

Quantifying the Body and Caring for the Mind: Self-Tracking in Multiple Sclerosis

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ABSTRACT

Consumer health technologies have an enormous potential to transform the self-management of chronic conditions. However, it is unclear how individuals use self-tracking technologies to manage them. This in-depth interview study explores self-tracking practices in multiple sclerosis (MS), a complex neurological disease that causes physical, cognitive, and psychological symptoms. Our findings illustrate that when faced with the unpredictable and degenerative nature of MS, individuals regained a sense of control by intertwining self-care practices with different self-tracking technologies. They engaged in disease monitoring, fitness tracking, and life journaling to quantify the body and care for the mind. We focus attention on the role of emotional wellbeing and the experience of control in self-tracking and managing MS. Finally, we discuss in which ways self-tracking technologies could support the experiential nature of control and foster mindful experiences rather than focusing only on tracking primary disease indicators.

Author Keywords

Self-care technologies; personal informatics; self-tracking; perceived control; chronic conditions; multiple sclerosis

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

INTRODUCTION

Consumer health technologies, such as wearable fitness tracking devices, symptom journals, and mental health apps have an enormous potential to transform self-management and empower people to better understand and live with chronic conditions [1, 39]. Previous research in HCI has paid significant attention to understanding the use and

design of bespoke medical devices and disease monitoring applications that address common chronic conditions, such as diabetes [28], hypertension [21], and asthma [44]. However, the role of both contemporary consumer health technologies and of self-tracking practices in chronic illness management that go beyond disease monitoring have received much less attention.

In this paper, we focus on MS, the most common inflammatory chronic condition in young adults. MS affects the central nervous system causing physical impairments and also symptoms related to vision, cognition, and mental health [13]. Monitoring symptoms, being physically active, and pursuing good psychological health are important in MS self-management [10, 13]. However, studies suggest that the documentation of individual symptoms, continual reporting of relapses, and balancing physical activity can be challenging [10, 11]. Contemporary health tracking technologies have the potential to empower people in self-managing these challenges. Yet, little research describes how individuals with MS use and experience self-tracking technologies in everyday life.

Here, we present an in-depth interview study on self-tracking practices in MS self-management. Our research contributes to the body of research on self-care technologies [34] and personal informatics in HCI [2]. Primarily, this research provides a qualitative account of the motivations for and roles of self-tracking practices in MS management. We found that people living with MS experienced a lack of control when coping with unpredictable relapses and the degenerative nature of the disease. Despite this, our participants gained a sense of control over MS by intertwining individual self-care practices with different self-tracking technologies such as paper-based symptom diaries and wearable fitness tracking devices. This study draws attention to the role of emotional wellbeing in self-tracking and highlights the role of self-tracking in regaining a sense of control over an unpredictable and degenerative disease. Based on this understanding, this study discusses design considerations to facilitate self-tracking in MS and similar chronic conditions, namely: supporting self-exploration before self-diagnosis; drawing not only on pathological knowledge, but also mediating practice-based health expertise; and, rather than concentrating only on tracking primary disease indicators, fostering mindful experiences.

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BACKGROUND

To provide background to this research, we begin by describing seminal work on self-monitoring with self-care technologies and then outline emerging research on self-tracking practices in personal informatics. Next, we introduce the pathology of MS and interdisciplinary research on health tracking technologies in MS.

Self-Monitoring with Self-Care Technologies

Much research in HCI has focused on understanding self-management practices and the use of self-care technologies for common conditions [26, 34], such as diabetes [28, 36], hypertension [21], and asthma [44].

Qualitative studies of self-management highlight the individual experience, idiosyncratic character, and open-ended nature of self-care practices in everyday settings [42]: Chen, for example, sheds light on the varied health information management practices of diabetes patients and stresses the need for individualised health technologies [6]. Mamykina et al. [28] describe how experienced diabetes patients appropriated an open-ended and flexible self-monitoring application to track routines, reflect upon their personal stories, and perform identity construction work in daily self-management. Park and Chen [38] provide a detailed account of self-management practices performed by people affected by migraines. They describe how the unpredictability and intermittency of migraines affected people's efforts to identify individual triggers, and also stress the importance of their need for social recognition.

Self-care technologies play a central role in self-managing chronic conditions [34]. They are not limited to medical devices, such as blood glucose meters [36], but include a wide range of different interactive systems, such as web tools for capturing and exploring health-related data [28] and smartphone applications for monitoring symptoms [42]. Typically, self-care technologies enable people to record primary disease indicators, which is often described as 'self-monitoring' [34]. For example, self-monitoring blood glucose levels in diabetes [6], blood pressure by people with hypertension [21], and mood in those affected by bipolar disorder [3], helped to develop understanding about the course of the disease, react to fluctuating measures, evaluate health behaviour, and adjust to the respective condition in everyday life.

Self-Tracking in Personal Informatics

In recent years, there has been a notable increase in both consumer self-tracking technologies and related research endeavours in HCI [2]. Studies have explored different self-tracking practices, involving physical activity [18], food intake [8], and sleeping behaviour [24]. Rooksby et al. [15] characterise these self-tracking practices as '*lived*' - enmeshed in everyday life - and reveal five overlapping self-tracking styles. Through *directive tracking* people often pursue a specific goal such as losing weight. *Documentary tracking* highlights that people not only track to change

behaviour, but also out of curiosity. *Diagnostic tracking* aims to uncover relationships between different phenomena such as diet and medication. *Collecting rewards* refers to people's will to compete and receive rewards. In *fetishised tracking* people are primarily interested in the appeal and functionality of technologies per se.

