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Self-Tracking to Do Less
An Autoethnography of Long COVID That Informs the Design of Pacing Technologies

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ABSTRACT
Long COVID is a post-viral illness where symptoms are still experienced more than three months after an infection of COVID 19. In line with a recent shift within HCI and research on self-tracking towards first-person methodologies, I present the results of an 18-month long autoethnographic study of using a Fitbit fitness tracker whilst having long COVID. In contrast to its designed intentions, I misused my Fitbit to do less in order to pace and manage my illness. My autoethnography illustrates three modes of using fitness-tracking technologies to do less and points to the new design space of technologies for reducing, rather than increasing, activity in order to manage chronic illnesses where over-exertion would lead to a worsening of symptoms. I propose that these “pacing technologies” should acknowledge the interoceptive and fluctuating nature of the user’s body and support user’s decision-making when managing long-term illness and maintaining quality of life.

CCS CONCEPTS
• Human-centered computing → Interaction design; Interaction design theory, concepts and paradigms.

KEYWORDS
Self-Tracking, Phenomenology, Long COVID, COVID 19, Fitbit, Heart-rate monitor, Step counting, Post COVID-19 syndrome, pacing technologies, autoethnography, fitness tracking technologies

ACM Reference Format:

1 INTRODUCTION
The first wearable fitness tracking technology, the “Mambo-kei” which translates to “10,000 step meter”, was developed in Japan in 1965 and marketed as part of an anti-obesity campaign to encourage physical activity [100]. Since then, advances in hardware and sensors, low-power processing, and activity modeling have enabled new technologies that use on-body sensing and machine learning to automatically infer people’s activities throughout the day [18]. Modern fitness trackers have developed beyond being step-counting devices. These wearable technologies are typically embedded with sensors such as 3-axis accelerometers that track motion patterns, gyroscopes, altimeters, GPS location tracker, optical heart rate trackers and on-wrist skin temperature sensors [38]. Factors that these technologies track include number of steps, heart rate, body temperature, quality of sleep, stress levels and blood oxygen values. Though most commercially available self-tracking devices cater to users attempting to improve their health through collecting data on how the body functions and using this data to increase physical exercise, this paper addresses the adoption of commercially available self-tracking technologies to track ill bodies in order to do less.

The case specifically addressed in this paper is long COVID, a new, long-term illness that follows an infection of COVID 19. Motivated by the extraordinary experience of living with a new illness, and in line with a recent shift within the field of HCI towards first-person methodologies and phenomenological approaches, I use my own experience of having long COVID for 18 months and present how my experience of long COVID was shaped by my use of self-tracking technologies. The self-tracking device in question is a Fitbit - a wrist-worn sensor that is paired to a smart phone app that continuously and automatically tracks elements such as the number of steps taken, heart rate, blood oxygen levels and quality of sleep [33].

I present three vignettes that synthesize autoethnographic field-notes collected over 18 months. The first vignette describes how my Fitbit became a diagnostic device at a time when non-emergency medical expertise were unavailable due to the COVID pandemic and how this diagnostic information helped me understand my own illness and make decisions about day-to-day activities. The second vignette presents how I reversed the intended use of my Fitbit; the heart rate tracking and step counting affordances of the Fitbit were used to limit, rather than increase, my activity and fitness by not walking too many steps in a day, and by keeping heart beats per minute under a certain value. The third vignette depicts how using my Fitbit data to manage my illness became more complicated as I oscillated between illness and health.

The key contributions of this paper are the nuancing of the limited prior research on the use of commercial fitness tracking technologies to manage chronic illness through pacing. Pacing is a self-management technique for chronic illnesses that supports the balancing of energy and rest through dividing day-to-day activities into chunks. Decisions can then be made about which activities are appropriate in the context of the individual’s energy levels [40, 81]. Pacing techniques are relevant for illnesses that include the symptom of post-exertion malaise, where physical and mental exertion can exacerbate symptoms and energy levels, such as long COVID, multiple sclerosis and myalgic encephalomyelitis/chronic fatigue.
syndrome (ME/CFS) amongst others [31, 40, 43]. My autoethnography illustrates three modes of using fitness technologies to do less: pacing based on a “diagnosis”, real time pacing, and preventative pacing. This paper is a first step towards understanding the opportunities and challenges for designing technologies specifically designed to support pacing. “Pacing technologies” would be devices that would collect data from the user through worn sensors and self-reporting methods. This information would be presented to the user with the intention of helping the user avoid worsening of symptoms by over-exerting themselves. This paper contributes new questions about the optimal design of these pacing technologies, for example, that there is value in acknowledging and studying the interoceptive and fluctuating nature of the user’s body, and how designers should support user’s decision-making when managing and pacing during long-term illness in order to maintain quality of life.

2 RELATED RESEARCH
This paper builds on prior research on fitness tracking technologies and self-tracking chronic illnesses.

2.1 Fitness Tracking Technologies
Wearable fitness tracking technologies are employed to increase physical activity in order to improve health [18, 100]. Today, the most common examples of commercial wearable fitness tracking technologies are Fitbit [33], Garmin [91] and Apple watches [99]. Research within HCI has discussed how commercial fitness tracking technologies are designed as persuasive technologies [36]. Persuasive technologies are interactive devices that are designed to change a person’s attitudes and behaviors [34]. The most common persuasive method employed by fitness tracking technologies is self-monitoring [36]. Fitness tracking technologies translate physical activity into numbers and visual representations. This translation allows users to monitor their activity and set and achieve goals for themselves, for example, how many steps they want to walk and how many minutes of higher heart rate exercise they want to do per day. Previous research projects, e.g., Fish ‘n’ Steps [60] and Ubifit [18], found that providing data about physical activity raises consciousness and increases activity in the short term [18, 19, 38]. However, the effectiveness of longer-term uses and clinical applications of fitness tracking technologies has also been discussed [36, 79], and abandonment and episodic use have been shown to be common aspects of fitness tracking practices [17, 30, 39]. Critical design has been used to critique the ethics and normative and reductive approach to health embedded in commercial fitness tracking technologies [84, 97]. Other studies have also taken a critical approach to how inclusive fitness tracking technologies for users with different abilities and fitness levels [93], including wheelchair users [15] and the accuracy of the data provided by these devices [32, 103].

In line with the recommendations by Fritz et al., I present a long-term study of fitness tracking in the real world since a longer-term study can reveal how attitudes towards fitness tracking data change over time [36]. This is information that would be missed in a short-term study. However, in contrast to related research on fitness trackers, this paper addresses the rejection of persuasive methods in order to reduce activity, rather than increase it.

