



Crippling the Co-Design of Pacing Technologies For Energy-Limiting Conditions

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Abstract

People with energy-limiting conditions, such as chronic fatigue syndrome (ME/CFS) and Long COVID, need to limit their activity levels and balance exertion with rest and restorative activities. This practice is known as “pacing”. There is an opportunity for technology to help people with this process, but conducting research with this population can be difficult given their limited and unpredictable energy levels. This research explores how we can use crip theory to inform the development of co-design methods suitable for this cohort, and as an analytical lens to explore how these tools should be designed outside of normative and abelist assumptions about fatigue and productivity. This is done through a 5 week Asynchronous Remote Community study utilising various co-design techniques. These findings point to future designs of pacing technologies and contribute insights about developing more accessible approaches to conducting research with people with energy-limiting conditions.

CCS Concepts

• **Human-centered computing** → **Participatory design; Empirical studies in interaction design.**

Keywords

chronic fatigue syndrome, ME/CFS, long COVID, post-COVID syndrome, pacing, self-tracking technologies, crip theory, co-design

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1 Introduction

In recent years, researchers within human computer interaction (HCI) have begun to investigate the role of technology in the lives of people who have energy-limiting conditions (ELC) such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and long COVID. These conditions are characterised by symptoms such as extreme fatigue, and can include symptoms such as cognitive limitations, pain and sensory sensitivities. Our study extends HCI

research on energy-limiting living [18, 48, 58, 89, 100] by exploring how we might involve people with an ELC in the design of pacing technologies.

In an effort to manage energy levels in order to avoid worsening symptoms, people with an ELC limit activity and balance exertion with periods of rest. This practice is known as “pacing” [5, 43, 97]. Learning how to pace can be a challenge, as each person has to learn their personal limits, and, due to the dynamic and changeable quality of chronic illness, these limits can fluctuate day to day [70, 76, 90]. Additionally, there can be a mental and emotional burden associated with making these evaluations of whether an activity will fit into one’s “energy envelope”, a term referring to the sum of the total amount of energy a person has to “spend” on a given day [21, 76].

As a result, some people with ELC have adopted commercially available fitness self-tracking technologies and are using them in unanticipated and unintended ways by tracking exertion and using this data to inform their pacing decisions [29, 33, 56, 58]. This is despite critiques of fitness tracking technologies as perpetuating ableism by catering only to bodies that fit normative definitions of “health” [110]. Societal norms around bodies are embedded in the technologies we design [57, 95, 117, 124]. For example, fitness tracking technologies are not appropriate for wheelchair users or people who walk at slower speeds [24, 123]. Previous research has highlighted tensions between the designed intention of the fitness tracking technologies to encourage the user to “do more”, with the use of fitness tracking technologies during ELC to “do less” [56, 58]. Whilst there are some limited examples of commercial efforts to create technologies that support energy management through the integration of wearable technologies, e.g., [4], the fact that this is an under-researched phenomenon means that questions still remain about how we might design technologies specifically for pacing ELC. We expand this research aim to also explore how we might include the ELC community in this effort.

Due to the manifestations of energy-limiting symptoms, it is challenging, and often impossible, for people with ELC to participate in research studies due to accessibility factors. Previous research projects addressing ELC have reported difficulties with recruitment, as well as participants cancelling shortly before scheduled interviews [90]. Even with the possibility of meeting online, a video or phone call can be too draining relative to an individual’s energy on a given day since screens and verbal dialogue can trigger symptoms [16]. Beyond this, day to day fluctuations in symptoms make it difficult to predict future energy levels, which means that scheduling meetings with researchers is challenging [18]. With these concerns in mind, our research explores how we can reduce accessibility



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barriers for this population to participate in co-design research, and what major challenges may persist despite these efforts.

To this aim, we turn to *crip theory*. Crip theory is a branch of disability studies which draws on feminist and queer theory that contests how taking a solely medical model with which to understand disability and chronic conditions ignores socially and politically produced inequalities [67]. This approach explores how societal expectations around productivity and quality of life might mismatch with the experiences and goals of people with disabilities and chronic illnesses [66]. In our study, crip approaches are used in two ways, firstly to develop accessible and inclusive co-design research methods and, secondly, reject normative definitions of productivity and quality of life in our approach to the topic of pacing.

We conducted a five-week co-design study with people with ELC using the asynchronous remote community method (ARC), which advocates for using private social media groups as a site to conduct research with populations that are otherwise difficult to reach [77]. We then analysed both the content produced during the ARC study as well as participants' survey responses evaluating their experience.

Our study contributes knowledge on the tensions inherently present when conducting co-design with people with an ELC. We found that multiple aspects of the ARC were successful, but that creative thinking and physical prototyping during co-design activities were experienced as particularly challenging. Rather than representing a failure, we propose that a crip definition of failure would hold that *some* inclusion of people with ELC is better than *no* inclusion. We also propose some adaptations improving on our own methods, such as breaking creative tasks down over time, scaffolding creative thinking, integrating participant feedback into the co-design process itself and building on existing competencies by using creative writing tools. The data produced by our participants during the ARC also points to possible and preferable designs of future pacing technologies. These design proposals reflect users' desire for automated closed-loop pacing systems that simply allow them to feel better, whilst also compensating for the inadequacies of self-tracking technologies to capture the experience of ELC, and highlight that pacing technologies are not only used to store up energy for necessary tasks related to productivity, but could also be used to maintain and improve quality of life through supporting and validating restorative activities and rest. These design openings will inform the next steps of this research project, which will involve ideating on and prototyping crip pacing technologies. Finally, we will reflect on the tensions that arise when applying crip theory to the topic of pacing and designing technologies for chronic health conditions.

