Good Days, Bad Days: Understanding the Trajectories of Technology Use During Chronic Fatigue Syndrome

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People with chronic illness often fluctuate between “good days” and “bad days” where symptoms are more or less severe depending on a range of factors and triggers. Our research contributes preliminary empirical knowledge on technology use during chronic illness depending on fluctuations in symptoms over time. We conducted a scoping study with people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) to understand how their illness shapes how they use technologies in their everyday lives. This research contributes a timely HCI lens on the under-researched illness of ME/CFS, proposes the “trajectories of technology use” model that can be used to articulate how technologies are used during chronic illness, and points to design openings for technologies that are more accessible for people who experience chronic fatigue, sensory sensitivities and cognitive limitations. These design openings include non-screen-based technologies, and designing technologies that acknowledge and adapt to the changing body during fluctuations in symptoms.

CCS CONCEPTS

Human-centered computing • Human-centered computing ~ Interaction design • Human-centered computing ~ Interaction design ~ Empirical studies in interaction design • Human-centered computing ~ Interaction design ~ Interaction design theory, concepts and paradigms

Additional Keywords and Phrases:

Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, ME/CFS, Accessibility, Design, Dynamic Disability, Episodic Illness, Body in HCI, Chronic fatigue,

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1 Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic illness that impacts the whole body, including the neurological, autonomic, neuroendocrine, and immune system [10, 19]. ME/CFS is a long-term illness that often persists for years or even decades. People with ME/CFS experience extreme fatigue that is not improved with rest and may lead to individuals being unable to work and even being confined to bed [24, 61]. ME/

CFS is an understudied and enigmatic illness [58]. ME/CFS can be described as a dynamic disability that changes day to day, partly in response to different triggers, but also as an inherent aspect of the illness [33, 49]. Cognitive impairment is a particularly common symptom of ME/CFS and involves confusion, disorientation, vertigo and problems with concentration, memory and vision [19]. Other symptoms can include problems with sleep and pain [71]. ME/CFS also causes sensory sensitivities in respect to light, sound, heat and touch [19]. Symptoms may get worse after mental or physical activity or exertion. This is known as post-exertional malaise (PEM) [32]. Previous researchers have proposed that the dynamic and fluctuating nature of chronic illnesses is an important but under-studied phenomenon within HCI [22, 37]. In answer to this proposal, we therefore contribute the first scoping study of how technologies are used differently depending on fluctuations of symptoms experienced during ME/CFS.

We interviewed seven people with ME/CFS about their day-to-day lives and their use of technologies, with a particular emphasis on how the ever-changing nature of their symptoms influences their use and experience of technologies over time. Philosopher Havi Carel proposes that adopting a phenomenological approach by studying the holistic experiences of patients can help us avoid solely using a medical model to understand an illness. She proposes that this allows for the emotional, embodied and more positive aspects of their lives to surface that are not included in medical textbooks [18, 37]. We adopt this phenomenological perspective in our inductive approach to the research topic of technologies and ME/CFS. We believe this inductive approach will reveal the relations between technologies and symptoms as they change over time, as well as facilitating knowledge on the unanticipated use of technologies in unanticipated contexts [54]. This research is the first step in a wider project exploring the co-design of technologies that better accommodate the needs of people with ME/CFS. Due to a large overlap in symptoms, our research also contributes knowledge on the design of technologies more accessible to other people experiencing other illnesses and life processes such as stress, depression, multiple sclerosis, fibromyalgia, pregnancy, menopause and aging amongst many others.

Our contributions are as follows: 1. A scoping study that maps out technological use cases in daily life within the context of a chronic illness, 2. A preliminary model which facilitates the articulation of how dynamic chronic illnesses influence which technologies are used and how, 3. Design openings that address the accessibility challenges and unexplored avenues for the design of technologies for people with chronic fatigue, sensory sensitivities, and cognitive limitations.

2 Related Research

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 [2]. Chronic illness is typically addressed from a medical perspective within HCI [45]. Researchers have found that technologies can be used as a tool to manage chronic illness and thus live as symptom-free as possible [3, 9, 69] and to document chronic illness symptoms in order to present a record of data to health professionals [4, 70]. People with chronic illnesses have also been observed to use technologies to pace their energy and gain an understanding of triggers to symptoms, so that they can potentially avoid unnecessary pain or other symptoms caused by their illness through self-management [37, 67, 68].

Research on how chronic illness impacts other aspects of life such as work or social life during chronic illness is still underrepresented within HCI [45]. Exceptions include researchers discussing how chronic illness and disability change the experience of the world. For example, the term “crip time” reflects how even time is experienced differently by those outside of normative understandings of “health” [27, 56]. Autoethnographies and duoethnographies have also been employed as a tool to communicate the specific ways in which chronic illnesses and disabilities shape the experience of technologies, e.g., [37, 45]. Building on this, our research explores how the chronic illness ME/CFS shapes how people experience and use technologies, not only to manage their illness, but in all facets of daily life.