2.2 Self-Tracking Chronic Illnesses
A chronic illness is an illness that is experienced for more than one year and requires ongoing medical attention and/or limits activities of daily living [3]. Amongst many others, related research within HCI has addressed the self-tracking practices of people with chronic and long-term illnesses such as HIV, Parkinson’s disease, multiple sclerosis and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) [6, 8, 12, 72]. These examples predominantly address how technologies can be used by people with chronic illnesses to track their symptoms through smart phone apps that require users to manually input their daily symptoms and activities. Other related research has explored how commercial fitness tracking devices are involved in self-care practices of chronic heart patients with implanted cardiac devices [4]. These patients were found to use their fitness tracking devices in a range of different ways, including using the device to verify their bodily experience of their illness and to question associations between activities and events and symptoms [4].

Most relevant to my own research is Davies et al.’s [22] study of the wider self-tracking practices of people with ME/CFS. Though long COVID and ME/CFS differ in some ways, they share common symptoms such as post-exertion malaise, where mental and physical exertion causes a worsening of symptoms [43, 44, 54, 95]. Therefore, existing research on ME/CFS can contribute insights into long COVID [54]. Davies et al. draw on their interviews with people with ME/CFS to offer initial design recommendations for tracking tools specifically for ME/CFS. These recommendations include supporting the user in finding their own personal thresholds based on their individual needs through designing flexible self-tracking tools; helping users to budget their energy across daily tasks; finding ways to track mental fatigue as well as physical fatigue; motivating users to engage with their own data in the self-management of their own illness; and acknowledging that users will have “good” and “bad” days in terms of their physical and mental abilities that need to be accounted for by the tracking technology [22].

Davies et al. also observed that some of their participants with ME/CFS were independently adopting commercially available wearable self-tracking technologies and adapting them to use as “pacing technologies”. Davies et al.’s participants used the data gathered by wrist-worn fitness tracking technologies, such as number of steps, quality of sleep and heart rate values, to inform how much activity they could do in order to manage their symptoms. As one participant described “I use my step counter in reverse – to help me set limits on the number of steps I take so I am not suffering so much pain and fatigue the next day” [22] [p. 5].

Davies et al.’s study covered a wide scope of applications and did not provide an in-depth discussion or analysis of the use of wearable fitness tracking technologies for chronic illness tracking. Although Davies et al. recommend the design of wearable pacing technologies specifically for chronic illnesses, my autoethnography adds nuance to this recommendation and outlines the future steps towards designing pacing technologies for illnesses that include symptoms that can be managed through pacing.
3 METHODOLOGY

3.1 Autoethnography and Self-Tracking

Autoethnographies are typically longer-term studies where the researchers will place themselves in the research environment, either overtly or covertly. The experience of the researcher is captured through fieldnotes in the form of notes, photos and voice and video recordings and are later processed through “an extensive and skillful practice of writing” [23] [p.5] that allows for reflection on the “raw” field note data [28].

In recent years, the field of human-computer interaction (HCI) has increasingly acknowledged the first-person experience of the researcher as a valid source of knowledge [48], e.g., [24, 51, 62, 75, 102]. These types of research are carried out with the belief that there is value in the examination of the emotions, bodily sensations, and thoughts of researchers as subjects. For example, personal reflections on the emotional experience of design processes [9], and even research “failures” [45, 52] have become part of the HCI canon.

Similarly, in recent years, qualitative and ethnographic methods have begun to replace quantitative measures in research attending to the experience of using self-tracking technologies [7]. This shift in methods is driven by a shift in perspectives. From predominantly perceiving the user as a rational actor making informed decisions for self-improvement, researchers within HCI now see the user as collecting personal informatics through “a range of lived activities” [86], without necessarily having a specific goal to achieve [29]. Once HCI researchers moved on from viewing self-tracking through the lens of optimization, they could address how self-tracking shapes lived experience [20].

Autoethnographies are both product and process; where researchers position their own experience as the key data to be understood [28]. This method moves away from positivist approaches to data as being “neutral” and removed from its mode of production, i.e., the researcher’s own biases and interests, and the influence of the context of the data being collected [23, 62]. Autoethnography is an interpretivist and inductive research method that does not aim to produce reproducible truths about the world, but rather examines a particular phenomenon through the lens of the researcher’s body and subjectivity [16, 28]. The fact that the researcher is probably an expert in that particular topic is an important aspect of autoethnography – their autoethnographic account does not only equate to data gathered from a research participant [96].

Autoethnographies and doublethographies (where two or more researchers conduct autoethnographies on the same subject in parallel), have been proposed as feminist methods due to the examination of hierarchies of knowledge production, and for interrogating relational ethics [16, 37, 53]. For example, ethnographic methods have been used to examine the ethics of self-tracking technologies such as the Jawbone fitness tracker. During a 6-month doublethographic study of using the device, Cifor and Garcia found that it was gendered and constructed with a masculinist approach to the body as something that requires controlling practices through self-tracking [16]. Another doublethographic study documented the removal of self-tracking technologies as a method and found how menstrual cycle tracking technologies had inscribed societal norms about the menstruating body on the user in the long term, even after the menstrual cycle tracking technology was taken away [47].

Relating examples of autoethnographies specifically on chronic illness include Laura Forlano’s account of the “data rituals” involved in the complex experience of using an insulin pump and glucose monitor to manage type 1 diabetes [35]. Forlano uses autoethnography to “describe the day-to-day rituals required to participate in social norms, care for oneself, rest and recuperate, and even maintain relationships with loved ones.” Although they did not experience a chronic illness themselves, O’Kane et al., [78] employed autoethnography for the evaluation of a wrist blood pressure monitor used by people with conditions such as hypertension. O’Kane lived with the device for three months and used it to conduct twice daily tests on her body as if she did have hypertension, keeping fieldnotes such as photos and diary entries. O’Kane et al. argue that autoethnography is a useful first step in HCI research on medical technologies, that “allows practitioners to capture some of the subtleties and nuances of those contexts that can influence the adoption and use of a device not easily achieved without experiencing them” [p.990].

In this paper, autoethnography is employed in line with Forlano: to capture, examine and communicate the sensorial and emotional richness and complexity of the experience of using a technological device during illness, and in line with O’Kane et al.: to contribute knowledge to the development of new design spaces for self-tracking technologies designed specifically for chronic and long-term illnesses.