2 Energy-Limiting Conditions in HCI

Energy-limiting conditions is a grassroots term conceptualised by disability researchers and communities to describe conditions marked by significant energy constraints [47]. These conditions typically include long COVID, and ME/CFS, yet there are other chronic illnesses and conditions that fall under the umbrella of ELCs. For example fibromyalgia, multiple sclerosis, Parkinson's and conditions such as concussion, neurodiversity, stress, burn-out and

depression [17, 28]. A major symptom that can be experienced in connection with ELC is post-exertion malaise (PEM). PEM describes a worsening of symptoms (sometimes referred to as a "crash") as a result of physical or mental overexertion [53]. Importantly, PEM occurs from much lower levels of activity than the person would have found fatiguing prior to the illness. These symptoms may include cognitive difficulties, insomnia, sore throat, headaches, feeling dizzy, or severe tiredness, and can persist for days or weeks [29].

The unpredictable and under-understood nature of energy limiting conditions leads to a wide range of self-management strategies [74]. As mentioned, people with ELC have turned to commercial self-tracking technologies to manage their illness. These include wearable devices like Fitbits, Garmin watches and Apple watches, and apps like MyFitnessPal, Google Fit and Apple Health. However, since these tools are designed to promote fitness and encourage more movement and activity, which is counter to the goals of pacing, people with ELCs have to misuse these tools and actively ignore the systems' recommendations and instead "do less" [56, 58].

A large scale survey found that heart rate monitoring helped people with ME/CFS manage their energy expenditure and avoid post-exertion malaise, though their benefits did not necessarily translate into increased functional activity [29]. Participants in another study gave feedback about existing tools failing to account for non physical exertion, the difficulty of dealing with complex interfaces when experiencing brain fog, and inappropriate recommendations from the tools due to them being designed to motivate the user to be more active rather than less [33]. Similar concerns are raised in Homewood's autoethnography of her experience using a fitness tracker for pacing during long COVID [56], as well as a subsequent interview study with people with long COVID and their "unanticipated" use of fitness tracking technologies [58]. As a result of conducting online workshops with small groups of people who have long COVID, Sas et. al also propose that future pacing technologies should combine self-reporting of different kinds of fatigue (physical, cognitive, and emotional) [100]. Whilst existing work has begun to offer design implications for future pacing technology, it has not fully explored how individuals with these conditions can be directly involved in the work of imagining these technologies, or how crip approaches can be used to reimagine how we define aspects such as fatigue, rest, and quality of life in relation to ELC.

3 Crip Methodologies

Originating from disability studies and feminism, the usage of the term "crip" is similar to the reclamation of the word "queer" by the LGBTQ community. The term is used to denote a more "contestatory" position than that of "disability studies" and offers a more fluid term that is less tied to the strict disabled/able-bodied binary [67]. A key argument within crip theory is that society follows a "compulsive able-bodiedness", similar to the theory of compulsive heterosexuality conceived of in queer theory, thus leading to the othering and denigrating of people with disabilities and chronic illnesses [82]. Previous models conceptualized disability as either a personal medical problem to be treated curatively (the medical model), or as a purely social phenomenon, in which societal norms and barriers are responsible for access problems for people in

atypical bodies (the social model) [76]. Crip theorist Alison Kafer's political/relational model of disability holds space for both these realities whilst interrogating the politics that influence the lived experience of being disabled or chronically ill [67].

3.1 Crippling Co-design Methods

Aimi Hamraie and Kelly Fritsch's "Crip Technoscience Manifesto" considers the question of how technology, science, and politics intersect within a crip framing [49]. Crip technoscience call for technologists to centre the knowledge and experience of people with disabilities, framing them as "knowers and makers" in their own right. Technologists are asked to respect this expertise and design *with* people with disabilities, rather than *for* them. As Price and Kerschbaum describe, disability studies scholars "have understood that methodology is a key mechanism of disabled peoples' oppression, and that taking back our methodologies is a means of fighting back" [93, p.23]. Similar approaches within HCI include Bennet and Rosner's warning against empathy-building design activities that stage disabled bodies as spectacles, and instead argue that designers should aim to "be with" rather than "be like" people with disabilities [14]. Similarly, the design justice approach also draws on the "nothing about us without us" ethos of disability studies from the 1990s [32]. These approaches avoid designing "disability dongles" that solve problems that people with disabilities do not have [2, 39]. Mack et al. used interviews with accessibility experts to determine best practices for accessible HCI research methods for people with disabilities through the approach of "anticipation with adjustments" to improve the accessibility of research in HCI [75]. They emphasise the importance of flexibility in planning research activities with people with disabilities and recommend sensitivity to power hierarchies between researchers and participants. Labattaglia et al.'s process of co-designing co-design methods with University students with disabilities also highlighted the importance of flexibility and reflection from the researcher throughout, and recommend "allowing participants to self-manage between challenging and less challenging creative tasks, set their own limits, define their participation and maintain their engagement in the co-design process." [73].