2.1 ME/CFS and Technology

ME/CFS is an enigmatic and complex illness of unknown pathology and is a contentious topic in the medical community; there is an ongoing debate about whether ME/CFS is a result of psychological or physiological cause [33, 58, 71]. There is no cure for ME/CFS and attempts to develop treatments have been surrounded by controversy. For example, the recommendation of graded exercise eventually resulted in the recommendations being reversed after a backlash from the ME/CFS community that stated that exercise was harming, rather than helping, their condition [20, 66].

Online resources allow participants to adapt and maintain a sense of normality through forming and maintaining social relations that would not have been possible off-line due to their ME/CFS symptoms and fatigue [16]. Brewer and Stratton's research show the COVID 19 pandemic affected people with ME/CFS somewhat positively and found that the increase of virtual social events benefitted people who would not have otherwise been able to attend the non-virtual event due to their ME/CFS symptoms [15]. The medical and social isolation associated with having an under-understood and contentious chronic illness has also led to social media being an important resource for maintaining social relations and receiving support [16]. Best and Butler [10] found that Second Life avatars were used by people with ME/CFS to avoid the stigma of their illness by not disclosing it within the second life world, and even worked and earned money within Second Life, something they could not have done in the offline world. However, Best and Butler also found that navigating the Second Life avatars on-screen had an impact on the ME/CFS symptoms and led to fatigue and dizziness [10].

Bowler et al. addressed barriers to people with ME/CFS attending social events by interviewing people with chronic fatigue syndrome on their perceptions, practices and strategies around time and event planning. They found that ME/CFS symptoms meant that uncertainty was a key concern of people with ME/CFS when making plans since they would often need to cancel or delay events. Bowler et al. then propose and test the design of a scheduling app, Haze, with people without ME/CFS. Haze helps people communicate uncertainty about their attendance of events visually [12].

A notable example of the limited research that is not focused on how technologies mediate social interaction during ME/CFS is Davies et al.'s [22] study of the self-tracking practices of people with ME/CFS to manage their illness. Davies et al. use interviews with people with ME/CFS to produce design recommendations for tracking tools for ME/CFS. For example, Davies et al. observed that some of their participants with ME/CFS were independently adopting commercially available wearable self-tracking technologies and using them as "pacing technologies". [22]. Other related research relating to manage fatigue includes Ayobi et al.'s design research on tracking the symptom of fatigue during multiple sclerosis [7].

Rather than studying one particular technological device, or one specific use case within the topic of ME/CFS, we aim to use our scoping study to investigate the total experiences of people with ME/CFS to understand how their illness shapes their use of everyday technological devices on a broader level. Our longer-term intention is to find design openings for more accessible technologies to people with ME/CFS, and therefore scoping and mapping a broader understanding of technology use is one of the first steps in this research project.

2.2 Accessibility and Chronic Illness in HCI

Over the last three decades, accessibility research within HCI has transformed from being a niche topic to a being critical focus within industry and research. Accessibility research is based on a social, rather than medical, model of disability that shifts the focus of disability from the individual to society, and critically engages with how societal politics and norms produce the experience of disabilities [28, 41, 46]. The accessibility community critically evaluates technologies in terms of their accessibility to users with different abilities, studies how technologies are used by people with disabilities, and designs new enabling technologies [6].

Recent calls for improvements to accessibility research within HCI include demands for the inclusion of people with disabilities in the design of assistive technologies and non-medicalizing approaches to designing for varying mental and physical abilities [5, 62]. Other developments include recommendations of the adoption of an intersectional understanding of people with disabilities. This demands accounting for other influencing factors such as race, gender, socio-economic context, which also impact lived experience and accessibility requirements [64].

Researchers have argued that, although there are overlaps between the experience of disabilities and chronic illnesses, people with chronic illnesses have idiosyncratic experiences that are not yet included in existing literature based on disability studies [45]. Accessibility research has been found to address some disabilities and illnesses more than others. For example, Mack et al. found that over 43% of papers in the past 10 years are on accessibility for people with blind and low vision [46]. Mack and McDonnell et al. describe how chronic illness is still an under-addressed topic within accessibility communities and state that the limited research on chronic illnesses within accessibility often focuses on older adults or rehabilitative technologies that are still centered on the illness itself, rather than how the illness impacts daily life [45]. [45]Our scoping study contributes to this literature in developing an understanding of how the chronic illness of ME/CFS shapes technology breakdowns, workarounds, and user innovations.