3.2 Method

The autoethnography presented in this paper was not a pre-planned study, but rather began four months after catching COVID 19 - at the point when I bought a Fitbit fitness tracker and felt that the experience was interesting enough to document. The vignettes presented in this paper are made up of fieldnotes on events and thoughts about my illness and use of my Fitbit that I collected in the Notes app and recorded as voice memos on my iPhone. I recorded a total of 35 minutes of voice notes and spent approximately a total of one hour every four weeks writing fieldnotes. These notes were often made in short form on my iPhone when an event occurred and then expanded upon at a later point in time on my laptop. I did not pre-determine prompts or topics for these fieldnotes beyond them being related to my use of my Fitbit during long COVID. I synthesised my fieldnotes through thematic analysis alone in three separate sessions where I developed a narrative through transcribing my voice memos and reading through my fieldnotes. I have changed the tense of the vignettes to the past tense to reflect the fact that these are syntheses of my original fieldnotes, which were originally written in the present tense.

The first synthesis took place nine months into the autoethnography. This process resulted in the first and second vignettes. The second synthesis process took place 16 months into the autoethnography and resulted in the third vignette. At a third stage of synthesis, 18 months into the autoethnography, I analysed the three vignettes according to the common themes emerging and began removing aspects that were not related as closely to these themes.
These vignettes are not presented as medically validated recommendations about how self-tracking technologies can help people with long COVID. They are my own personal account of decisions I made about my own health and body. I am not a medical professional, and I was not advised by my doctor to adopt a Fitbit device.

4 BACKGROUND

To contextualise the following autoethnography, I will present some background information about me and my illness, drawn from memory as well as my autoethnographic fieldnotes. I am in my early thirties, and, before long COVID I regularly did yoga and went to the gym. I had no pre-existing illnesses and didn’t take any medication. I did not use any type of tracking device before catching COVID 19.

4.1 Long COVID

Long COVID, also called post-COVID syndrome, is an illness caused by an infection with the COVID 19 virus. The World Health Organisation (WHO) definition is that; “Post-COVID-19 condition occurs in individuals with a history of probable or confirmed SARS CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.” [2]. Over two and a half years on from the advent of the COVID 19 pandemic, long COVID’s pathology is still not understood; there is not yet sufficient peer-reviewed research that shows the causal factors of long COVID in the bodies of sufferers, and there are no fully validated cures or treatments available [21, 54]. Long COVID symptoms change over time, and we are still yet to see the long-term effects; how will the lives of those with long COVID be affected over the next few years and decades [11, 95]. There is no test for long COVID, though some are currently in development [83].

I first became ill with COVID 19 in the end of October 2020. My initial experience of COVID was as sensitivity to light, mild fever and, after four days, loss of taste and smell. It was not the worse flu I have ever had, and I expected to be back to work after two weeks. Once the flu had passed, I was very tired, and I noticed that I felt faint when I stood up, but I assumed that I was still just weak from recovering from the virus. A month passed and my smell and taste returned, though altered and severely weakened. I tried and failed to return to work. The fainting on standing persisted and was joined by constant vertigo and nausea. The fatigue became more severe, and the breathlessness became much more noticeable. I started to have gaps in my memory. I couldn’t concentrate and felt sensorially overwhelmed by too many people, lights, or sounds. Over the next 6 months my symptoms worsened to the point where some days I needed help to walk around the house and shower since I would feel so faint and nauseous when I stood, or my legs would collapse under me. I had post-exertion malaise, where any exercise would leave me shaking and faint for hours or days afterwards.

During the nights my feet and hands would become numb and painful. Now, 22 months on from catching COVID 19, most of my symptoms have improved, though the memory loss, breathlessness, headaches, and fatigue still need managing day to day. I am still unable to do exercise without relapsing. At the time of writing, I have begun to return to work four days a week as an Assistant Professor at the University of Copenhagen.

There is no proven clinical explanation for my symptoms beyond the fact that they are caused by COVID 19. I am enrolled in the Long COVID clinic at a hospital and have two cardiologist doctors. During my illness, I have had four rounds of complete blood tests, three stress tests on a bicycle to measure cardiac activity and oxygen uptake, three ECGs, one chest X-ray and one heart ultrasound, which have all come back “normal” except for one tilt table test that showed a blood pressure disorder caused by COVID 19.

4.2 Motivation to Start Tracking

I bought a Fitbit four months after the initial infection of COVID 19 because I suspected that my long COVID was causing an autonomic nervous system disorder that was triggering an increase in my heart rate when I stood up, and it was this that was leading to the fainting and dizziness. If the difference between the heart rate value when sitting and standing is more than 30 beats per minute, then it is a sign that the nervous system is not regulating the blood flow correctly and could be a symptom of POTS (Postural orthostatic tachycardia syndrome) or orthostatic hypotension [82].

The suspicion that long COVID had provoked an autonomic nervous system disorder arose when I was referred by my doctor to a physiotherapist for an initial health assessment a few months after catching COVID 19 when I realised that I wasn’t recovering as expected. The physiotherapist asked me to wear a heart rate monitor for a stress test that included me walking up and down a corridor to assess my fitness levels. She attached the monitor to my finger whilst I sat in her office. My heart rate was around 60 beats per minute (bpm) until I stood to walk to the corridor. As I stood up, she said “Oh the monitor must be broken” because my heart rate had quickly risen to 120bpm within one minute, even before I had begun to walk. We tried it again to check but had the same result every time.

One week after the health assessment, and before I could undergo follow up investigations, I had to move so that I could be looked after by my parents since I was too poorly to care for myself. It was almost impossible to access non-emergency medical help there due to the severity of the COVID 19 pandemic at that time. I was told that the only contact with a doctor would be over the telephone, and there was a several weeks or even months long waiting time even for that. Since I could not see a doctor to be properly assessed for an autonomic nervous system disorder, I purchased a Fitbit to track my heart rate and find out if my symptoms consistently matched with the diagnosis criteria for an autonomic nervous system disorder as described above. This diagnosis was eventually validated with a tilt-table test at the hospital where I was officially diagnosed with the autonomic nervous system disorder provoked by the infection of COVID 19 called orthostatic hypotension, a general blood pressure disorder, that was causing my heart rate to race when I stood up [68].
4.3 My Use of my Fitbit

I chose my Fitbit Charge 4 device because it has a clear display of my heart rate data on the watch face, and that was the element I originally wanted to track. It was mid-price and had good reviews from previous buyers. In fact, I did not like the look of my Fitbit, it is rubbery, large, and not something I would have chosen before having long COVID. When I chose my Fitbit I did not consider the aesthetics of the different tracking watches available; I bought it assuming I would wear it for a few months lying on the sofa at home and then I would recover and go back to wearing my non-smart watch. I did not use all of the functions offered by my Fitbit and did not pay for the premium account that would offer me more types of data. The main functions I consulted included the step-count, heart rate, sleep quality and menstrual cycle data. I also downloaded a supplementary app called Cardiogram that uses data collected from my wearable Fitbit device to give a finer grain of detail about my heart rate than the Fitbit app can offer [80].