People engage in self-tracking because they gain self-awareness of their health behaviours and can develop good physical and nutritional practices [15, 22, 23]. Nevertheless, studies suggest that a significant proportion of people stop using self-tracking technologies because of a lack of actionable insights, poor aesthetics, and unmanageable maintenance [18, 22]. Notably, abandonment is not always due to failure: some people abandon self-tracking technologies after having developed a routine, while others do not aim to reach a goal, but gain a new awareness of their behaviour; and a few people lapse and resume self-tracking over time because of shifting priorities [9, 15, 22].

These findings, based primarily on healthy populations, also point to challenges and opportunities for self-tracking technologies to support people with chronic conditions to self-manage their health and wellbeing. For example, Felipe and colleagues [17] describe roles for personal informatics in chronic pain and MacLeod et al. [27] illustrate the potential of personal informatics in chronic illness management, stressing opportunities to support curiosity and self-discovery rather than behaviour change.

Pathology of MS and Health Technologies in MS

MS is the most common inflammatory chronic illness in young adults. It is not curable, but is manageable: people living with MS may obtain a satisfactory quality of life by, for example, engaging in regular exercise, good nutritional practice, and mental health management [13].

MS affects the central nervous system, including both the brain and spinal cord. Neurons are the core components of the central nervous system and transmit signals to and from the brain, other neurons, sensory organs, and muscles. MS is an autoimmune condition, in which the immune system mistakenly damages the myelin - the insulating layer of the neurons - and, consequently, disrupts the communication between the brain and body, leading to a complex range of symptoms, involving cognitive, visual, and physical impairments [24]. Most people with MS develop the relapsing remitting type, which is characterised by periods of relapses, when symptoms occur for a few days or months, and remissions, when symptoms are mild or disappear for several months. Approximately 65% of people with relapsing remitting MS are also diagnosed with secondary progressive MS, a condition in which the severity of symptoms increases and the periods of remissions decline [13]. MS leads to increased physical and cognitive impairments over time. Treatment for MS symptoms includes both drug and non-drug based therapies, such as physiotherapy and psychotherapy [10].

There are different lines of research that have addressed MS. Medically informed studies highlight that a healthy lifestyle might alleviate several MS symptoms and foster an increased quality of life [10], but maintaining physical activity is considered to be a key challenge [41]. Studies within health informatics have explored whether wearable physical activity tracking devices could be leveraged to measure gait patterns and assess the progression of MS. For example, Shamma et al. [41] used 3D accelerometers to track changes in disabilities more effectively than clinical methods, such as standardised walking tests. McIninch et al. [31] evaluated the use of a consumer activity tracker with MS patients for a period of three weeks, reporting that the overall “*user experience was extremely positive and MS patients found the FitBit One device a useful aid in helping quantify their walking.*” HCI research with MS patients has focused on the clinical assessment of disability with the help of Microsoft Kinect [32] and personalisation in MS rehabilitation training in laboratory settings [35].

In summary, previous HCI research has paid much attention to self-management practices and self-care technologies in common chronic conditions, which often involve monitoring disease indicators [26]. Prior studies on personal informatics offer valuable models and descriptions of how and why primarily healthy adults use and abandon consumer health technologies [15, 22, 40]. However, the felt experience [30] of contemporary consumer health technologies and self-tracking practices in chronic illness management that go beyond disease monitoring has not been examined closely enough. This study focuses on MS, a chronic condition that requires a high level of self-management to support medical treatment, cope with the degenerative progression of the disease, and gain a satisfactory quality of life. In this study, we aim to explore the wider experience of self-tracking in MS self-management: what are the motivations for engaging in self-tracking and how do people living with MS use and experience self-tracking tools in everyday life?

METHODOLOGY

To explore the questions described above, fifteen in-depth interviews were conducted with people diagnosed with MS. The study had institutional research ethics approval.

Participants

Since our interest was in understanding people’s experiences with self-tracking technologies, the study focused on people diagnosed with MS who use or have used any kind of tools (e.g. paper diaries, spreadsheet software, mobile apps, fitness tracking devices, etc.) to track their health and wellbeing. Participants were recruited with the help of charities, including *MS Society UK* and *MS Trust UK*, which published our study advert on their websites. Furthermore, administrators of the online community *shift.ms*, and the MS meet-up group *My Spirited Friends* shared the advert with their members. Fifteen

people with diverse backgrounds participated in our study, from individuals who have been newly diagnosed with MS to those with long-term experience in self-managing the disease. Among our participants, eleven were female and four male, which mirrors the 3:1 prevalence ratio of women to men in MS [13]. Most participants were passionate about pursuing a healthy lifestyle and all engaged in self-tracking practices of their own volition.

Data Collection and Analysis

In order to gain a deeper understanding of our participants’ experiences of living with MS and their self-tracking practices, we conducted in-depth interviews [4]. Questions covered the following topics: diagnosis; symptoms; relapse experience; lifestyle routines; and self-tracking tools and practices, and focused on attitudes, goals, challenges, and learnings. Participants chose the time and place of the interviews. Twelve interviews were conducted via Skype or FaceTime, two interviews in person at the university, and one interview over the phone. Interviews took between 40 and 135 minutes and were audio recorded.