3 Method

3.1 Recruitment

Our research study received pre-approval from the University of Copenhagen ethics board, including approval of the information letter, consent form and interview protocol used in this research. We recruited a total of seven participants from Denmark and Sweden for remote semi-structured interviews. The gender distribution of our participants was six women and one non-binary person. This reflects the gender disparity in people with ME/CFS; one study found that 85% of people with ME/CFS are women [14, 63]. To recruit participants, we leveraged online ME/CFS communities (Facebook groups, Reddit groups) and personal networks. Participants were included based on the criteria that they had the diagnosis of ME/CFS. The sample size reflects that this is a scoping study similar to [12], and reflects recruitment challenges encountered in studying the ME/CFS community. Recruiting participants with ME/CFS was particularly challenging due to their limited energy, which meant they had to carefully prioritize their activities. As an example, one participant mentioned having to decide not to shower on the day of the interview to conserve enough energy for the discussion. On top of difficulties recruiting participants, several had to cancel the planned interview at the last minute due to their ME/CFS symptoms and did not respond to further requests.

3.2 Data Collection

The interviews were conducted over phone calls and computer video calls (Zoom and skype) depending on the participants' preferences and symptoms. The interview length varied from 20 to 90 minutes, most lasting 60 minutes, and we regularly reminded participants that they could take breaks or stop the interviews as needed, considering their symptoms. One interview was conducted asynchronously over email so that the participant could answer questions in her own time due to the severity of ME/CFS symptoms (P7). Our interview protocol was adjusted for the email interview for the sake of clarity.

The semi-structured interview is an exploratory but structured approach to the investigated phenomenon and provides the opportunity to pursue unexpected narratives from interviewees when they arise whilst keeping to the topic at hand through the use of a pre-prepared interview protocol [42]. We first gathered information about the participants' specific home context, including household setup and members, type of home environment, and

location. We then inquired about their illness, covering their diagnosis date, state of the illness, their five main symptoms, and how it affects their bodies. From this background, we were able to address the core element of the interview to understand their use of technologies in relation to fluctuations of their symptoms. We therefore asked them to describe their day to day lives and their use of technology during the day before the interview. We then asked them to describe what a “good” and “bad” day meant for them, and what their use of technologies throughout a "good" and "bad" day might be. We asked them to be very specific about how they used the technologies, how their physical and mental state evolved while using them, and why they used them.

Figure 1. **Table describing participant age, occupation, state of illness and types of technology used.**

Participants	Age	Nationality	Gender	Activity	State of the illness	Technologies mentioned
P1	57	Denmark	Female	Research secretary	Medium severity	Smartphone, Vacuum, Desktop Computer, Coffee Machine, Smartphone, TV, Laptop.
P2	51	Denmark	Female	Early retirement	Severe: she was forced to stop working seven years ago.	Radio, electric wheelchair, electrical scooter, old phone, smart phone, Smart TV, Hairdryer, laptop, electrical piano, infrared sauna, tracking watch, car.
P3	52	Denmark	Female	Early retirement (Quality Assurance of IT application)	Very severe	Iphone, Apple watch (monitor her sleep)
P4	17	Denmark	Non-Binary	Student (9th grade).	Severe: must study online apart from 1 hour once a week on-site.	Smartphone (Youtube, Discord, alarms), computer (Youtube, Discord).
P5	60	Denmark	Female	Nurse, educator, and consultant in the education of different health care education.	Very severe	Smartphone (FB, SMS, WhatsApp), tablet, PC (not use it that much anymore). Electrical bed, light controllers (wants to have blinds remote controllers).
P6	57	Denmark	Female	Early retirement (Finance)	Recovered slightly	Smartphone (Steps counters, mindfulness, time tracking, note, reminders apps), no watch, robot grass cutter.
P7	41	Sweden	Female	Early retirement (nurse)	Very severe ME: in bed 22-23 hours a day for 9 years.	Smartphone, noise canceling headphones, smart watch (pulse tracking but not using it anymore).

3.3 Positionality

Both authors are female researchers in their mid-twenties and early thirties working at a university in Denmark at the time of the research being conducted. Both authors have chronic illnesses that impact their daily lives. The first author has experienced her chronic illness since 2016, and the second author since 2020.

3.4 Data analysis

The two authors analyzed the seven interviews conducted with people with ME/CFS over two sessions using thematic analysis [13]. Thematic analysis is a qualitative analysis method widely used in psychology, and more recently adopted by HCI researchers, which allows theoretical flexibility and accessible identification of patterns within a qualitative dataset [13]. We first identified key elements in the transcripts of our interviews and notes through fine-grain reading, and then reported them on colored post-it notes, to finally arrange them visually on a board to identify patterns. During this process, we also wrote integrative memos. The integrative memos aim to clarify categories and themes and connect them to each other by: "connecting data that initially may not have appeared to go together and by delineating subthemes and subtopics that distinguish differences and variations within the broader topic." [26].