5 SELF-TRACKING TO DO LESS

I will now present the three vignettes synthesized from my autoethnographic fieldnotes collected over 18 months.

5.1 First Vignette

From when I purchased my Fitbit, until 6 months later when these symptoms mostly faded away, every time I went from sitting or lying down to standing up, I would pause, staring at my Fitbit device interface on my wrist. The initial value would be around 60 bpm. After one minute, the numbers would slowly start increasing faster and faster. As I watched these number rise, I felt a hot rush of blood to my head that would result in faintness and a headache. The final value could be anywhere from 90 to 140bpm (figure 1). After a few minutes of standing the numbers would start cascading down to a more normal 70 or 80bpm.

The value at the peak of this spike in heart rate shaped how I viewed the severity of my long COVID illness; the higher the value, the sicker I would see myself on that day, even though this wasn't based on validated medical information. If I got out of bed and the peak of the heart rate spike was 140bpm, I felt like I would have a bad day and would probably just stay in bed rather than try to take a walk. Since I couldn't get access to a doctor for a clinical assessment, and because there was so much unknown about long COVID at that time, this was the only objective information I could use to decide on what activity was appropriate that day. I would often deliberately stand up more quickly than I needed to just to see the state of my condition reflected in the numbers increasing on my Fitbit tracker interface, even though standing up quickly would make me feel ill. This information would over-ride how I felt physically that day.

5.2 Second Vignette

Around 3 months after buying my Fitbit, I joined my friends on a weekend trip to the seaside. I managed to participate in a few of the activities and spent the other time in bed at the hotel. Despite this, I pushed myself to do more than I had before. On the second day of the holiday, we were walking through the local village when my wrist started vibrating. It took me a while to work out that the sensation was coming from my Fitbit since this was the first time it had happened. I looked at my Fitbit and saw there was a pixelated animation of fireworks and flying birds lighting up the screen. I was very confused. One of the birds in the animation was pulling a banner and I saw that it said “10,000 steps!” I immediately felt a powerful flush of horror and started crying. Had I really walked 10,000 steps? How could I have done this without noticing? Rather than being happy that I had managed to walk so much further than I had before without feeling the effects, I instantly played out the repercussions of this in my head. I felt sure that walking 10,000 steps would cause a relapse. It was not that I was feeling tired and
could feel in my body that I’d walked too much, but rather, it was seeing the numbers that caused this spiral of anxiety. The joyful animations make this data even harder to accept. Being given bad news in the format of “good news” highlighted how far away I was from a normal, healthy, user of a Fitbit device.

Since I had post-exertion malaise, where symptoms worsened after physical and mental exertion, limiting my daily activity was much more important to me than leading Fitbit’s definition of a “healthy lifestyle”. For healthy people, 10,000 is supposedly a good amount to walk to maintain fitness. Instead, I would congratulate myself when I stuck to under 5,000 steps, preferably around 3,000 on a day when I wasn’t feeling well, since I’d learnt that walking more than this would lead to my symptoms getting worse over the next few days. I turned off Fitbit notifications that prompted me to walk 250 steps an hour to keep up with the pre-set fitness goals and ignored the banners within the Fitbit app interface that suggest I get my heart rate in the “zone” to burn fat and increase stamina.

As well as limiting my steps, I also began using my Fitbit to set my walking pace to make sure my heart rate didn’t go over 110 beats per minute (bpm) for too long. I did this after seeing other people in long COVID support groups on Facebook saying they did the same to help them avoid post-exertion malaise. When climbing a flight of stairs, I would look at my Fitbit and walk slowly enough to avoid a big spike in heart rate and pause at the top step to wait for my heart-rate to return to 100 bpm before I continued walking. Because my illness changed from day to day and week to week, what it took to raise my heart rate also changed. Some days I could walk at a nearly normal speed and my heart rate would be 120bpm, and some days I could reach 120bpm when walking slowly at a snail’s pace.

5.3 Third Vignette

After having long COVID for 15 months, my symptoms began to change. I could start to live as I did before COVID 80% of the time. My cognitive symptoms were almost gone, with occasional relapses when I didn’t pace myself properly. The last hurdle was exercise and physical exertion as any attempts to work out and cycle resulted in a raised heart rate for days afterwards and possibly a relapse in symptoms.

After a final test at the Long Covid Clinic at the hospital, where they measured my heart activity and oxygen uptake whilst I peddled on a stationary bike, I was told that my cardiological and lung health is concerning. From a scale of health from green to red, I was in the orange, almost red. This was shocking in comparison to how active I was before COVID 19. I was told by my doctor that I need to start increasing physical activity to avoid other health problems. This felt like a very thin tightrope to walk; not provoking post-exertion malaise by doing too much, and not allowing other health problems to surface because of inaction.

After being given this warning, my use of my Fitbit changed. If it was a good day, when I didn’t feel any severe long COVID symptoms, then I could consider increasing my number of steps and would even take the longer route walking to the metro. I’d deliberately increase my walking pace so that I reached 120 bpm with the longer-term goal of getting my body used to exercise. On bad days, when I felt tired or breathless, I was back to walking as little as possible, taking short-cuts, and cancelling activities. If my heart rate went over 110 bpm I experienced a sense of panic; I felt my energy being burnt up when I really wanted to conserve as much energy as I could for healing.

In this phase of long COVID, the desire to maintain my recovery also transferred into my choice of stationary activities. On my Cardiogram app, if my heart rate is under 60 bpm the graph turns blue (figure 2.). This colour is not given any specific meaning in the Cardiogram app. In this later phase of long COVID, my stationary heart rate was lower than it was during the majority of my illness, and I could get more of these blue zones during the day. This led to me chasing these blue zones with the belief that these were good sign, since, if my heart rate was low, then I was in a state of relaxation where my body could heal. I felt like I was playing a game where the goal was to collect as many blue zones during the day as possible. If I was sitting still and my heart rate was in the orange zone, then I saw it as a sign that my body is in a state of stress and that I was not resting and healing properly. In figure 2. it is visible that on days I walked more, my heart rate was higher even when I was stationary.

None of these beliefs were founded in information given to me by my doctor, and though they are accurate in terms of general pacing guidelines [31] and my own experience that exertion and a high heart rate causes a relapse and post-exertion malaise, this is a very simplistic and not totally logical way of defining a health goal for myself.