Analysis started after the first interview and guided subsequent interview questions. The qualitative data analysis software *NVivo* was used to transcribe the audio recordings and thematically code data [5]. The data corpus was iteratively analysed in an inductive, ‘bottom up’ fashion drawing on open and axial coding. We focused on the individual experience of each participant who had a unique presentation of MS, individual coping strategies, and particular ways of using self-tracking tools. At later stages, the mind mapping software *SimpleMind* was used to create mind maps visualising emerging themes, associated categories, and sample quotes in order to support axial coding and explore differences in motivations, entanglements between different self-tracking styles, and descriptions covering reflective thinking practices. Mind maps also supported the discussion of quotes and emerging themes within the research team.

FINDINGS

We first report how the participants in our study experienced a lack of control over the unpredictable and degenerative nature of MS. Subsequently, we describe motivations for beginning to self-track and illustrate the ways people regained a sense of control over MS through intertwining individual self-care practices with different self-tracking technologies, namely: (1) gaining knowledge about the pathology of MS and self-knowledge about their own MS through disease monitoring; (2) pursuing a healthy lifestyle and self-tracking physical activities and dietary habits; (3) maintaining mental health management practices involving life-journaling; and (4) engaging in reflective thinking across tracked personal data and health behaviour.

Lack of Control in Adjusting to MS

People affected by MS reported experiencing a lack of control when going through unpredictable relapses, coping with the uncertain and degenerative progression of MS, and dealing with the resulting psychological burden.

Dealing with Ambiguous and Unpredictable Relapses

MS is characterised by unpredictable relapses and remissions. A clinical relapse is defined as “*either the appearance of new symptoms related to MS or very definite worsening of old symptoms, which lasted for at least 24h and occurred after the patient had been stable for at least a month (with the absence of raised temperature, infection, or any other health problem).*” [11]

Identifying relapses was not only important to adapting medication and document the progression of the disease, but also to experience clarity, assurance, and some degree of control over the uncertainty of the disease, as P8 expressed: “*I think [I track a relapse] for peace of mind. [...] For me it's important to know. I would prefer to know and deal with something rather than be in ambiguity.*” (P8)

Some participants claimed confidence in their own ability to identify, document, and report relapses. However, newly diagnosed individuals considered recognising relapses to be challenging. In particular, people reported facing challenges when distinguishing between clinical relapses and pseudo-relapses, since both types lead to an increase of MS symptoms. Pseudo-relapses are not caused by new lesions in the central nervous system but, for example, by heat sensitivity or infections, and can often be resolved within a short period of time. However, pseudo-relapses might also trigger clinical relapses. For example, P8 expressed uncertainty when distinguishing between infections and relapses: “*The answer is: I don't know. I don't think that anybody does [...]. I can never be sure because if I catch things like a cold it will bring all of my symptoms. So, I am never quite sure.*” (P3)

Moreover, participants faced a lack of control when coping with the unpredictability of relapses, which can cause a sudden loss of bodily functions and lead to significant physical deficits, as the following example shows: “*And at any point in time, my life could change because I have a relapse. You could lose your eyesight, use a wheelchair; that possibility never escapes from your head. [...] I never know when it's going to strike.*” (P7)

Coping with Mental Health Conditions

MS cannot be reduced to only physical disabilities, but affects people's “*mental health as well. That's equally if not more important.*” (F5) Specifically, participants highlighted that the uncertain and degenerative nature of MS depicts a major psychological challenge, as this quote exemplifies: “*For me the biggest thing about living with MS is coping with the knowledge that you have something*

that is going to get worse in time. And there is a lot of uncertainty ahead. And that psychological burden is the biggest one to deal with.” (P13)

Many participants reported receiving therapy to cope with mental conditions, such as anxiety, stress, and depressive episodes, and managing their fears of losing physical abilities, autonomy, and social life at some point. For example, P5 reported experiencing anxiety, especially when dealing with the constantly changing character of MS: “*So, when something new happens, or changes, or alters, I have to get used to that change. And that's something I can struggle with. And I actually have had CBT [cognitive behavioural therapy] to support me with that.*” (P5).

P2 was seeing a psychologist who specialised in the specific needs of MS patients in order to cope with the many mental challenges: “*I felt like a CBT therapist was not good enough; they were overwhelmed when I told them what I've to deal with regarding my MS. I had to apply for a proper MS psychologist to cope with feelings such as anger, loneliness, uselessness, frustration, and sadness.*”

Motivations to Engage in Self-Tracking

In order to cope with the lack of control and uncertainties in self-managing MS, most participants developed a proactive attitude and engaged in different self-care practices, such as learning about the pathology of MS, maintaining regular physical activity and good nutritional practices, and caring for their mental wellbeing. Notably, the use of self-tracking tools, such as paper diaries and wearable fitness tracking devices, was enmeshed in their self-care practices. These were motivated by the following factors across our participants: wanting to delay moving to secondary progressive MS and being afraid of losing their physical and cognitive abilities at some later point in life; being proud to be physically active - to be able to walk, run, cycle, swim, and lift - despite having MS; thinking prospectively about the potential effects of a healthy lifestyle and preventing future regret of not having made all possible efforts; as well as wanting to stay as healthy as possible to be eligible for a cure in the near future.