4 Findings

Our scoping study reveals how the use of technology is shaped by the experience of illness over time, being significantly affected by the symptoms experienced, stage, and progression of the illness. ME/CFS patients have found ways to adapt and utilize technology to meet their specific needs. Here we present some ways they adapted and crafted strategies for using technology in the home.

4.1 Energy-Saving Strategies to Manage Fatigue

Fatigue is a prominent symptom of ME/CFS, "you have like a bowl of sugar and you have a spoon, once the bowl is empty, there's no more." (P5). It is therefore essential for people with ME/CFS to carefully choose how they will spend their limited energy. To do this, they implement specific strategies including adopting new technologies and adapting the home, for example, using a robot hoover and an electric adjustable bed, and using mobile and portable technologies that could be used in different settings, for example, in bed. Sometimes preserving the energy of caregiving partners and family was the impetus for adopting technologies, "We've also got a robotic lawnmower. [...] But it has really mostly been for my husband, so he didn't have to spend his energy on it, then could do some of the things that I couldn't do anymore." (P6).

Online resources were repurposed in order to manage fatigue and save energy. For example, P6 described using Instagram and Pinterest to find recipes that need to be done in stages so she can rest in between these stages since she finds cooking tiring. Similarly, P1 described other methods of pacing cognitive exertion by simplifying the complexity of information; *"I follow the BBC News (on Instagram), if I see something on Instagram that I'm interested in, then I'll go looking for it on their website or another news agent website."* (P1). Many participants testified that online communities compensated for not having the energy or being able to interact with the outside world in person; *"if I'm on social media, or I'm looking at some reels on Instagram, I somehow feel a little bit like I'm out in the real world."* (P6).

Self-imposed limitations were also a tactic used by our participants to help manage energy use and avoid worsening symptoms. P4 restricts themself to using their phone, rather than their laptop, when they need to conserve energy; "*when I'm on my phone, the only thing I can really do is watch YouTube. When I'm on my computer,*

that's like a bunch of other things that I could do that I don't really have the energy for. Sometimes I get lured into doing those things." (P4). Time tracking was a similar strategy commonly used by our participants to set limitations for themselves to avoid fatigue (P3). P6 allows herself a screen time of 5–6 hours on her smart phone and uses a greyscale notification on Instagram: *"it pops up and says, now you've been* (using Instagram) *as long as - I think I have half an hour."* (P6).

4.2 Technology abandonment

Sometimes our participant's strategy was *not using* technology. In these circumstances, no adaptations could make these technologies usable, so they were not used or abandoned. Screens were often described as being a challenge to our participants; *"if I'm nauseous, just movement in front of my eyes (TV) will make me feel worse"* P2. Similarly, using a desktop computer was too demanding and not possible at certain stages of the illness *"the screen is too big now, so I use a tablet, it's too much information."* (P5). P2 describes not using any technologies on really bad days. Similarly, P2 has two phones; one non-smart phone dedicated to making calls and one smartphone to stream television, play games and use apps. She described how she would use her non-smart phone when out of the house to avoid being overwhelmed; *"When you have brain fog, you have problem concentrating, multitasking, and processing information [...] Having a smartphone would just add on to those things."* (P2). P3 also chose to go outside without using her phone, but for different reasons, *"Six years ago (before having ME/CFS), I was not able to be present, not in a conversation, not walking, so that's one of the things I had to relearn [...] if I'm in the forest, (I) look at the birds and look at the flowers, or just be my own mind."* (P3).

4.3 Managing Sensory and Cognitive Limitations

People with ME/CFS often have overstimulated sense responses to their environment that impact the way they interact with the objects around them [19]. As described by one of our participants: *"I am extra sensitive to noise, light and the outside world in general."* (P7).

Sensitivity to sound was prevalent among many of our participants. Mostly, our participants described needing to reduce the volume on their devices: *"The sound is turned off, so people find it quite amusing, [...] the volume is really low"* (P3). P3 also uses sound reduction technologies*; "when I'm with somebody where there's a lot of noise, I put in my AirPods, and they have a sound reduction. That (also) means that I can actually go to the cinemas."* (P3). P2 keeps her phone on silent mode to avoid notifications and minimise startlement and disruption. For the same reason, P3 uses vibration rather than the audio alarm on her smart watch when timing exercises or meditation (P3).

A sensitivity to light and visual movement caused our participants to adapt their screens, e.g., *"I almost always have it dimmed"* (P5) and avoid large screens due to the symptoms caused by the visual movement, as discussed above (P2, P5).