I knew cognitively that to divide my life into activities that give me a blue zone (under 60 bpm) or an orange zone (above 60 bpm) isn’t sensible. For example, I had blue phases when scrolling on social media for hours but knitting gave me a heart rate over 60bpm, this doesn’t mean that social media is more “healing” than knitting. On hot summer days when my heart rate was higher just because my body was trying to keep cool, I berated myself for not reaching the blue zone. Despite knowing that it doesn’t make complete sense, checking my blue zones was clearly something I found emotionally useful and meaningful since I kept doing it. I checked my Cardiogram app every hour or so, almost obsessively, to the point where my girlfriend commented on it. When the Cardiogram app was down for maintenance for 24 hours, I felt very frustrated. When I was resting it didn’t feel validated as really resting because I couldn’t visually document that I was in the blue zone.

I did not use any type of activity tracking device before catching COVID 19. This meant that I didn’t know what my Fitbit data looked like when I wasn’t ill. This led me to wonder whether my health goals in this final stage of recovery were meaningful. Maybe my heart rate was always 120bpm when walking? and maybe I normally walked 6,000 steps a day, rather than 10,000? And when would collecting data lose its value? I looked forward to getting rid of my Fitbit when I was more fully recovered. After living with long COVID for eighteen months, my concept of a health was one that was boundary-less and that didn’t require pacing. Living without needing to track was my definition of full health. I wondered: when would I deem myself “healthy enough” to stop tracking?
6 DISCUSSION

6.1 Misuse of Self-Tracking Technologies

The tagline on the Fitbit website reads “Packed with the features that fuel your fitness journey, these trackers were made to help you live a healthier life” [15]. Fitbit devices are designed for, and marketed towards, people aiming to improve and maintain fitness through encouraging activity and increasing stamina and strength in order to reach full health. There is an assumption that the user is in good health in a normative sense, and that increasing physical activity will merely enhance this level of health [93].

Though my use of a Fitbit to do less can be labelled as “misuse” because it contrasts the intentions the Fitbit designers had for the device, misusing self-tracking devices is in fact in the lineage of biohackers and members of the global Quantified Self community, also known as Quantified Selfers. These are people who collect data from their bodies through sensors and self-documentation and use medical knowledge to interpret the meaning of this data to inform their lifestyle decisions and their understandings of their own bodies and health. They adopt and adapt existing technologies and develop their own technologies and tools in order to gain “self-knowledge through numbers” [101]. For example, by using glucose tracking technologies designed for people with diabetes to gain insights into how their blood sugar levels react to particular foods [1]. The rhetoric is that having access to their own health data empowers them as individuals and enables them to make better choices in improving their health [66, 74].

The stereotype of the biohacker and quantified selfer is a healthy individual who is pushing the boundaries of what we consider good health; for example, with the aim of living drastically longer than the average life expectancy. The aim is to “hack” life and health [56]. However, chronic illnesses are a common topic on the Quantified Self website, and the notion of “health” is not only in terms of achieving transhuman goals [92, 101]. For example, Nafus and Sherman describe how quantified selfers use “soft resistance” against norms around health and data analytic to escape the biopolitics of “expert categories of health” [74] [p.1792]. My own misuse of a Fitbit reflects this use of technologies to attempt to achieve my own individual definition of “health” as someone with long COVID.

Johan Redström suggests the term “use-design” to describe the way in which users re-define the use of the device through their mode of interacting with it by rejecting the intended use of the device - the “thing-design”. He discusses how use-design can lead to changes in the thing-design by adding or removing elements of the initial design [85]. For example, how the skateboard was invented after children started playing with scooters that had lost their handle.

It is clear that chronic illnesses, and particularly the recent prevalence of long COVID, has led to use-design informing the thing-design of self-tracking technologies. As observed by Davies et al., I am also not alone in misusing commercial self-tracking devices such as Fitbit and Garmin watches to manage chronic illness [22], and as I described, my own use of my fitness tracking device was informed by others on long COVID Facebook support groups who had adopted Garmin and Fitbit fitness tracking devices with the same intention. Similarly, the founders of a commercial start-up, Visible, were also inspired by the experience of having long COVID. Visible are currently in the early stages of developing a wrist-worn device that is described as the first pacing device of its kind. The device “track(s) illness-specific metrics including HRV (heart rate variability), fatigue, sleep disorders, dysautonomia & more” and is specifically designed for people with long COVID and chronic fatigue syndrome [98].

In these cases, fitness tracking technologies have become “pacing technologies”. As mentioned, pacing technologies are devices that collect data from the user through worn sensors and self-reporting

Figure 2: Screenshots from my Cardiogram app from August 2022 showing the difference in the amount of “blue zones” from one day to another depending on physical and mental activity. The green bars on the bottom of the graph show the step frequency at that time.
methods in order to provide information to help the user avoid over-exerting themselves and worsening symptoms by pacing their energy through deciding which activities appropriate to do that day. These technologies are relevant for illnesses that include the symptom of post-exertion malaise such as long COVID, multiple sclerosis and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) amongst others [43].

Except for the nascent Visible device, pacing technologies for managing chronic illnesses that involve post-exertion malaise do not yet exist. However, existing lay-person practices, such as described by Davies et al. [22] and evident in my long COVID Facebook support groups, and my own experience of managing long COVID points to the clear value in the design of pacing technologies [22]. This means that there are still many unanswered questions about how these devices could be designed in terms of their function and aesthetics. I propose there is value in further HCI research on technologies used as pacing devices to better understand this unexplored design space. For example, further studying the existing fitness tracking practices of people with chronic illnesses, including long COVID, as well as analyzing the Visible device (once it is deployed) from the perspective of HCI, in order to understand the implications and opportunities of this new “thing-design” of fitness tracking technologies [85].

6.2 Modes of Pacing

If we are to design pacing technologies, we need to understand the different ways in which these technologies might be used to manage chronic illnesses. One contribution of my autoethnography is that it adds nuance to Davies et al.’s recommendation for the design of wearable technologies to help people with chronic illnesses pace their activity. My autoethnography illustrates three different modes of pacing that are possible when using a fitness tracker to do less during chronic illness.

- Pacing based on a “diagnosis” – I used the value of the peak of my heart rate spike when going from sitting to standing to diagnose the severity of my illness that day to dictate how much activity I could do.

- Real time pacing – I would use self-imposed limits on my real-time heart rate and step count data to continuously adjust my movements and activities in the moment to avoid worsening of symptoms in the short-term.

- Preventative pacing – I attempted to keep my heart rate data as low as possible when doing sedentary activities with the belief that this would contribute to my long-term recovery.

