5.1. Situating Our Work and Transferring Findings

The research we conducted with people living with Parkinson's is situated: it is a result of our interpretation of the very particular contexts we observed, the literature we reviewed, and our previous experience. Here we look at characteristics of our study that situate our results and then position this study with other related work, noticing characteristics that indicate our conclusions may be transferable to other contexts.

Characteristics that situate our work. As explained in the Methods section, this study was conducted in the Portuguese urban context. Interviewed participants were recruited in a patients' association in an urban town, and observations were conducted in a central hospital, in a nearby urban town. As such, there are particular characteristics of our study context that might have had an influence in our results.

In the Portuguese context, family ties are strong and usually remain so through life. It is common, for example, to find multiple generations sharing a home or gathering on a weekly basis. As people age or their health becomes more fragile, families are likely to take an active role in their care. In some situations, family members will visit their relatives regularly, supporting their self-management in multiple ways. Other times, they will bring them to their homes and take an even more active role. Nursing homes also exist, but they are seen by many as a last resource. The close relationships between family members might explain the relative absence of professional carers and the presence of adult children in consultations. In societies with not-so-close family ties, the proximity between patients and carers might be different, and so relationships in self-care may differ.

The urban context also had an influence in our findings. We interviewed a number of participants who engaged in formal ways of exercise, such as physiotherapy or swimming classes, which are easily available in an urban town but not so much in a rural setting. If we had participants from a rural area, they would probably engage in less diverse forms of exercise, as available, or maybe rely on informal ways of exercise.

Another important characteristic of our participant sample is their success in building self-care together. It is realistic to expect that the relationships between patients and carers are not always constructive and positive. In many cases they might be conflictive and problematic. Patients and carers will probably have issues in self-care if they have a conflictive relationship, but we did not observe such relationships in our work. Therefore, the success of self-care in conflictual relationships with carers remains to be explored in future work. We can also point the reader to work regarding the successful and unsuccessful couples managing self-care by Corbin and Strauss (1984).

Transferability of findings to other contexts. Having focused on the characteristics that situate our work, we now turn to the transferability of our findings to other contexts. Although we do not aim to "generalize" the findings beyond the context we researched, we see that our analysis is confirmed by other studies that observed the use of self-care technologies, and so the argument may hold in other settings. In the introduction, we cited a number of technologies that were designed to be used individually by patients, but interestingly enough, some of these studies documented ways in which carers still collaborated in self-care using the technology. For example, carers (a) used technology that was developed for patients (e.g., watching recordings of consultations; Aarhus et al., 2009), (b) took actions on the results of the technologies (e.g., emailing test results to the doctors; Aarhus & Ballegaard, 2010), or even (c) taught patients to use a specific self-care technology (e.g., teaching how to interpret and act on blood glucose measurements, Storni, 2010). So even in some cases in which the technology was not meant to be used in collaboration, patients and carers appropriated and adapted it to fit with the ways in which they collaboratively performed their care.

Having said this, it is important to mention that there may be patients who manage the condition by themselves. Patients may perform self-care in isolation as a result of exceptional life situations, not having access to support from others or even by their own choice. Therefore, self-care should not be considered an individual activity from the beginning, but rather an activity which is likely to be done in collaboration, especially where people live with others. Recognising the collaborative nature of self-care means that self-care needs to adapt to the particularities of everyday life, including the availability of carers to participate, so caring for the condition by one self is a special case of our concept of self-care.

5.2. Implications for Design

There are important implications for design arising from conceptualizing self-care as a collaborative activity. In particular, we see these implications in the theoretical framing of the studies, the methodological options, and the practical or technical design decisions.

Theoretical framing. There are theoretical implications regarding how patients and carers should be framed in care literature. Although it has served other political and activist agendas well, it is not useful to continue advocating a strong divide between patients and carers in terms of self-care, especially when it comes to design. Patients and carers are likely to collaborate and influence each other, so they should be addressed as having a role in self-care, and in particular one that can vary based on a number of different factors.

It might also be useful to reconsider the language around this and start using the concept of "people living with a chronic condition." This expression captures what is essential about a chronic condition, that one has to *live* with it. However, living with a chronic condition is not an individual experience but a situated and collective experience that many patients and carers share. By referring to people with chronic conditions, we recognize that carers are also living with the chronic condition, although not in their own body.

Methodological. On a methodological level, we see a need for focusing on collaborations. Focusing on the patient or on the carers is not enough, because they are likely to collaborate and influence each other in multiple ways. When focusing on the collective unit and on their collaborations, we will be better able to understand how self-care is being performed in a specific situation, how carers and patients are dividing their activities, how they are solving their issues, and how the technology could complement care in more meaningful ways.

Using such a unit of analysis will enable one to focus on the collaborations that happen in self-care. This does not mean that researchers should avoid focusing on the particularities of patients and carers. Studying the different roles will bring important 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.

There is also a great need for involvement in the research setting. If we consider that every self-care situation is different and our understandings incomplete, it is important to leave space for people to appropriate the solutions so that they can address their context completely. So when designing technology, there should be a degree of openness to adapt to the ways in which patients and carers integrate technology in their own setting. Learning from these interventions is therefore crucial to understand how self-care is working and could happen with the help of technology.

Practical or Technical. On a practical level, technologies should empower collaborations in self-care, enabling patients and carers to divide and share their activities.

Self-care technologies can help dividing self-care work between patients and carers, provided they both have access to the technology. As different roles have different perspectives, they can benefit from having distinct interfaces as well. One way to provide distinct access is to offer multiple interfaces in the same device, each for a specific role. Another option is to provide multiple devices or terminals adapted to patients or carers. Both strategies enable self-care work to be shared so they may be equally valid.

Sharing can be achieved, for example, by merging the data sources from patients and carers terminals, improving the quality and amount of information available to reflect on self-care or feed discussions with clinicians. One way to implement this would be to allow both patients and carers to monitor the disease symptoms in their own devices. Joining both data streams would provide a richer source of information for reflection. Having specific adaptations to patients and carers might be beneficial for collecting extra information about their condition, making use of multiple perspectives to feedback self-care.

The different interfaces provided for patients and carers define a specific self-care division. However, this division should not be static. Fluctuations, progression, unavailability of carers, or important everyday life activities might require quick changes in the care division. To implement such changes, devices might benefit from somehow duplicating interfaces. This would enable patients or carers to perform the self-care that was usually assigned to the other role more easily, simply by following other options in their user interface.

6. CONCLUSIONS AND FUTURE WORK

This work has enabled us to expand the understanding of self-care to consider the ways in which people living with Parkinson's collaborate in their self-management. We noticed that the self-care literature has many times fragmented its analysis and focused alternatively on either patients or carers. Doing so has made the literature oversimplify self-care and lead to the design of technologies that are individual and probably not able to fit with the complexity of many self-care cases. Building on work from others, we show how self-care can consist of collaborative activities. Using examples from our fieldwork, we demonstrated that for different dimensions of the self-care of Parkinson's disease, patients and carers interact with each other to adapt self-care and create a good life. We also derived a number of implications for design pointing to actions that recognize the collaborative nature of self-care.

Our work is situated on the contexts we observed, the literature we reviewed, and our previous experience. Therefore, there is the opportunity for others to build upon our analysis, or to question it based on incompatibilities with their observations. In any case, if our argument holds, the community has the opportunity to improve the design of self-care technologies and contribute to a generation of technologies that embrace self-care more holistically.

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