Due to cognitive symptoms, P3 described slowing down the speed of speech when listening to audiobooks and P6 described repeating video content; *"(it's) hard to learn new things, so videos are easier, repeating videos"* (P6). On bad days, P4 tries not to *"do two things at once"* on the computer due to their symptoms. P2 also described experiencing people on television talking too fast *"I can't even follow what's going on! That's quite disturbing."* (P2). P6 also described how cognitive symptoms means she is no longer able to listen to audiobooks or podcasts because *"I forget what I've heard and I can't concentrate… it all has to be visual."* (P6). P6 also described how she would deliberately *"use my Mindfulness apps in English so my mind does not wander"* in order to keep her focused on the task of meditation as this took more effort than if it were in her native language of Danish.

4.4 Good Days vs Bad Days and Fluctuating Symptoms

Our study showed a diverse use of devices depending on whether the participant was experiencing a "good" or "bad" day in relation to their symptoms. On good days, our participants described performing more creative or physically demanding tasks that *didn't* involve technologies *"a good day means I can do something at the house besides lay in bed like cook or paint or maybe sit in our garden a bit."* (P7). Other participants described performing more cognitively taxing tasks on good days such as listening to music, shorter lectures (TED talks) (P5), or *"play*(ing) *a board game with my daughter"* (P7). Participants also described that on good days they can also plan to perform more complex tasks with technology, such as designing video games (P4) and printing documents, *"I would do that when I have more energy because there's always something wrong with the printer."* (P2).

Consequently, for some of our participants, technology use increased on bad days (P1, P4, P6). P6 compensates for her frustration about the fact she has to *"lay in bed and I don't want to"* by writing messages on Facebook and using her iPhone and iPad. As mentioned in section 4.2, the severity of symptoms on a very bad day means not using technology at all due to sensory sensitivities and cognitive limitations (P2, P5). For example, *"on bad days I can't text, I can better make a short call."* (P5). In contrast, P1 and P2 acknowledge that they make fewer phone calls on bad days whilst, P7 *"cannot communicate in any form with other people."*. This reflects the diversity in symptoms and abilities amongst people with ME/CFS.

Physical symptoms as well as cognitive symptoms influence technology use on bad days. P1 mentioned that she uses headphones to listen to podcasts, as she is unable to hold the phone in her hand due to physical fatigue and P4 described how "*when I'm using my computer, like sitting in my chair, I have to spend a little bit more energy, like posture, moving my hands with my mouse and stuff*" so uses their phone in bed instead.

It is very clear that fluctuations in symptoms prompted our participants to change their technology use. P2 and P6 chooses to play different smart phone games depending on how they are feeling. P6 described how her *"eyes move around too much with Maya* (a smart phone app game)*"* so she wouldn't choose to play it on a day where her symptoms are more severe. P6 also describes choosing whether to stay and watch TV with her husband or to use her iPad in bed, depending on how sensitive to sound she was that particular day. *"It's different from day to day what sounds I can not have, so all of a sudden, the TV is too loud, and then he* (her husband) *doesn't understand what's happening because nothing has changed."* (P6). Likewise, P4 described checking their energy levels before making the decision to join a video call with friends *"I'm checking my energy and I think okay, I have enough energy to just hang out and call".* When we asked P4 how they *"check their energy"* and they told us *"It's mostly a feeling, I know it. But one of the parts is how much of a headache I have."* (P4).

4.5 Managing ME/CFS

As mentioned, ME/CFS is at present still poorly understood, so patients rely upon crafting strategies to manage the enigmatic and unknown aspects of the illness, particularly because of the controversies and negative associations with the illness both within the medical field and society. All our participants used social media to discuss and gain support in relation to ME/CFS.

As a method to gain an understanding and manage their ME/CFS, some participants tracked their symptoms. For instance, P3 has a spreadsheet and takes photos as evidence of her symptoms to take to her doctor. P3 also uses a fitness watch for monitoring her physiological data. She has an alarm to see if her pulse is too high and tracking sleep helped her diagnose that she has sleep apnea. Several participants explained why they had decided not to use, or had abandoned, fitness tracking watches since they could not act on the data; *"in my bad days, if I'm just in bed, I can't change anything new if my pulse is too high."* (P2). Another participant expressed their resistance to consistently wear a watch due to the anxiety it might cause, preferring to rely on personal judgment of her state of health rather than relying on data (P6).

Some of our participants also described how the ME/CFS tracking apps currently available are not appropriately adapted to their needs. P2 does not use ME/CFS tracking apps because it is too much work for her. She also described how there is no pattern in her data, therefore there is no point tracking. The design of technologies was also a barrier for some; *"I have tried to use a smartwatch that monitors my pulse to map out my symptoms and help with pacing, but it was too complicated for my tired brain."* (P7). P6 mentioned they learnt to pace their energy from the Australian ME app (ME/CFS Pacing) in 2020 that allows users to manually document activities and help them calculate their energy allocation; *"I don't think it's optimal, but it helped me figure out what was taking my energy."* (P6). Having learnt the pacing strategies from the app, she described no longer needing it. Similarly, P3 described a similar phenomenon with meditation apps; *"now I just do my own mindfulness in my own head, I don't use any apps anymore."* (P3).