The type of tracking recommended by Davies et al.’s relates only to the second type of pacing evident in my autoethnography: real-time pacing where pacing is done based on real-time data to avoid short-term relapses. This example of pacing represents a tight loop between the self-tracked data and the decision made based on this data. For example, I see on my Fitbit interface on my wrist that my heart rate is 120bpm so I slow my walking pace until it is 100bpm since I have experienced in the past that I will feel worse tomorrow if I walk at 120bpm for a long period of time. The other two types of pacing evident in my autoethnography - pacing based on a “diagnosis” and preventative pacing - represent a messier relationship and looser coupling between the action and the impact of this action on the health of the user.

Pacing based on a diagnosis represents a messier relationship between 1. the status of the illness “diagnosed” by the value at the peak of the heart rate spike when going from sitting standing (e.g., as described in the first vignette, a diagnosis of a “bad day” because the peak of my heart rate spike was 140bpm when standing up), and 2. my behaviors as informed by that diagnosis, (e.g., to stay in bed rather than go for a walk). The term “diagnosis” is not used here to denote that there is some kind of scientific validity to the meaning of the value at the peak of the spike, but rather to communicate that I treated this value as such due to lack of access to medical experts during the pandemic and a general lack of information about the illness of long COVID. I felt that the value at the peak of the heart rate spike was giving me a diagnosis of the impact of less tangible factors that influenced my health that day. This could be past actions, such as how many steps I’d done the day before, but also general fluctuations in my health that I didn’t have an explanation for. This example of pacing represents an attempt to find a way to gain a sense of control over the uncontrollable and unexplainable aspects of illness, and pace activities based on that information.

Preventative pacing is an example of a looser coupling and a longer-term relationship between the action (movement and physiological exertion) and the impact of this action (worsening or improvement of symptoms) during pacing. Though the mechanics of this kind of pacing are similar to real-time pacing (using self-imposed limits on my heart rate data to make decisions on which activities were appropriate) the mentality behind it was very different. At the core of this mode of pacing was the belief that keeping my heart rate as low as possible would improve my future health and quicken my recovery time from long COVID. If I could “collect” as many blue zones as possible, then my overall health would improve. Rather than pacing to avoid symptoms worsening in the short-term, preventative pacing was done specifically with the aim of optimizing health from a longer-term perspective.

6.3 The Design of Pacing Technologies

Although pacing technologies would probably have many similarities with fitness technologies in that they could use sensors attached to the body to collect data and a visual interface for self-reporting data and accessing information, my experience of using a Fitbit whilst having long COVID points to new design openings for technologies that provide novel experiences of being ill. As well as the previously mentioned different modes of pacing that designers could consider in the design of pacing technologies, I also contribute the following design considerations drawn from my autoethnography in the form of questions about the possible and preferable aspects to be considered when working within the new design space of pacing technologies. Although further research methods could be applied to evaluate these design directions in terms of their generalizability, predominantly these design directions represent ways to think through how we could conceptualize illness and the body within HCI.

6.3.1 Relegating Interoceptive Information. As mentioned, my initial motivation to buy a Fitbit was to document my heart rate...
increasing as I stood up. I felt the effects of my heart rate increasing (feeling faint and sometimes feeling my heart beating in my chest) but I needed an external device to keep count and document this data for it to become something that I could relate to the medical diagnosis of an autonomic nervous system disorder – where the heart rate rises by more than 30 bpm when standing up [82]. Clearly, when trying to reach an explanation or diagnosis for felt symptoms, translating the body into an objective form of data is useful. It is difficult to accurately articulate and compare our felt experiences of our bodies and illnesses with other people, partly because our experience of the insides of our bodies is vague and often temporally and spatially ambiguous and because we can never know how our own word for pain, for example, relates to another person’s experience of pain [58]. For these reasons, the epistemologies of modern medicine are built upon finding objective methods to track and compare communalities and trends between the experience and pathologies of illnesses to eventually attempt to find a treatment or cure [58, 94]. However, self-tracking technologies are not diagnostic devices in the typical medical sense. Although normative metrics and medical knowledge about the body is involved, these devices will be predominantly used not to compare the user to other people, but rather, to compare themselves to a past and sometimes future self through data collection and algorithmic predictions, either simply to document for documentation’s sake, or to achieve a specific goal [29, 86].

In my autoethnographic account, it is evident that knowledge produced by my body was seen as less valuable than data produced by my Fitbit. This is in spite of the fact that fitness tracking devices are often known to be inaccurate, for example Fitbit was found to meet acceptable accuracy for step count approximately half the time and is especially inaccurate in contexts where the walking speed is reduced [32, 103]. The three modes of pacing presented above clearly show that I would use my Fitbit data to make decisions about how I would pace, regardless of how I felt physically and mentally in the moment. My own experience related to other users of fitness tracking technologies, who have an “extreme focus” on numerical goals and numerical data rather than data gathered through our interoceptive sense [36]. Smith and Vonthethoff found that members of the Quantified Self community “outsourced” their sensory and phenomenological knowledge about their bodies to self-tracking devices in order to achieve their own definition of health by using quantitative data to compensate for the “deficient” data emanating from the felt sense of their body alone [92]. Andersen et al. also found that chronic heart patients’ main use of their fitness tracking device was to verify their experience of their illness by matching their symptoms with data patterns provided by their fitness tracking device [4]. Similarly, in a previous study, my colleagues and I found in our duetethnography that removing menstrual cycle tracking technologies from our lives left us feeling “abandoned” and “lost” without definitive external data to compare our vague and indistinct lived experience of our menstrual cycle against [47]. This is also reflected in the third vignette in my experience of feeling real frustration when I couldn’t access my heart rate data to validate the fact I had been resting when my Cardiogram app was updating.

Self-tracking technologies such as fitness tracking technologies and health tracking technologies communicate specific societal and cultural perspectives on the body [46, 64, 93]. It is evident that objectifying epistemologies and perspectives on the body from modern medicine have seeped into non-diagnostic practices of self-tracking; objective data on the body beats interoceptive experience of illness [45]. Feminist theorists and philosophers state that this represents Cartesian and androcentric epistemologies that value certain ways of knowing above others and relates to societal perspectives on the body as something negative and unruly that can only be understood and compensated for through objective methods of documentation [41, 88, 90].

Feminist theorists state that this perspective is problematic since promises of false objectivity risks obfuscating the societal norms and prejudices embedded by designers and developers into the technologies themselves, i.e., we can never gather “raw” or “true” data on the body since technologies always colour the data they produce [10, 25, 41, 55]. False objectivity communicated by quantitative data risks obfuscating the societal norms and prejudices embedded by designers into the technologies themselves [25, 46, 55]. For example, where the “preferable” and “normal” bodies in society are defined by arbitrary metrics and numbers [46]. This relates to the biopolitics surrounding what Deborah Lupton describes as “the digitally engaged patient” [65]; one who responds to external pressures to stay productive and avoid becoming a burden to society through self-monitoring through adopting quantifying and objectifying technologies in sickness but also health [87].