Adopting a crip approach to designing technologies for ELCs makes co-design methods relevant since co-design "is a shift in attitude from designing for users to one of designing with users" [98]. Co-design has been previously employed for conducting design research in relation to a range of chronic health conditions and contexts. For example, with people with visual impairments [62], chronically ill teens [60] and people with Parkinson's disease [81], HIV [30], dementia [80, 105], aphasia [122], diabetes [12, 111] as well as to improve the design of the environments [83] and technologies [126] healthcare takes place within and through. Co-design provides an opportunity for researchers and designers to collaborate with potential end-users and combine their shared expertise into something that neither group would have conceived of alone. This approach is often used to gain a deeper understanding of an end-users' lived experience, as well as generating ideas for future products or solutions [99, 112]. An important aspect of co-design that aligns with crip theory is community [67]. Co-design activities are often conducted in groups of people in order to support sharing

of perspectives and to produce materials not available from individual methods such as interviews [64]. Community is key to crip approaches to sharing interdependent care practices and emotional support, information on ways to hack and adapt non-inclusive tools and systems, and experiences of being dis-abled by societal and political norms [13, 15, 26, 67].

Adopting crip approaches to co-speculate on possible futures of energy management with people with ELC addresses related work critiquing privileged biases in who gets to speculate on the design of futures of technological devices [10, 92]. Although participatory design methods like co-design aim to be inclusive, there are concerns about whether they are truly inclusive for everyone [52]. Therefore, methods used for conducting co-design with people with disabilities and chronic illness must be adapted to suit the specific population's health needs [75]. Although co-design aligns with crip approaches in that it supports the inclusion of subjective end-user perspectives in the design of technologies, it is clear that further considerations have to be made in order to ensure co-design methods are accessible and do not cause harm to research participants to fully qualify as a crip methodology. In this study, we therefore explore whether adopting the method of an asynchronous remote community in order to conduct co-design could represent a crip methodology that facilitated the participation of people with ELC in designing technologies for energy management.

3.2 Crippling Definitions of Productivity and Quality of Life in Pacing

In line with Documaki's concept of "activist affordances" - how people with disabilities ingeniously improvise ways of making the world around them work for them - using fitness tracking technologies to pace energy already represents a form of crippling [34]. This form of pacing involves the deliberate and contestational misuse of current fitness and health technologies, thereby reclaiming them from normative understandings of health and tracking [49, 56]. Following this, we explored how we might adopt a crip approach, not only to our co-design methods, but also towards the topic of pacing energy more generally. Ultimately, this means that crip theory informs the co-design activities we gave our participants and our future ideation and prototyping activities. Our use of crip methodologies reflects the call to action by Mack et al. "for HCI practitioners to contest the dominance of medicalisation and emphasis on patienthood when designing technology for people with chronic illnesses", and instead attend "to both embodied and sociopolitical aspects of chronic illness." [76, 85]. Taking up this approach meant orientating ourselves to the affective experience of ELC, and how the embodied and social realities of living with an ELC impact what our participants wanted for their futures, beyond ableist assumptions of transhumanism, productivity and technosolutionism [109].

However, as we will discuss, applying crip theory to designing pacing technologies for ELC surfaces three key tensions. The first tension is how we as designers of technologies negotiate the medical models of pacing. Crip approaches reject a medicalising and pathologising approach to disability that defines people by the physical features of their bodies [67]. Our focus on the topic of energy management and pacing, which involves the tracking and

embodied noticing of complex physiological processes, troubles the fact that we can solely address the social model of disability in this context. The second tension, related to this, is that it could be argued that our approach is already disqualified as being *crip* since we are working towards a curative technological “solution” to the problem of ELC, rather than addressing the social and political conditions that produce the impairments related to ELC [49]. The third tension relates to the question of whether *pacing* itself is really *crip* since it can also be understood as an attempt to fix the problem of ELC through energy management. As Sheppard describes, *pacing* can be framed both as “an ableist rejection of chronic pain and fatigue, but also a *crip* embracing of living with chronic pain and fatigue. *Pacing* can thus be considered a *trickster* strategy, a way of passing as non-disabled while simultaneously embracing a disabled life, but it can also be a site of conflict, of internalised ableism simultaneously” [101]. We will discuss these tensions in relation to our research findings below and propose that our research can “talk-back” and develop *crip* theory itself in this respect [94].

4 Method

4.1 Asynchronous Remote Community

MacLeod et al. introduced the Asynchronous Remote Community (ARC) method as a “web-based focus group, augmented with additional activities often used in design research (diaries, scenarios, personas, etc.)” [77]. ARC has been used within the broader topic of chronic illness in HCI to access stigmatised and hard-to-access groups and communities [78]. One feature which sets the method apart from other social media-based research approaches is that the study takes place in a private group created specifically for the study.

One of the key motivations of this research was to have as little negative impact on our participants as possible through considering what a sustainable mode of participation would be for them. As mentioned above, participating in research activities can lead to negative health consequences for people with energy limiting conditions and chronic conditions [65]. Avoiding this means considering what kinds of “design relations - the forms of sociality engendered by, mobilized through, and reformulated within design practice and methodological procedures” our research affords [35]. This approach can also be framed in terms of the care practices we enacted towards our participants [115]. In light of our aim to care for and not negatively impact our participants, the ARC method seems potentially well-suited. The remote nature can relieve some of the energy burden, since participants are not required to go to a physical location. Beyond this, the asynchronous aspect allows participants to engage with the study at times when they have enough energy and can break up their participation into smaller chunks of time to avoid excessive exertion. Using an existing social media platform also supports participants since adapting to suit users’ existing “digital ecologies” has been shown to lessen the burden of onboarding and participation in online participatory studies [25]. Using an online social media platform also allowed users to upload a video or photograph, rather than writing text, in a way that was familiar to them. Since people with conditions like ME/CFS and long Covid often seek out communities online for

emotional support and information sharing [33, 68], we also hoped that the community aspect facilitated by the ARC method could allow participants to gain a greater personal benefit from joining the study [71]. Other considerations in relation to participant well-being included highlighting that participants could pause or leave the study at any point without explanation, as well as responding to their feedback on improvements to the study as it was in process, including our use of language, as we will outline below.