Although we did not find many examples of technologies being used to get better, which is unsurprising as there is no current cure to ME/CFS, using technologies to *not get worse* is an important aspect of maintaining health during ME/CFS. One strategy adopted by some participants is to train their cognitive abilities. For example, *"I play card games, word puzzles, Sudokus, I'm trying to keep my brain working with numbers and, word games."* (P2), *"I speak German, I speak English, and I don't want to see those abilities to go away. So, I will watch sometimes really bad movies, but in German. I also listen to audiobooks in English."* (P3).

5 Discussion

Our findings illustrate how technologies are used by people with ME/CFS in many different ways and to achieve many different goals. We found that the effects of ME/CFS on the senses of our participants led them to adapt technologies to fit their changing sensory sensitivities, but also adopted technologies in order to overcome these sensitivities. Similarly, cognitive limitations were challenged, but also managed through the use of technologies. Technologies were both used and abandoned in their quest to understand the enigmatic illness of ME/CFS, both from a medical as well as individual perspective, and social interactions were both facilitated and limited by their mediation through technologies.

5.1 Trajectories of Technology use During Chronic Illness

It is evident in our findings that complex decisions are made by people with ME/CFS at a minute, hourly and daily basis in regards to which technologies are used, and how, in relation to their changing symptoms. Our participants described crafting various strategies to meet their fluctuating needs, either by adopting, adapting, or abandoning technologies. We found that on good days, technologies would often be used less, and outdoor and social activities would take place instead. On bad days, our participants turned towards their technological devices in order to participate in social relationships and complete everyday tasks. However, for some participants, on very bad days, technologies would also be abandoned, this time due to their capacity to cause cognitive or sensory overwhelm.

We propose the model of "trajectories of technology use" to illustrate the decisions that shape technology use during ME/CFS (Figure 2 and Figure 3.). These trajectories reflect how our participant's activities differed based on symptoms experienced at that time, and calculations about the impact of these activities on their symptoms in the future. We propose our model can be helpful in better understanding and articulating technology use during chronic illness [45].

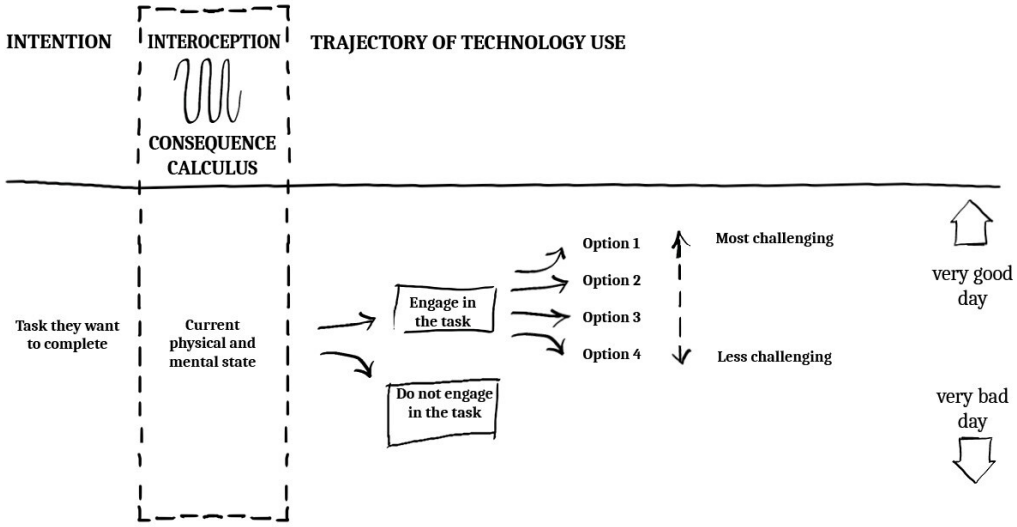

Figure 2. **The Trajectories of Technology Use Model**

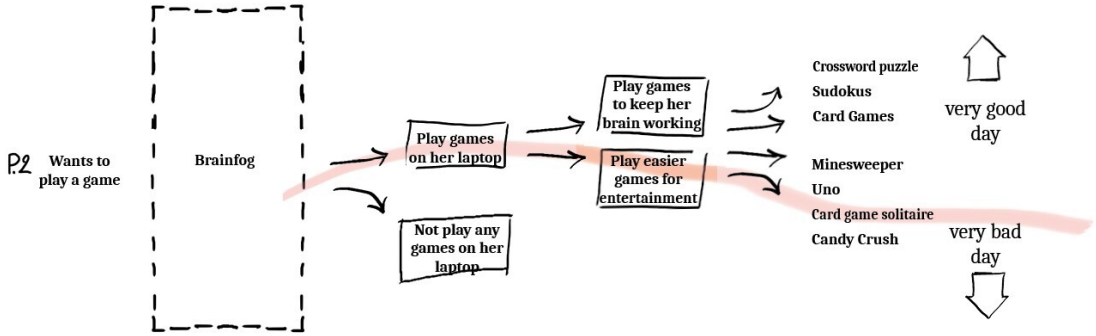

Figure 3. **Trajectories of technology use for P2's example of choosing which games to play**