Similar to lifestyle changes, self-tracking often started upon diagnosis, when people tried to grasp the complex nature of MS and to gain some scaffolding by reading about it and using different tools, such as paper diaries: “*I didn't know what was going on, I didn't know where I was going next. I suppose that I just started to write stuff down as some sort of record, really, of what was happening to me.*” (P11)

Since presently neither drug-based treatment nor non-drug-based strategies can cure MS, many participants had reservations about clinicians, questioned the ways MS is treated, and in an act of defiance focused on and believed in their own self-care skills to explore and adjust to MS, as the following examples illustrate:

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	Use	Abandonment
Disease monitoring																	
Symptom monitoring																	
Medication tracking																	
Fitness tracking																	
Physical activity tracking																	
Heart rate monitoring																	
Sleep tracking																	
Food journaling																	
Weight monitoring																	
Mental health tracking																	
Life journaling																	
Meditation																	

Figure 1. Participants used paper diaries, PC software (e.g. MS Excel), tablets (e.g. timer), fitness trackers (e.g. Fitbit), smart phones (e.g. Headspace), and smart scales to engage in disease monitoring, fitness tracking, and mental health management.

“And they have treatment, but they do not know how to cure it. And they do not really know what causes it. That doesn’t fill you full of confidence, anyway. [...] And they are sceptical of the drugs, and the drugs are not the whole answer, but I decided to take the drugs and do everything I can [to self-manage MS].” (P7)

“So, I feel like I need to have a better idea of what is going on in my body [...] Because I don’t feel like my medical professionals do. That gives me even more motivation to go and find out. I feel like I need to be an expert in myself and be an expert in my condition.” (P8)

Self-Tracking Practices in MS

Participants in our study engaged in a wide range of different self-tracking practices (see Figure 1). They used various tools from traditional paper diaries, spreadsheet software, and web applications, to wearable fitness tracking devices and diverse mobile applications. In the following sections, we focus on entanglements between different self-care practices and self-tracking tools addressing emotional wellbeing and the experience of control.

Disease Monitoring: Understanding MS Symptoms

Diagnostic practices were often conducted using paper-based health diaries, mobile food logging applications, and consumer fitness tracking devices. Individuals reported that disease monitoring affected their emotional wellness: sometimes this was in negative ways because of overly focusing on symptoms, and sometimes positively when exploring causal relationships and developing a sense of control over MS triggers and symptoms.

Participants had been encouraged - often over a short, defined period of time - to use structured pain, bladder, and bowel diaries provided by clinicians to document symptoms and inform clinical decision making. Some filled out these types of diaries methodically, others on the fly before appointments. Most participants kept their own paper-based

health dairies for their “own benefit” appreciating that there is “no one over [their] shoulder.” (P5) Drawing on our participants’ descriptions and photos of symptom diaries, we have identified three different types of entries: the first was self-reported descriptions of symptoms, such as “double vision,” “pins and needles types of sensation,” “head of cotton wool and porridge,” “mood, like anxiety,” “energy levels,” “spine feels like I have sunburn,” and “heavy and useless legs.” People tended to use self-designed scales based on their own words rather than medical scales to define the severity of their symptoms. The second type of entry was measures from external tools. For example, participants manually transferred selected data from weight scales, thermometers, and blood pressure monitors to their diaries in order to visualise, annotate, and compare the recorded metrics with symptoms, medication intake, and life-events. The third type of entry covered narratives of everyday life, including mundane activities and sketched thoughts. Impressionistic notes, such as “Really struggled today - heat?” (P11, paper diary) contextualised the tracked actions and helped people to revisit past experiences. Participants also used health diaries to prepare themselves for medical appointments in order to be able to effectively communicate symptoms and demonstrate competence.

In addition to paper-based health diaries, people employed food logging apps to monitor and understand MS symptoms and triggers related to their wellbeing. Some participants explored relationships between food intake and symptoms, such as fatigue. Others already made some findings, such as P4, who found a relationship between sugar intake and quality of sleep: “If I have too much sugar it keeps me awake at night and it’s not good for my sleep.”

Moreover, wearable consumer fitness tracking devices supported diagnostic practices. Some participants associated physical activity data of fitness trackers with periods of increased or decreased severity of symptoms.

Others interpreted physiological measures of fitness tracking devices as indicating illness. For example, when reflecting on her heart rate data, P8 considered the possibility that she was getting a cold: *“Actually, my heart rate is up a little bit and maybe I am coming down with something.”* Based on her past experience, she explained further: *“If you are coming down with a cold, that two days prior my cold started, my heart rate went up by average 5 beats per minute a day.”*

Monitoring MS symptoms and triggers helped especially newly diagnosed individuals to better understand their bodily reactions in everyday life. Notable, a few participants revealed that disease monitoring sometimes led to unintended effects: focusing on a predefined list of symptoms might lead to *“worry unnecessarily about symptoms they don’t have”* (P5) and also monitoring symptoms in open-ended ways caused sometimes negative feelings, as P4 describes: *“I guess sometimes, I feel a bit obsessed with it. Maybe, I should not be thinking about it too much and just getting on with life. But I think that could come later on [...]. But I’ve had MS just since 2015, so I am still learning the ways how my body is.”*

Finding a balance between monitoring and an excessive focus on symptoms involved different coping strategies, such as developing a mindful attitude and intertwining different self-tracking styles. Exploring causal relationships between MS symptoms and different factors, such as physical activity, diet, and sleep, provided, all together, a sense of having some degree of control over the disease. For example, P8 explained that using a Fitbit Charge HR device to monitor her heart rate and cope with stressful life events provided a sense of control over MS: *“Because research does say that there is correlation between MS and stress, I am like, well if I manage my stress, I’ll be managing my MS. Obviously, this is not a complete truth but in my head it gives me control over something.”*

Activity Tracking: Maintaining One’s Physical Abilities

When using wearable activity tracking devices a few participants reported feeling pressure to perform despite their physical limitations, but many explained having gained an increased bodily self-awareness and a sense of control over the physical symptoms, especially, when identifying short-term improvements and periods of stabilisation in the long-term.