4.2 Recruitment

This study received prior approval from the University of Copenhagen ethics board. The participants in the study were recruited via existing online groups for people with ME/CFS and long COVID on Facebook and Reddit, with permission from the administrators of these groups. One of these groups is centred on using wearable technologies for *pacing*, so some of the participants may have been more experienced with using technology for this purpose than others. Additional recruitment was done via a ME/CFS charity network.

Nineteen people provided informed consent to participate in the study and joined the Facebook group. However, only 15 of them filled out the introductory survey, and only 11 went on to engage actively with the activities and other posts in the Facebook group. Of the 11 active participants, all but one filled out the intro survey. The survey demographics are presented in Table 1. Respondents were also asked to self-identify¹ which energy-limiting condition(s) they have, with a note that this did not need to be an official diagnosis from a doctor due to the difficulty of getting a formal diagnosis of ELC, and partly because this study is centred on experience, not medical treatment [87].

4.3 Study Design

The study was hosted within a private, unlisted group on Facebook. Facebook was chosen as the platform primarily because there is an existing presence of ME/CFS and long COVID communities there and, as mentioned, it is one of the social media platforms already familiar to many people. Additionally, Facebook has been the most common platform used in previous ARC studies [7, 71, 78, 91]. The groups visibility was set to “hidden”, in order to avoid people who did not provide informed consent attempting to join the group, and to prevent the group from being visible on participants’ profiles. Participants were asked to post their responses to activities as posts in the group feed, rather than commenting on the activity posts. This decision was made to give the same prominence to participant and researcher contributions. In line with the *crip* approach prioritising aspects of community building, participants were also welcomed to start their own conversation threads in the group aside from the activity responses, provided that the topics were relevant to energy management and *pacing*.

¹Self-identification overlapped in many cases. Participants also identified Postural orthostatic tachycardia syndrome (POTS), Macrocephaly, Alopecia, Cutis Laxa and Scoliosis (MASC) and dysautonomia as secondary conditions.

Table 1: Demographics of the study according to introductory survey.

Gender (self-identified)	N(%)
Female	12(63.15%)
Male	3(15.78%)
Currently Based	N(%)
Denmark	4(21.05%)
UK	4(21.05%)
Canada	3(15.78%)
Australia	1(5.2%)
Sweden	1(5.2%)
USA	1(5.2%)
South Africa	1(5.2%)
Employment	N(%)
Retirement	4(21.05%)
Medical leave(due to ELC)	4(%)
Part-time	3(15.78%)
Unemployed	2(10.50%)
Self-employed	2(10.50%)
Full-time	0(0%)
Living Household Condition	N(%)
With family	13(68%)
Alone	1(5.2%)
With roommates	1(5.2%)
With others (medical experts, pets, etc)	1(5.2%)
Energy-Limiting Conditions reported	N(%)
Long-COVID	10(52.63%)
Chronic fatigue syndrome (ME/CFS)	9(42.10%)
Time living with ELC	N(%)
< 1 year	1(5.2%)
1-3 years	8(42.10%)
3-8 years	5(26.31%)
> 8 years	1(5.2%)
Total Participants = 19, Mean Age = 49.8	

4.4 Study Activities

Activities were posted consecutively in the first, second and third week of the study. The participant survey was distributed individually during the final week of the study. With each activity description we encouraged a mix of media contributions, such as writing text or using voice to text, taking a photo, or recorded audio or a video. This was with the aim of increasing the accessibility of the activities in relation to their idiosyncratic limitations around technology use [90].

Activity 1 asked participants to record three times where they made a decision based on their energy levels. The primary goal of the activity was to gather details about the factors that go into

pacing decisions, the contexts in which these decisions are made, and the impacts of pacing. A secondary goal was to ease participants into the study with a simple recall task, while priming them to think more introspectively about the role of pacing in their lives. We added the caveat that posting fewer than three posts was also acceptable.

Activity 2 asked participants to share images they connected to certain prompts related to PEM and pacing and to caption them with explanations. This activity draws on prior work using cultural probes, in particular providing participants with a camera and asking them to take photos in response to certain prompts, as well as photo elicitation [42, 44]. The intent of this activity was to gather as much rich and idiosyncratic detail about the relationship between emotions and pacing as possible by asking them to take photos of “Something that tires you (that you love)” and “Something that tires you (that you wish you could avoid)”, as well as to document their use of tools and methods for rest and pacing more generally. We also proposed alternative options aside from taking photos such as using the internet to find existing images - a technique previously employed for a photo elicitation activity around the lived experience of bipolar disorder [107].