However, although quantitative tracking practices perhaps exemplify a normative perspective on health and wellbeing in society, self-trackers themselves find quantifying practices beneficial. For example, Smith and Vonthethoff describe how a Quantified Selfer with diabetes found “this shift (of the burden of healthcare onto the individual) was empowering: she felt reassured from being able to reclaim control over the management of a condition that had previously felt intractable” [92] [p.11]. This is evident in my own autoethnography; how I gained a sense of control over my illness when I could make pacing decisions based on objective data, even if this data was not proved to be medically valid, accurate or informative. As I described in the first vignette, I would even deliberately provoke feeling unwell by standing up quickly, just to have my symptoms validated by quantitative data from my Fitbit.

I propose that pacing technologies could be designed to include the bodily experience of the user in the tracking process alongside quantitative data. Collecting more data on the bodily experience of the user might help temper the dominance and false objectivity and neutrality of the quantitative data. Pacing technologies could be designed to bring the quantified data on the body into a discourse with the lived experience of the user. For example, on days when I woke up and my Fitbit showed me a high heart rate difference when I stood up, perhaps I could have been invited to take a moment of interoception to contextualise this data before making decisions about what I would or would not do that day. Perhaps I would have made different pacing decisions and taken a more positive outlook if I had understood quantitative data as just one piece of information on my illness, rather than a totalizing diagnosis; I might have gone on to have a “bad day” from a quantitative perspective, but a “good day” from a qualitative perspective.

As well as having benefits from the perspective of deciding which societal values are, and are not, embedded in technologies, related
HCI research on symptom tracking technologies for other illnesses has shown that the interoceptive abilities of the user are a valuable asset, not only in terms of gathering more in-depth data about the symptoms experienced so that the user could track patterns and triggers for their chronic illness, but perhaps also in providing experiences that support additional benefits psychologically [8, 69]. Although pacing technologies have different aims – to collect data to make decisions about present and future activities, rather than construct a picture of the cumulative history of the illness, I propose that designers of pacing technologies can also draw on findings from design research on symptom tracking devices. For example, the multiple sclerosis symptom tracking app, Trackly, allows users to colour in and design their own images to represent their symptoms. This led to an increased sense in control and empowerment and self-reflection on emotions; qualities that were deemed beneficial by participants [8].

Although it seems like a promising direction to explore, if we are to design pacing technologies that involve the interoceptive skills of the user in their pacing, designers would need to address questions such as: what aspects of bodily experience could be and should be included in the process of pacing? And since numerical data is apparently the preferred form of knowledge, what is the perceived value for the user of including their bodily experience? How can we design technologies to fully capture the rich interoceptive experience of the user?

6.3.2 Supporting Decision Making During Pacing. Self-tracking technologies are, by their very nature, reductive [63, 67]. Self-tracking technologies only count the number of steps and the heart rate values of life’s rich experiences. In practice, pacing involves making complex and emotionally informed decisions about which activities to do and which activities not to do in order to avoid making symptoms worse. Quality of life is in constant dialogue with the status of the illness. Prioritizing activities that aid recovery makes sense when recovering from a short-term illness, e.g., where a week in bed would get rid of a cold. However, chronic illnesses last for years, and sometimes a whole lifetime [3]. As exemplified in the mode of preventative pacing, the relationship between present actions and future wellbeing is incredibly complicated. During long-term illness, the binaries of illness and health, typically applied in HCI, break down. Rather than longer periods of health being punctuated by short infections and viruses, chronic illness is experienced as a spectrum of good days, bad days, and relapses and remissions.

In contrast to fitness tracking technologies, which promise optimized access to a faster and more active life, pacing technologies would deliberately turn the user towards a reflective and slower mode of living. In line with Hallnäs and Redström’s design philosophy of slow technology and the related practice of slow design, chronic illnesses such as long COVID invite for the design of technologies that reflect an emphasis on reflection and experience, and an alternative conception of time and productivity [42, 76, 77]. For example, “a basic principle of slow technology is to amplify the presence of things to make them into something more than just a silent tool for fast access to something else.” [42] [p. 209].

People with chronic illnesses would not expect technologies to offer a fast track to recovery (if they even expect recovery at all). There were many examples during my illness where I decided to abandon my pacing practice for a short time in order to do activities that were fulfilling in other ways. For example, to go away with friends for a weekend by the seaside, even if it led to me walking 10,000 steps and risking a relapse. If I was solely focused on maintaining inactivity in the here and now for the sake of a future self, is that the “healthy life” I really wanted? Do I really want to choose scrolling on social media rather than knitting just because it keeps my heart rate under 60 bpm? What is my priority in the short-term and the long-term and how do I balance these two aspects? As illustrated by my autoethnography, when someone is ill for such a long time, choosing inactivity over activity can evidently have negative impacts that perhaps outweigh the risk of over-exertion.

Once we reject a normative definition of “illness” as something to be recovered from, rather than something to live with, I propose that slowness and reflection can also be reflected in the design of these pacing devices that abandon normative ideals about what activities are and are not appropriate during illness, and instead engage the user in reflective conversations about what is important to them in that particular context. This leads to questions such as: How can pacing technologies support the prioritization and decision-making process when finding a balance between managing a chronic illness whilst maintaining quality of life? And how could designers work with medical professionals to manage the risks around managing chronic illnesses from a medical perspective whilst still attending to the user’s psychological wellbeing?

6.3.3 Understanding and Designing for Dynamic Illnesses. Chronic illnesses are inherently long-term. Therefore, interactions with pacing technologies will also take place over the long-term. Some argue that long-term interactions with technology is still an under-explored aspect of HCI [76, 77]. I propose that an even less explored aspect is how our long-term interactions with technologies are shaped by how our bodies change over time, especially during illness when the body is in a more frequent state of change. Many chronic illnesses, including long COVID, are “dynamic disabilities” that are episodic and are experienced as a continuous spectrum of relapse and remission [11, 73]. The chronically ill body is constantly in a state of flux.