All participants stressed that being physically active was essential in everyday life: it affected mood and energy levels (P1), made people *“feel happy”* (P2), provided *“mental space”* and was a *“stress reliever”* (P8), strengthened muscles, improved balancing (P11), and helped to reduce fatigue (P4). Using fitness tracking devices (e.g. *Fitbit Charge HR*) and various fitness apps (e.g. *Argus*), people tracked physical activities, such as yoga, walking in everyday situations, walking and running defined routes, balance exercises, indoor and outdoor

cycling, and weight lifting (e.g. *Wendler Log*). Furthermore, they also manually captured certain activities, such as sedentary behaviour and meditation.

Most people in our study suggested that wearable fitness tracking devices play a crucial role in maintaining their physical and psychological wellbeing. For example, participants used measures, such as steps and heart rate, in order to gain an awareness of their physical abilities, and tried to avoid overdoing it in order to prevent potential MS symptoms caused by overexertion, such as double vision.

Core functionalities of fitness tracking applications, such as setting goals, receiving rewards, and exploring visualisations of tracked data, led to mixed experiences. On the one hand, goal-setting functionalities were used by three participants who had minimal physical symptoms in order to improve weight lifting, walking, and running performances. Measures of activities made short-term achievements tangible and participants felt proud to be physically active despite of being affected by MS: *“Also, as a positive thing, say, you know, I have MS but I can still bench press so many kg.”* (P8) On the other hand, many tried to meet well known fitness norms, such as the 10000 steps per day goal, which could cause pressure and *“be quite discouraging when you know that you can only walk so far.”* (P10) Rather than increasing performances, most participants, especially with physical impairments, were interested in recovering and maintaining their physical capabilities. P9, who used an indoor exercise bike, revealed this attitude in the following way: *“I’ve found setting a target of exercising every day with MS is not feasible. It just seemed like pointless pressure. Now if I feel like it, I exercise but it’s more to do with maintaining flexibility rather than achieving targets.”*

A few participants were not keen on receiving rewards for their healthy lifestyle choices in fitness apps. They expressed that they *“don’t care to get a badge”* (P9) and focus rather on other functionalities such as using heart rate measures to inform diagnostic practices. In contrast to this, many participants stressed the importance of receiving rewards for their effort and work to maintain their fitness. For example, P7 explained: *“Everyday I look at the score card and I want to check that I got a gold star. And then it reminds me that I’ve done everything I can on that day to be healthy and that I can do no more.”*

Charts that visualised low steps counts and negative trends were sometimes perceived as discouraging due to the progressive physical decline that people with MS have to cope with. For example, P10 described: *“The graphs for me are kind of counterintuitive. [...] For someone with MS or for someone has got mobility issues, it can be another sign that you are not the same person you were a few years ago. If you are already feeling like it is an uphill struggle, then having something like that discourages you even more.”*

In contrast to this point of view, visual representations of mobility data - recorded over the long-term - could be a helpful tool to cope with the progressive decline of physical abilities. Long-term activity data revealed periods of improvement, stabilisation and stagnation and, in doing so, made people feel more rational, experience hope, motivation, and vindication for their efforts, and a sense of control over the progressive nature of the disease. For example, P11 had recorded her walking performance and balancing exercises in a paper diary for over five years. Reflecting upon her data she explained: *“When it’s going badly, I feel, it’s helping me to see how fast it’s getting worse and it sort of gives me some sense to try to slow it down which is better than the feeling, not having any data; it’s going to be hopeless. I can look at the graph and go: actually, over that period of time of five years, I definitely improved my condition. So, I feel some form of vindication that the effort that I put into it, made some difference. [...] For me documenting stuff is being partly about staying in control, knowing what is happening to me.”*

Food Logging: Improving Wellbeing through Mindful Eating

Most people explored different diets over time and aimed to *“avoid food that has been shown by MS research studies to have negative effects on MS,”* as P8 representatively explained. They tried to avoid wheat, gluten, dairy, meat, and sugar in order to follow an *“anti-inflammatory”* diet. People engaged in food logging because of the increased priority *“to look after the body”* after diagnosis (P5); to lose or maintain weight in order to be *“able to exercise better”* (P11), and to gain weight because *“under weight persons are more vulnerable to infections, which can trigger relapses”* (P4).

In the past, participants had used paper-based health diaries to document their dietary practices including detailed information from consumed products to the specific amount of saturated and unsaturated fat which required manual calculation. Many switched from keeping paper-based diaries to food logging apps over time in order to reduce the manual work of tracking. One participant switched from using a food journaling app to a lightweight paper diary which she placed in the kitchen in order to collaboratively manage a healthy diet with her family.

Most participants, who tracked their nutritional practices and physical exercises, connected the two: food journaling apps were often linked to physical activity tracking applications to determine the relationship between calorie intake and calories burned (e.g. *Weight Watchers*). Some registered physical activities manually in food logging apps (e.g. *MyFitnessPal*) because they were not accurately recorded by fitness tracking devices, such as yoga or individual balance exercises.