Activity 3 is an adaptation of the format of a “magic machine” workshop [8]. In a traditional magic machine workshop, participants are given materials and asked to develop a mockup or low-fidelity prototype for a “magic machine” which can address a given prompt [8]. The goal of these workshops is not to design a working prototype, but to engage with topics through making without being limited by present-day technical constraints. We introduced the magic machine method to support people with ELC in imagining an alternative future of pacing technologies in relation to their subjective experiences, rather than medical models. In the activity, participants were asked to imagine a machine which could identify when they are reaching the limit of their energy, and tell us what they would want to be able to do, where, when, and who else might be involved. Unlike in-person magic machine workshops, we did not provide prototyping materials to the participants, due to their wide geographic distribution. Instead, participants were invited to find simple materials at home to make a mockup, or to draw a sketch or storyboard, or to simply answer with a text response.

Finally, we presented the exit survey to the participants individually outside of the ARC group over email. Unlike the previous activities, the survey was anonymous and did not involve group interaction. The survey asked participants to reflect on various aspects of the experience of participating in the study through a mix of multiple choice and short answer questions. For those who did not actively engage with the previous activities, the survey also provided an anonymous form for providing feedback about why they did not participate.

4.5 Data Analysis

In order to make sense of the data gathered in the study, we conducted thematic analysis [19]. We copied the anonymised data from Facebook into a board on Miro, a collaborative whiteboard tool [3]. Using Miro allowed us to organise posts by the activity they corresponded to and maintain the organisation of comment threads. All three authors then coded the data and images individually

before collectively generating an initial set of codes, and then collaboratively synthesised these codes into larger themes described below.

4.6 Positionality Statement

All three authors identify as cis women and are European and North American, currently living in Denmark and Sweden. The first author has been managing an energy limiting condition for 5 years, and the third author has been managing another type of enigmatic chronic condition for over 2 years. The second author has had an ELC related chronic condition since youth, but is not impacted by it on a daily basis. The fact that we have first-hand experience of a chronic condition shaped our research [50]. Firstly, our experiences made us particularly sensitive to how to maintain our participants' wellbeing during research activities. This was due to our own embodied experiences of chronic conditions and the challenges they pose to everyday activities, let alone research activities. However, as we will discuss below, these positionalities did not mean we completely avoided tensions in relation to how our research methods were experienced by our participants. Secondly, our experiences of living with chronic conditions also motivated us to explore and challenge how chronic conditions are understood in society, including factors such as stigma, and the possibilities and limitations of technologies to manage chronic conditions such as ELC. These two facets of our positionality informed our decision to take up crip theory in our research study.

5 Findings

The findings in this section are based on the ARC, as well as the results of the participant exit survey.

5.1 Living with Energy-Limiting Conditions

A key theme evident throughout all three co-design activities was the large variation in how participants characterised their ELC symptoms. The richness in the language used to articulate idiosyncratic manifestations of ELC – and even the inadequacy of language to fully capture their experiences – represents that there is no one common experience of an ELC. Most importantly, participants described symptoms of their conditions beyond fatigue, describing a myriad of pains and sensations in various parts of their bodies, and feelings of discomfort like breathlessness, thirst, and dizziness. For example, *“I tend not to use words that associate with fatigue unless I’m talking to [doctors]... I use words like smashed, unwell, or not well to capture all the other symptoms too”* (P7).

5.1.1 Social Impact of Energy-Limited Living. As mentioned, energy-limiting conditions were described as having an isolating effect on our participant's social lives. For example, P8 posted a cartoon image and captioned it *“In this image, the two friends are laughing at the lone girl - I have had a number of friendships die because people just don’t understand”*. Some described how social isolation made it even harder to pace since living alone meant the burden of housework and chores fell on them. Participants also discussed the conflicting feelings around wanting to take an action that shows care for a loved one, when they know it will have a negative impact on their condition. When making pacing decisions in a social

context, participants described being forced to choose between two opposing aspects of well-being: preserving energy or nourishing social connection through acts of care. As P9 wrote *“I have had to let go of the guilt when I can’t help with things like I used to”*.

5.1.2 Types of Activities Undertaken in Energy-Limiting Conditions. Unsurprisingly, the most common fatiguing activities described by participants were physical activities. Many participants also associated fatigue with cognitive activities, including both analytical and creative tasks. Examples included reading about ELC medical research, following a grocery list, and the ideation and prototyping required for Activity 3, as we will discuss further below. Some participants also reported feeling fatigued as a result of sensory overload, which could be caused by activities like being in a busy area of a shopping mall or riding in the front seat of a car. A particularly insightful aspect of our findings are the responses to the prompt relating to fatiguing activity that they “love”. The responses to this prompt ranged from activities such as walking, travelling, to coding, solving complex problems and analytical work. In a caption under a photo of flowers cut from her garden P10 articulated a common theme relating to balancing mental and physical wellbeing when pacing - *“[gardening] allows me to dream, it gives life meaning and makes me look forward to getting up in the morning and getting started. But I want way too much and find it hard to stop. So often I cross the line of what’s good for me”*.

Resting is an integral aspect of avoiding post-exertion malaise. P5 described their strategy of preventative resting to avoid flare-ups, *“I normally get to a point during the day where I know that if I don’t take a 2 hour to 2:30min nap, I will crash and I will then have a recovery period of 3 to 4 days.”* Participants described how temporalities around resting are different during an ELC; *“Sitting down and resting after going for a walk like a normal person does not fix it - I would have to sit down for hours, if not days, to restore from it”* (P8). P9 also described how the effectiveness of rest is inconsistent and changes over time. Common practices described included sitting or laying down and removing stimuli by doing nothing or wearing an eye cover or ear plugs. One participant explained, *“When I mentally overextend [...] I need to spend time literally just staring at the walls”* (P1).