The trajectories of technology use model firstly encapsulates the initial intention that the user has. The next stage in the model is the process of consulting the state of the body and illness through "interoception", where bodily senses are used to gather information such as the levels of fatigue, pain, sensory sensitivities, and cognitive limitations, for example when P4 described noticing how much of a headache they had. This information informs the "consequence calculus", a concept proposed by Mack and McDonnell et al. to represent the calculations conducted by people with chronic illnesses to predict the outcome of an action on their future state of health [45]. The outcomes of this second stage inform the trajectory of technology use: which technology will be used and how it will be used depending on whether the individual is having a "good" or "bad" day. On the example given in Figure 3., the pink line represents the trajectories of technology use described by P2 when she decides which game to play.

Several researchers call for a greater understanding of chronic illness patients' motivation, needs and everyday practices in order to design better technologies [4, 40, 51, 69]. Nunes [51] states that technologies for illness self-management are designed from a medical perspective, and they thus do not take into account daily routines and practicalities of people with chronic illnesses. In addressing these critiques, we believe our model can be used to articulate the reality of how technologies are used during chronic illness. This may help to dismantle assumptions such as the belief that people with chronic illnesses only use technologies to perform tasks related to improving their health, rather than maintaining quality of life [37, 45]. As we will discuss in the section 5.2.2., our model also makes an argument for technologies that can support users throughout their fluctuating symptoms, on bad, as well as good, days.

5.2 Designing More Accessible Technologies

Our findings illustrate many examples of when technologies were adapted and used in non-normative contexts to improve access to the existing world around them. This repurposing of technologies has been described by Redström as "use-design" where the initial design of the technology is in contrast with the actual use, and this points to new design developments for these technologies [42, 63]. For example, P3's use of noise canceling headphones to lower the volume of the voices of friends and family in conversations to a bearable level and to be able to go to the cinema.

The way in which technologies were adopted and adapted by our participants in innovative ways to manage their illness and allow them to lead meaningful lives point to design openings for new technologies. As mentioned, our findings are drawn from people with ME/CFS, but also relate to other illnesses that involve the symptoms of fatigue and sensory sensitivities and cognitive limitations. The breadth of instances where these symptoms are experienced highlights the importance and applicability of this research and how the design of accessible technologies might avoid exacerbating these symptoms for a wide range of people. This relates to the "cut curb effect", where accessibility features are used and appreciated by a larger group than the people they were designed for [64].

5.2.1 Beyond the Screen

The reasons behind the *abandonment* and *non-use* of technologies illustrated in our interviews also contributes knowledge in relation to how technologies could be made more accessible for people experiencing symptoms related to ME/CFS. A large theme in our findings was how screen-based devices are a barrier to people with ME/CFS, as they find that the bright lights, size and movement on screens trigger symptoms. This is reflected in Best and Butler's research on the use of Second Life by people with ME/CFS where time spent looking at the screen provoked fatigue and vertigo [10]. With the exception of the radio used by P2, the majority of current technologies described by our participants are screen based, or, like the robot vacuum cleaner, require a screen to interact with them. Screens are therefore a large barrier to accessing technologies that are required to carry out basic everyday activities and facilitate social relationships. It therefore seems promising to explore the value of non-screen-based devices as more accessible technologies for people with symptoms related to ME/CFS. Non-screen-based interactions have been developed for users with visual impairments, but not specifically for people with symptoms such as sensory sensitivities and fatigue. Non-screen-based technologies for people with visual impairments include the use of screen-readers [68], on-body interaction techniques [21], the use of gestures and motion capture [49] and speech input [1, 9, 62]. Due to the fact that people with chronic illnesses such as ME/CFS have other symptoms influencing the accessibility of technologies, namely cognitive limitations and sensory sensitivities, these existing non-screen-based technologies would have to be first assessed and perhaps adapted. Just as P2 slowed down the speed of speech when listening to audiobooks, screen-readers would have to have a function to slow down the speed of the information being read aloud in order to avoid cognitive overwhelm.