Compared to the perceived benefits of being physically active, most participants explained that it was not clear to them whether pursuing a healthy diet significantly affected

the presentation of MS. However, they emphasised that engaging proactively in good nutritional practices fostered certainly positive emotional wellbeing which *“itself is a good thing.”* (P11) Both, food and physical activity tracking were considered as *“fundamental part[s] of maintaining on a healthy path”* (P7).

Life Journaling: Coping with Everyday Life

Most people started to engage in mental health management practices, such as life journaling and the use of meditation apps (e.g. *Headspace*), when they tried to cope with the disruptive changes and psychosocial impacts caused by MS. Life journaling involved the use of paper diaries, gratitude journals, and digital smart journals (e.g. *Five Minute Journal*). They used diaries in order to capture MS-related experiences, non-MS-related thoughts, and specifically positive feelings. Many perceived the process of writing as enjoyable and therapeutic. Keeping a journal helped individuals to cope with and be in control of negative thoughts related to the unpredictable implications of living with MS. For example, P11 perceived her diary as a way to *“talk to herself”* within a private and protected space: *“I suppose that it’s also a part of escape for me, because it’s the one place I can talk about MS without burdening anybody else with the problems of it.”*

Aside from addressing MS, many other topics and life events were recorded. P7 stated that, in contrast to the fitness tracking and food logging applications, her paper diary is less about the physical, but more about the emotional issues she faced in life: *“I would just capture some of the thoughts that I had about losing my mother and how that feels. Not just about my MS.”*

Moreover, some participants recorded specifically *“things you are positive about [...] and grateful for in life”* (P8) or *“something very small that other people might just look over”* (P5), such as having a catch up at Starbucks with friends, learning some new stretches at a ballet class, and taking time to use the Headspace app to meditate. Participants looked back at these captured experiences when they went through the ‘bad days’ of living with MS.

Keeping diaries or gratitude journals seemed to help people to cope with everyday life, develop confidence, and gain optimism and hope. P11, who recorded her walking performances, experiences, and thoughts in her diary, explained that the experience and practice of writing can be a motivational coping strategy: *“If you had a bad day, you just write it down, you close that book, and go: all right that’s fine, I am done, tomorrow I will try again.”* In a similar way, P5 reported that having filled out her gratitude journal after her symptom diary, helped her to avoid focusing on symptoms and negative experiences: *“Kind of ending the day on a positive note, rather than thinking about stuff that stresses me out.”*

Reflective Thinking through Self-Tracking

Participants in our study reported engaging in reflective thinking across different self-tracking tools and practices. In doing so, they explored causal relationships between symptoms and everyday actions, dealt with uncertainty in self-tracked data and the unpredictability of MS, and gained self-awareness and health expertise over time.

Varied Interest in Reflection

People with MS had a diverging interest and expressed a varying degree of engagement in exploring tracked health data. For example, P8 took a look at the tracked data only occasionally and briefly when there was some time available (*"I don't really look back at it either, to be honest. I roll back on the data when I've got a free couple of minutes, when I am early for a dentist appointment."*) P7 seemed to spend more time exploring her fitness data and was driven by joy and passion (*"And I enjoy looking at it. I love tracking the charts and seeing how I am getting on."*). P11 was keen on conducting self-experiments in order to investigate actions that had a positive impact on her MS in everyday life: *"Like any good scientist, I went: OK, I am going to try this experiment now and I am going to record what I measure and see if it helps."*

Connecting Self-Tracking Tools and Practices

Most participants connected different self-tracking styles, such as fitness tracking and life journaling. For example, P11 explained that tracking physical activities helped her to understand and adjust to MS in everyday life, whereas capturing her thoughts motivated her to maintain good physical practices: *"The numbers [of tracked steps] are there to really help me to retain some sort of control and help me to practically manage my condition and trying to do the things that make it less bad. It [life journaling] is the emotional will: it helps you for your motivation to go on and do the things that rationally, probably, I need to do to stay as healthy as I can. So, it works together."*

While making sense of different self-tracking practices and personal health data, most participants experienced a lack of seamless connections and interactions across technologies. Many stressed that they are the ones who are not only connecting but also contextualising tracked data across tools: *"I don't think there are connections at the moment. Other than what I think is in my head, there is no connection between the data. It all comes together to become part of everyday."* (P8)

Causal Relationships and Uncertainty

Participants in our study developed causal relationships across individual triggers, symptoms, and mundane actions in order to better understand their unique manifestation of MS and explore how to adjust to MS in everyday life. This was a time-extensive learning process in which people developed their own unique and idiosyncratic 'best practices.' In doing so, they often perceived self-tracked data as evidence for observed phenomena and assumptions

they made while being aware of the uncertain and constantly changing nature of MS. P10, for example, expressed the relationships between critical dimensions, such as time and the unpredictability of MS, and emotional factors such as being proactive and gaining a sense of control, when exploring causalities in everyday life in the following way: *"I have also realised that where fatigue happens quite immediately after something, like going of the tube, then I know, there is a more direct correlation between one and the other. When it is something like stress and how busy you are that's harder because the cause and effect is a greater distance in time. I try, I mean, that's the thing, you just don't know. You can't say exactly, hand on heart, that's exactly what it is. You do your best to try and work it out because, I think, if I didn't, I wouldn't be feeling like I was being proactive. If I am proactive I am more in control and the bully [MS] is less in control."*