While resting was beneficial to recover or avoid crashes, participants also described the importance of restorative and recreational activities. Restorative and recreational activities are distinguishable from rest due to fact that they require some level of exertion. These activities were important in maintaining quality of life due to the amount of time participants spent at home. Restorative activities included knitting, re-reading old favourite books, and watching or cuddling with pets. One participant described how their cats could help them to relax because they are *“champion resters and often entertaining to watch for hours”* (P7). The importance of pets was echoed by other participants who shared photos of their own in the thread below the post.

Activities that actively aimed to restore energy levels, rather than just pass time, were also discussed and included mental relaxation techniques such as meditation, yoga nidra, and listening to low-frequency music, as well as using physical relaxation tools like a lying under a weighted blanket, or using a foot spa.

5.1.3 Addressing Strategies in Energy-Limiting Living. Given their reduced capacity for exertion, people with energy-limiting conditions have to develop strategies for pacing in order to determine what they can do without exceeding their energy envelope. As ELC impacts the cognitive and physical state of individuals, pacing requires individually tailored modifications to everyday life. One such modification involved careful planning to “bundle” activities based on where they are in the home, so that multiple tasks can be accomplished with minimal physical movement, a technique that P8 called “*the octopus*”. P1 then replied to P8’s comment “*I totally octopus too!!*” and described gathering objects on a walking aid to move them to another room, rather than making subsequent trips. Another modification described breaking activities into smaller sub-tasks with rest periods in between. These rest periods may be on the scale of seconds or entire days. For example, P2 outlined their approach for baking bread that takes place over multiple days in order to avoid over-exertion. Yet another approach was to find less energy-demanding ways to accomplish a task, even if it took longer - e.g. “*waiting for a slow elevator, rather than taking the stairs, at the cost of missing a train*” (P9).

Pacing requires individuals to develop an interoceptive energy assessment system rooted in their bodily knowledge, maintaining a constant awareness of signs that warn of worsening symptoms [58]. Participants discussed a variety of warning signs that can indicate they are nearing the limit of their energy expenditure. These ranged from physical sensations like pain, itchiness, and dizziness, to more cognitive and emotional effects such as irritability, confusion, and slurred speech. However, embodied warning signs were not a faultless system for predicting fatigue, and sometimes warning signs would come too late for them to avoid the onset of symptoms. As an attempt to compensate for this, many of our participants opted for higher-tech self-tracking devices like Fitbits, Apple Watches, and Garmin watches that support pacing strategies with heart rate, heart rate variability, and sleep reporting. A few participants also discussed linking the devices to other apps, namely HeartGraph, Visible, Google Fit, WatchME, SleepCycle, Tachymon and Athlytic to access different types of data and different visualisation methods. Several of these are more targeted towards managing chronic illness rather than pushing for physical fitness. While the promise of objectivity of self-tracking solutions is appealing, several participants noted that they do not rely on digital assessments as they “*don’t always agree with it*” (P1). P1 elaborated, “*I tend to feel that I can best understand these things holistically - they only make sense to me in the context of what I’ve done/overdone, how well I’ve slept, the other symptoms*”. P2 also described how “*HRV/HR [doesn’t] always correspond to my energy levels*”.

5.2 Re-imagining pacing technologies when living with ELC: Design Considerations

In the third activity of the study, participants were asked to design a “magic machine” to represent their ideas of how technology could help them with understanding and managing their energy levels.

5.2.1 Desired Outcomes of Use. The overarching trend amongst our participants’ concepts represents their desire for the automatic detection of levels of fatigue and related symptoms in order to compensate for their perceptions of the shortcomings of existing

self-tracking tools and their own interoceptive abilities. For example, P3’s magic machine could detect warning signs in the body earlier than the wearer could; “*PEM usually sets in one or two days late for me. This information would help me rest as needed sooner*.” Beyond this, participants communicated their hope that improved self-tracking devices could help them to learn how certain actions tend to impact their energy levels. P7 discussed the potential for a data-focused tool to “*help me identify particular activities, food, environmental conditions etc. that cause flares*”. Some participants identified design concepts which could quantify fatigue for communicating their condition to others. P3 raised the possibility for data to be “*shared with family and physicians - as proof of my daily exhaustion, but maybe also to show up ways to help (managing daily living and medications)*”. P2 echoed this desire in her design concept of a wall-mounted shape-changing display inspired by the existing “Birdie” wall-mounted smart home device that rotates when carbon dioxide is detected [1], which could display the user’s energy level to themselves and their household. For P2, this would mean “*my family could easily see, what I can do - what to expect from me*”.

5.2.2 Modes of Interaction. The concept developed by P1 (see 1) combined multiple wearable elements, with the goal of providing therapeutic treatment in response to biometric data, rather than focusing on pacing energy. The design stemmed from her reading of biomedical research on her condition and included a cap for stimulating cranial trigger points, gloves which change temperature to soothe aching joints, and flexible tubing and electronic leads which are clipped to the shoulders so that the required minerals and nutrients can be injected into particular body parts. A TENS stimulation was used to soothe sore muscles and an ear clip provided vagus nerve stimulation to help calm the body. P1 described how needles delivering nutrients and anti-inflammatory medication would need to be inserted by a partner each morning. Her lack of mobility removed any portability concerns and motivated the chair-based design that can be used whilst engaging in other activities (e.g. using a computer).