5.2.2 Designing for the Changing Body

Our trajectories of technology use model (Figure 2.) contributes a clear illustration of how the body changing over time impacts technology use, an important topic currently under-discussed within HCI. It has been argued that the current conception of the body in HCI is a "stable" body that does not change [34, 37]. Researchers have argued that norms around bodies in society have led to those with changeable bodies either being encouraged to conceal those changes, such as the menstrual cycle, or not being accounted for at all [35, 36, 38, 39, 60]. Articulating the technological experiences of people with more changeable bodies, such as people with chronic illnesses, leads to new questions: Should we design for technologies that follow and fit to these changing bodies, rather than technologies needing to be adapted or even abandoned during physiological fluctuations?

Our proposal relates to the accessibility subfield of adaptive accessible technologies (AAT) where technologies sense the user's current and past performance and adapt their functionality accordingly [31]. AATs currently track and assess factors such as the accuracy of clicks, and mis-types on a keyboard and adapts the functionality to better support the user's needs. For example, by enlarging the size of the cursor to a "bubble" in response to perceived difficulty in clicking on links [53]. These technologies are documented as particularly useful for people with disabilities and chronic illnesses such as Parkinson's disease and hand tremors [35]. Our preliminary research suggests the value in developing and expanding the subfield of AAT and points to how this approach could benefit other conditions and illnesses such as ME/CFS since these illnesses often include fluctuations in symptoms over time [20, 59].

Our findings point to other applications of the AAT approach beyond adaptive mouse and keyboard controls, and even beyond screens themselves, as we have discussed previously. Beyond the motility-based variations in ability already accounted for in existing research [23, 30, 47, 55], AATs might be useful for supporting users during sensory and cognitive fluctuations. For example, we found many cases where the complexity of technologies required them to be abandoned by our participants. Our participants described how even the technologies designed for people just like them, such as the Australian Emerge ME/CFS pacing app [56], were too complicated and cognitively overwhelming to use. We propose the exploration of technologies where the complexity could be scaled according to the abilities of the user at that particular time. This relates to P1's use of the BBC news Instagram profile to scout for interesting articles in short-form, so she could decide which articles to spend her limited energy reading in full. This design concept could utilise AI systems similar to the Diffit tool designed for teachers to adapt material to children of different age groups, to allow users to scale up or down the complexity of news articles depending on their level of cognitive clarity that particular minute [25].

5.3 Future Research

This scoping study is the first stage in our larger research project working towards designing more accessible technologies for people with ME/CFS. The next stage of our research will be building on these preliminary findings by collecting more fine-grained experiences of technologies over time through cultural probes and/or photo elicitation. We will unpack the underlying motivations and experiences related to the behaviors changing the trajectories of technology use. Rather than predict people's behaviors, our model maps dynamics intersecting fluctuating bodies and technology use. One shaping the other. As mentioned previously, recruitment and retainment of participants with ME/CFS is influenced by the "cost" of the research in relation to energy levels. Sample size is one limitation of our work, but also provides valuable pointers for future research. Therefore, one of the next stages of this research will be designing research methods that will avoid participants being negatively impacted by participating in our research [11, 29, 57]. We will follow recommendations from existing research on conducting accessible research within HCI [44].

In consequent research projects, we will then use these findings in the codesign of more accessible technologies for people with ME/CFS based on their levels of fatigue, sensory sensitivities, and cognitive limitations. These codesign sessions will explore potentials in both non-screen-based technologies for people with

ME/CFS as well as expanding the subfield of AAT as described above. One question to address will be: how is the state and "performance" of the user sensed? AATs classically measure movement, but this is perhaps not as useful when the condition at hand is ME/CFS. Knowing when to rest required our participants to use interoceptive skills and therefore might not be able to be sensed automatically without self-reporting measures. Our future research will address the question; could existing fatigue-sensing technologies that track, for example, the frequency of yawns, eye movements, or the user's cognitive agility capture the experience of fatigue during ME/CFS [50]? We will explore the value of these automatic fatigue-sensing technologies and self-reporting methods to track the state of the user and their symptoms as they fluctuate over time, as well as the adaptations people with ME/CFS might want technologies to make in order to make them more accessible for them.

6 Conclusion

People with chronic illness often fluctuate between "good days" and "bad days" where symptoms are more or less severe depending on a range of factors and triggers. Our research contributes empirical knowledge on technology use during chronic illness depending on fluctuations in symptoms over time. We conducted a scoping study with people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) to understand how their illness shapes how they use technologies in their everyday lives. This research contributes a timely HCI lens on the under-researched illness of ME/CFS, proposes the "trajectories of technology use" model that can be used to articulate how technologies are used during chronic illness, and points to design openings for technologies that are more accessible for people who experience chronic fatigue, sensory sensitivities and cognitive limitations. These design opening include non-screen based technologies, and designing technologies that acknowledge and adapt to the changing body during fluctuations in symptoms. This research is the initial step in this research project. Future research will include the codesign of research methods to more accurately capture how fluctuations in symptoms impact trajectories of technology use. This second stage of research will then be used to inform the codesign of more accessible technologies.

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