Notably, inaccuracy, uncertainty, and ambiguity in tracked data did not necessarily lead to frustration, but sometimes made room for speculations and explorations. For example, P6 reflected on the causal relationships she anticipated in the past and the uncertainty of her recently increased symptoms: *"But actually, if I was able to answer it [reasons for increased severity of symptoms], would I even want to know the answer anyway? Because if I can't do anything about it, then it would make it even worse. So, not being able to answer it and trying to, that, actually, gives me a purpose to explore it."*

Self-Knowledge and Health Expertise

Participants claimed to have gained bodily self-awareness, self-knowledge, and health expertise regarding how to live with MS. They reported obtaining practical knowledge about the disease and self-knowledge through both doing research online and self-tracking, which appeared to make them feel more rational, self-confident, and accountable. For example, before keeping a bladder diary, P4 thought: *"If I don't drink too much and I am going out, I won't need a toilet just halfway down the road."* After having kept the diary, her thinking was to some extent medically informed and more holistic in terms of the pragmatic implications of being hydrated: *"I've to think of the bigger picture that actually, being dehydrated will irritate my bladder even more. [...] By drinking more water in the morning rather than in the evening, that can stop me from going to the toilet more at night; [...] it flushes away toxins; it can help your immune system."*

However, people with MS explained that they were sometimes not able to find answers for their health related questions, especially, when medical data was not available or accessible. For example, P7 reported: *"I've been collecting data in my journal and now on my Fitbit, it's not the right data. It's not all of the data."* In addition to fitness data, she was interested in using annual MRI scans or blood values to infer whether her lifestyle had a positive impact on the progression of her MS.

DISCUSSION

This study has investigated self-tracking practices in MS self-management. Below, we use this understanding to discuss the intertwined role of the experience of control and mental wellbeing in self-tracking and address design consideration for future self-tracking technologies.

Self-Tracking to Support the Experience of Control

Participants in our study reported facing a lack of control when adjusting to the ambiguous, unpredictable, and degenerative nature of MS in everyday life. Our findings suggest that people regained a sense of control over MS through intertwining individual self-care practices with a wide range of different self-tracking technologies.

Perceived control is a seminal psychological construct that is defined as the “*belief that one can determine one’s own internal states and behaviour, influence one’s environment, and/or bring about desired outcomes.*” [43] A significant body of interdisciplinary research suggests that perceived control is an important factor in adopting and maintaining good physical and psychological health [37, 43]. Within HCI, Mamykina et al. have utilised the Health Locus of Control questionnaire in order to evaluate the application MAHI with diabetes patients and reported an increase of perceived control [29]. MAHI supported individuals with diabetes in changing their diet through self-monitoring and social interaction with diabetes educators.

In contrast to blood glucose values in diabetes self-management, there is no primary disease indicator in MS that can be effectively measured and controlled through self-care. Notably, MS is a degenerative and unpredictable disease that is neither curable nor controllable. The experience of control that we encountered here appeared to be grounded in a mindful mindset and positive wellbeing, involved coping with uncertainty when exploring causal relationships, and faded when experiencing relapses. Using self-tracking technologies alone did not support people to gain a feeling of being in control. Our study illustrates that the experience of control was related to entanglements between idiosyncratic self-care practices and different self-tracking tools, involving knowledge about the pathology of MS and self-knowledge about MS (disease monitoring), healthy lifestyles (fitness tracking), mental health management (life-journaling), and reflective thinking across personal health data and behaviour. Altogether, these key practices empowered people to regain a sense of control over MS.

Along with paper-based diaries, wearable fitness tracking devices played an important role in empowering people to self-manage MS. For example, participants used the ‘*novel*’ physiological data of activity tracking devices, such as heart rate, to not only maintain their fitness, but also to explore symptom triggers, such as stress. By gaining an understanding of their body and exploring how to adjust to these triggers they gained a sense of control over the

complex nature of MS. In contrast to prior studies [18], accuracy of tracking devices and uncertainty in personal health data played a minor role. Most participants in our study did not conduct experiments like scientists (cf. [40]), but tracked their individual symptoms in an idiosyncratic, open-ended fashion developing their own personal health data ecologies. They trusted not only in their agency to develop ‘*mental connections*’ across tools, tracked symptoms, and mundane actions but also stressed the benefits of the experience of the self-tracking practice itself, and, most importantly, believed in their own interpretations and assumptions they made.

This lived character of tracking practices in MS reveals a critical dimension that needs to be considered when designing self-tracking technologies for self-experimentation and self-diagnosis, which are increasingly explored within HCI [19] and beyond [25]. Self-experimentation tools have great potential to support self-tracking practices by providing guidance and evidence when identifying not only correlational but also causal relationships between symptoms and triggers [20]. Designing self-experimentation applications that encourage users to formulate a valid hypothesis, identify independent and dependent variables, and choose a single independent variable to test in the real world, poses not only conceptual challenges. Our findings suggest that pre-defined, dualistic, and deterministic design approaches of diagnosis could violate people’s agency and experience of control in self-managing their health.