In relation to more periodic use, multiple design concepts were centred on a device that is stationary in the home, such as a walk-in scanner similar to an MRI machine or a massage chair which scans the body and applies therapeutic treatment like massage. P3’s magic machine was in the form of a “wand” that “*knows when my cells are depleted of energy before I do*”. P3 later replied “*one can dream*” to P8’s comment that it “*Sounds like a magic wand - Or maybe like one of those handheld devices they used on Star Trek for detecting illness*”. The reason given for this was that “*I would probably only use the wand once a day, since continuous monitoring can be stressful*” [P3].

5.2.3 Biomarkers and Data Collection. All magic machines involved sensors collecting some type of biometric data from the body in order to inform insights about energy levels and reserves. Many participants seemed to be comfortable with wearable devices. One concept used the familiar form of a smartwatch while others all imagined new forms like a skin-worn patch that collects biometric data or contact lenses that both collect and display data relevant to energy management. A few participants highlighted the issue of the lack of a known biomarkers for ELC related illnesses. P3 alluded to this issue when describing how their concept would be “*similar to a HR monitor but at a deeper level, since I find HRV/HR*

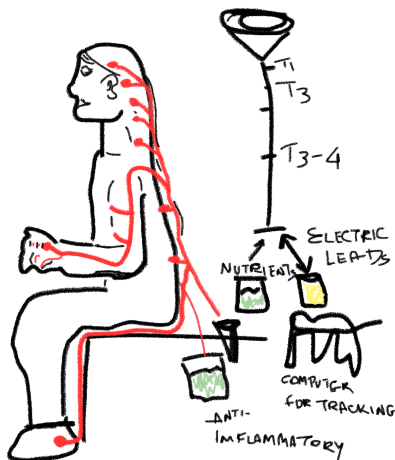


Figure 1: P1’s sketch of their design concept that tracks physiological markers through wearable sensors and responds to energy-limiting symptoms by delivering nutrients and anti-inflammatory medication.

don’t always correspond to my energy levels”. P2 agreed and added: “As long as we don’t have a biomarker it seems difficult to work out a machine. In diabetes you can measure your blood sugar level... When we act it is always an educated guess on a large set of felt data, which is difficult to measure.”. In order to incorporate this notion of felt data, P2 proposed the “The Colour App - Feeling to Machine App” design concept where “Everyday we press a color for how we felt during the day - in an app. We could press a color for physical, one for cognitive and and one for emotional distress. Then some sort of algorithm [would] add all the colors and mix-match them up and give us an estimated guess as to how we feel - and how much we are ALLOWED [sic] to do”. The data gathered from the device would be in the form of one single metric or letter related to a code book and could be communicated to the user and their family by the previously mentioned wall-mounted “Birdy” device. P2 also described how the output from this device could also include a supportive message from a therapist or family or friend for the user.

5.3 Participant Use and Assessment of the Methods

This section examines what participants thought about the Asynchronous Remote Community method and the activities used in the study based on their posts in the ARC group and their responses to the exit survey. Responses to the survey were anonymous, so quotations taken from the survey are attributed with a respondent ID number (R#) that does not correspond to a participant ID number (P#).

5.3.1 Overall Impressions. The overall impressions of the study were generally more positive than negative. Positive responses described the experience as “calm and relaxed” (R8) and others added that they “enjoyed the tasks and the flexibility the study gave” (R4). A few participants commented that they felt the study could have been longer to allow for more detailed contributions, explaining

that it “feels like we’re just getting started” (R2). However, some participants left the study with uncertainty about the benefits of this type of study to their community; “I felt this had less of a driven purpose, hard to see what the outcome was going to be or lead toward” (R6). Another participant describing their preference in “prioritising biological research” (R9) over participating in our research study. This communicates that this respondent felt their limited energy was better spent on participating as *research subjects* in present-day biomedical research on their illness, rather than acting as *experts* informing the provisional design of future technologies.

Respondents had largely positive views on the energy required to complete the tasks and the flexibility of the ARC method for people with energy-limiting conditions, as reported in Figure 2. In response to a question about how they adapted the study to their energy levels, many respondents wrote positively about the time given to respond to activities, highlighting that it made it possible to complete the tasks at times when they had energy, or broke tasks up into smaller chunks to complete over a longer period of time. However, one participant responded “I tried to do the activities as soon as it was posted, otherwise my poor memory would forget it was posted” (R1), suggesting that additional reminders may be necessary when facilitating the participation of a group that commonly experiences cognitive symptoms.

One factor perceived negatively by participants was our use of the word “tired” in the original activity 2 prompt “something that tires you” in an attempt to establish a less clinical and more colloquial communication. Participants in activity 2 expressed their dissatisfaction with our word selection based on previous negative experiences with non-ELC individuals disregarding or downplaying their fatigue symptoms, highlighting the lack of understanding of ELC. One person explained that even the word “fatigue” was flawed since, “I don’t think words like tiredness or fatigue really work because people (including me before illness) associate it with being able to recover with rest”.

5.3.2 Comparing Activities. The survey asked participants to select their favourite and least favourite activity (see Figure 3.).

Most respondents reported that they appreciated the lower cognitive effort required for Activities 1 and 2, with some stating that an activity was their favourite purely because it required the least effort. Some also responded that they found Activity 1 interesting because it “jump started a different way of thinking about everyday decisions” (R5) and “made me aware of what I am doing” (R8). When reflecting on what they liked about the earlier activities, some also mentioned the community aspect. One respondent wrote that Activity 1 “was a good introduction to group members and similar experiences” (R1), while another participant expressed that they “enjoyed seeing other’s images” (R6) in Activity 2. The number of comments and reactions on the activity responses shows that the rate of inter-participant communication in the group was indeed higher in the earlier activities.