The sub-field of the philosophy of phenomenology, phenomenology of illness, attends specifically to how illness is experienced, and how illness shapes our experience of the world around us [14]. Phenomenologies of illness argue how an individual’s phenomenological (from a first-person perspective) experience of illness is not fully captured in the medical diagnosis of the illness itself. The experience of illness is informed by a plethora of factors including the everyday aspects of being ill; the changing sensations and bodily experience of the illness; and medical encounters. The argument for adopting a phenomenological approach is that, by investigating subjective experiences, we can articulate a more nuanced understanding of illness, outside of the definition given in a medical textbook [14, 58, 59]. This approach is particularly relevant in my case. My Fitbit literally defined what long COVID was since the illness was, at that time, undefined in medical discourse due to its newness. All I had was my own experience and the phenomenological accounts of others presented on social media support groups for long COVID. Philosopher Havi Carel proposes that a phenomenological
approach to illness can help combat the negative associations of the body during illness in society and draw out the positive aspects through studying the day-to-day emotional aspects of being ill [14].

Based on my autoethnography of long COVID, I propose that there is a lot to be gained from adopting a similar perspective attending to the experience of illness in HCI in 1. developing methods to explore how users’ changing bodily states influences interactions with technologies, and 2. designing technologies that account for the changing state of the user during illness.

Currently, phenomenologically informed methods within HCI do not focus on how the changing inner state of the user influences interactions with technologies. Merleau-Ponty, the philosopher of phenomenology whose work is arguably most commonly adopted in research on the body in HCI, only briefly referred to how phenomenological experience is also a product of the inner body processes and states [57, 58, 70, 71]. Phenomenologically informed approaches within HCI, such as embodied interaction design and somaesthetic interaction design, propose methods to explore our interactions with technologies at a bodily and emotional level [26, 27, 50, 61, 89]. These methods attempt to capture the state of the body of the user in the moment through techniques drawn from meditation, dance and movement practices such as interception and body-mapping, but they do not attempt to capture a longer-term picture of the body in a state of flux.

I have shown how studying long-term use of technologies during illness contributes new knowledge both about illness and technologies. My three vignettes exemplify how my needs and expectations of my Fitbit changed over time at different stages of my illness. For example, how I switched from using the device to pace my walking speed, to using it to deliberately increase my heart rate over 120bpm as my symptoms improved. Drawing on the fact that illness changes how we experience the world over time, and consequently the technologies we interact with, it seems that HCI is missing out if we only capture snapshots of the experience of technologies during illness, for example through one-time interviews or surveys.

But how could we capture long-term, fluctuating experiences of technologies during illness? Here, autoethnography has been shown to be a good method to capture the body in flux, but it is limited by the fact that it is typically a method restricted to motivated researchers [78]. It would be inappropriate to expect research participants to commit to a long-term self-reporting study of their day-to-day experience of their illness, especially from people with chronic illnesses and restricted energy levels. As well as beginning the process of designing pacing technologies, one of the next steps of my research will be to attempt to develop appropriate methods that could capture how the experience of illness shapes interactions with technologies over time, but that do not impose inappropriate workloads on research participants. For example, inviting users to document diary entries with simple prompts or multiple-choice options could be one method, and picture, audio or video recordings might be more appropriate than written entries [39]. Another aspect to consider is – how can we capture a rich representation of bodily experience? Are literary and verbal methods adequate? Or could more abstract methods using visual and material tools for expressing changing emotions and bodily sensations over time be more appropriate, e.g., [5, 8, 13]?

Returning to how my autoethnography inspires a new design space for pacing technologies, I believe that designing technologies for a body in a state of flux might produce more useful and appropriate technologies for chronic illness. Rather than designing with a fixed textbook definition of an illness, this would allow the user to see their changing bodily state mirrored in the pacing technology, and perhaps even reflect the journey from illness to recovery as illustrated in my experience. Self-tracking technologies related to illness tend to focus on documenting the negative, rather than positive, aspects of the experience of illness [49]. Relating to the previously mentioned biopolitics around the ill body being a negative aspect to be controlled through self-tracking, if we as designers were to attend to the nuanced and subjective fluctuating experience of the body, we might design technologies that celebrate and augment these changing states, rather than try to control and mitigate them through medicalization and a too-heavy focus on negative symptoms.

An obvious design idea is that pacing technologies could be designed with different profiles for users to choose based on how they are feeling that day, and this would adapt the types of data displayed and the language used to convey information. As recommended by Davies et al., applying this approach would result in a design space of tools that could adapt to the body of the user through fluctuations between relapses and remissions [22]. Davies et al. suggest that users should be able to disable motivational prompts to do more exercise on bad days. For example, if my Fitbit had been aware of my illness and my physiological state then it would not have notified me that I had walked 10,000 steps with fireworks, rather it might have communicated the same information as a gentle warning. These profiles could also be self-determined by the device based on the data gathered; how much and how fast the user is walking might denote a “good day” or a “bad day” and automatically switch profile. The specific factors that the app tracks could also reflect different aspects of illness. For example, I describe in the final vignette how my definition of health will be not needing to track at all. Perhaps more types of data could be collected during relapses, and fewer types of data could be collected during remission.

However, these design concepts raise important questions to be explored such as: since we need to define metrics and norms about what a “good” or “bad” day is in order to program these “profiles” into pacing technologies, how can we adequately account for the changing state of the user in the design of technological devices without becoming reductive and essentialist in terms of how we conceptualize illnesses since metrics are required for these technologies to function autonomously?

7 CONCLUSION

Long COVID is a post-viral illness where symptoms are still experienced more than three months after an infection of COVID 19. I present three vignettes from an 18-month long autoethnographic study of using a Fitbit fitness tracker whilst having long COVID. In contrast to its designed intentions, I misused my Fitbit to do less in order to pace activity and manage my illness. The first vignette describes how the device became a diagnostic device at a time when non-emergency medical expertise was unavailable due to the COVID pandemic and how this diagnostic information helped me
understand my own illness and make decisions about day-to-day activities. The second vignette presents how I reversed the intended use of my Fitbit; the heart rate tracking and step counting affordances of the Fitbit were used to limit, rather than increase, my activity and fitness by not walking too many steps in a day, and by keeping heart rate beats per minute under a certain value. The third vignette accounts for the experience of how using my Fitbit data to manage my illness became more complicated as I transitioned from illness to recovery. The key contributions of this paper are the nuancing of the limited prior research on the use of fitness tracking technologies to manage chronic illness. Specifically, my autoethnography illustrates three modes of using fitness technologies to do less: pacing based on a “diagnosis”, real time pacing and preventative pacing. This paper also outlines a new design space for pacing technologies and contributes new questions about designing technologies that acknowledge the interoperative and fluctuating nature of the user’s body, and that support user’s decision-making when managing long-term illness and maintaining quality of life. I also argue that my autoethnography highlights the benefits in studying the subjective experience of illness in the long term to inform the design of self-tracking technologies since interactions with technologies are influenced by how the body changes over time.

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REFERENCES