In order to avoid dictating and mindless experiences, self-tracking technologies could empower people to proactively care for their health and wellbeing by mediating practice-based health expertise and fostering self-exploration. Rather than focusing on binary outcomes, applications could focus on the self-tracking process itself in order to support people’s reflective thinking and opportunities to explore what health behaviour might help to adjust to MS in everyday life. These considerations underpin the need for self-tracking technologies that consider the individual’s context [7], support personalisation [42] and customisation [18], and also foster self-discovery [27]. However, since knowledge about the complex pathology of MS was key when engaging in diagnostic tracking and gaining a sense of control over ‘*the unknown*,’ self-tracking technologies could provide practice-based health expertise. Relevant pathological knowledge, such as scientifically grounded associations between MS symptoms and health behaviour, can be translated from medical models to common language, iteratively elaborated, and evaluated with people affected by MS in order to uncover uncertainties and mismatches, surface their hidden health competence, and together co-create informative content for self-tracking technologies. In this way, we could mediate practice-based knowledge concerning why, what, and how to self-track and become more in control of “*the bully MS.*” (P10)

Self-Tracking to Foster Mental Wellbeing

Most previous research in HCI has addressed mental health tracking and management in populations that are affected primarily by mental illnesses, such as depression [16] and bipolar disorder [3]. We would like to draw attention to the role of self-tracking with the less visible but still significant mental challenges that people experience when living with unpredictable chronic conditions, such as MS.

Research has paid much attention to tracking physical mobility in order to assess the progression [32] and foster physical activity in MS [35]. Indeed, many participants in our study tracked their fitness in order to maintain their physical abilities. However, our findings highlight that there are concerns beyond tracking the performance of primary disease indicators: people living with MS had to deal with enormous mental challenges, such as dealing with the degenerative course of the disease and unpredictability of the next relapse, and being afraid of not being able to participate in social life at some indeterminate point. Our findings illustrate that people with MS were able to cope with some of these psychological challenges when engaging in self-tracking their health and wellbeing. Similar to Elsdén et al.'s work [12], we found that keeping a diary was perceived as therapeutic and supported people in coping with negative thoughts. In addition, our findings suggest that further self-tracking practices affected people's emotional wellbeing in similar ways. For example, some participants perceived documenting and identifying relapses as depressing, while others explained that it was important for their peace of mind. Many who engaged in disease monitoring admitted that focusing on symptoms could be sometimes hopeless but reported being proud and confident when they identified relationships between symptoms and triggers. In some cases, physical activity data revealed periods of stabilisation and enabled people to become more in control, instead of being led by fears about the progression of physical impairments.

These observations suggest that the design of self-tracking technologies should not only consider primary disease indicators but also needs to acknowledge the emotional and mental wellbeing of people who are living with an unpredictable and degenerative condition. Moreover, these findings exemplify that *mindful* self-tracking depicts a powerful strategy to cope with the psychological challenges people experience in everyday life. Mindfulness, the "*process of drawing novel distinctions,*" enables people to develop sensitivity, adopt alternative viewpoints, adapt to constant changes in life and, therefore, fosters the experience of control [37].

In order to aid mindful disease monitoring, the design of health tracking applications could, for example, be informed by an emerging class of hybrid systems that have not been explored in the context of chronic illness: smart journals are autonomous life-logging applications that draw on personal social, fitness, and contextual data [12]. They

facilitate open-ended self-tracking and imply in which ways entanglements between different tracking styles, such as life journaling, fitness tracking, and disease monitoring, could be supported. In this way, self-tracking applications could stimulate parallel thinking and reduce unintended effects, such as overly focusing on symptoms.

Moreover, fitness tracking applications could help individuals with MS to not only be mindfully active but also cope with physical decline in the long-term. Since people with MS had relapses and remissions over time, their experiences of being physical active were emotionally rich. Instead of focusing on increasing performances, design approaches of contemporary fitness tracking devices and applications need to be sensitive to considerable fluctuations in physical capabilities, motivations, and engagement. Tailored framing and visual cuts in data representations have been shown to be valuable techniques in the context of personal informatics [14] and offer further design opportunities to help people, who are affected by physical symptoms, not only to become aware of short-term improvements but also to recognise periods of stabilisation and stagnation in the long-term. Furthermore, drawing on biofeedback [37] and fostering an awareness of physiological changes before, during, and after being active could support people in recovering, avoiding overdoing it [33], and obtaining a balance between body and mind.

CONCLUSION

Most previous research has focused on common chronic conditions that typically involve disease monitoring. This study investigates different self-tracking practices of individuals living with multiple sclerosis, a complex neurological condition causing a wide range of physical, cognitive, and psychological impairments. We found that when experiencing a lack of control due to the unpredictable and degenerative nature of MS, individuals regained their sense of control over MS through intertwining individual self-care practices with different self-tracking tools ranging from paper-based diaries to wearable fitness tracking devices. In doing so, they engaged in disease monitoring, fitness tracking, and life journaling to understand the body and care for the mind. In this paper, we have focused attention on the role of emotional wellbeing in self-tracking and the role of self-tracking in regaining a sense of control over an unpredictable and progressive disease. We have discussed in which ways self-tracking technologies could support the experience of control and, rather than focusing only on tracking primary disease indicators, foster mindful experiences.

ACKNOWLEDGMENTS

Many thanks to all participants for sharing their experiences and to Clara Marques Caldeira, Katarzyna Stawarz, and our reviewers for providing constructive feedback on earlier versions of this paper. Amid Ayobi is funded by an EPSRC DTG studentship and Overseas Doctoral Award.

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