Multiple respondents reported that the cognitive effort required for Activity 3 was responsible for their lower ranking of this task. Three respondents also expressed difficulties with creating a concept or prototype, causing them to not respond to the activity. Five out of 7 respondents who gave responses to activity 3 described their idea using only text rather than a sketch or photo. One of

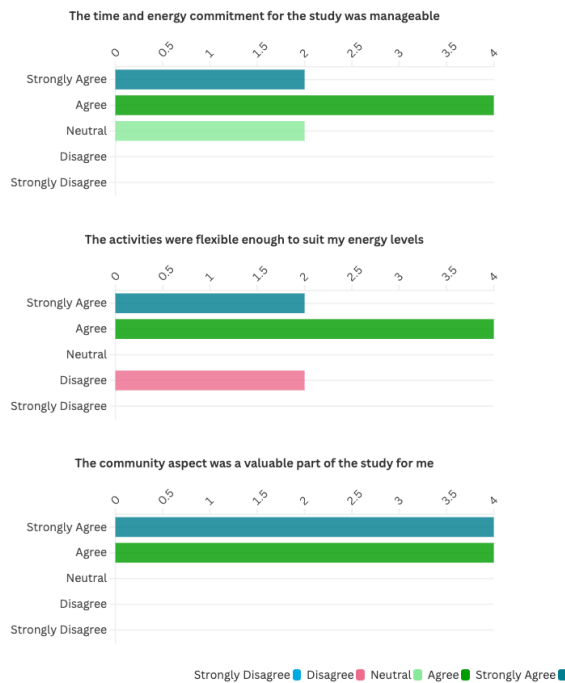


Figure 2: Participant survey responses to questions relation to the ARC study activities (N=11).

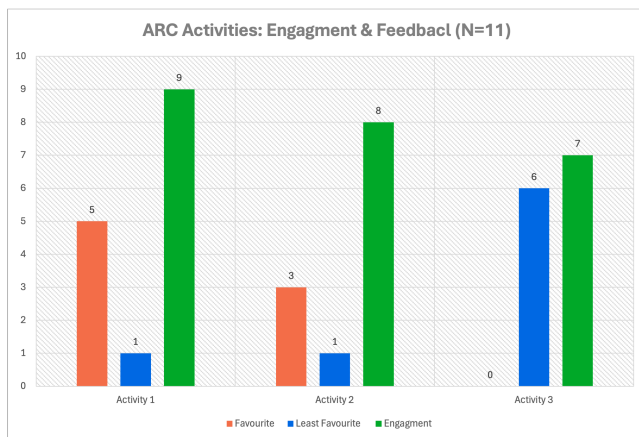


Figure 3: Engagement throughout the study and statistics on the most and least preferred activities according to the exit survey.

these respondents highlighted how the instructions for this activity impacted their perception of the study overall, writing “I thought just the idea that someone with limited energy would be able to devise a story board or cardboard model was a little ambitious, and made me a less confident in the study as a whole” (R5). Another respondent explained that the request to think creatively at all was overwhelming, “Too complicated, needed too much brain focus which I could not give, too broad” (R6). This sentiment was also reflected in the activity

responses in the Facebook group, with one participant posting that “the creative and cognitive effort to sketch something out is a little too beyond me at the moment as much as I used to love that ideation” (P3).

5.3.3 *Community Aspect.* In line with our crip commitments to engender community through our research methods, our participants did engage with each other within the ARC. The majority of activity responses received at least one comment from another participant. The comments tended to be friendly and supportive in tone, with participants tending to agree with or expand on points raised by others or offer advice or encouragement. The only case of disagreement took the form of one participant commenting that they did not experience the same sensory triggers as another participant. Participants also created their own posts seeking or sharing information outside of the study activities similar to how they would use other internet-based support groups. For example, seeking recommendations for tracking tools or asking what terms other participants use to describe their fatigue. They did this through comments, as well as posts to the group feed outside of the activity responses. The exit survey showed that the respondents viewed the community aspect of the study favourably. All respondents to the exit survey agreed (or strongly agreed) with the statement “The community aspect was a valuable part of the study for me” and reported that they read other group members’ posts and comments. One respondent wrote that the study “made me think about my condition as well as how it compared to others. I didn’t [feel] so alone” (R7). Another respondent also expressed that they wished the study had been longer, “with additional tasks/open posts with questions that the group could answer and share experiences” (R4), suggesting that learning about others’ experiences was a motivating factor in their participation in the study.

6 Discussion

Our study crippled both our approach to the topic of pacing and energy management as well as the methods we used to include people with an ELC in co-design processes.

6.1 Crip Design Methods For Energy-Limiting Conditions

Firstly, we will reflect on our explorations of what crippling co-design methods meant in practice, including limitations of our methods, future directions, and how taking up a crip approach challenges how we measure “failure” in participatory research.

6.1.1 *Asynchronous Remote Communities as a Crip Method.* Crippling co-design methods meant using the ARC method to allow our participants flexibility in the timing and pace of participating in co-design activities, and in the mediums through which participation could take place. We found that the asynchronous aspect of the ARC was successful in allowing participants to break up activities over time or fit them in on days when they had adequate energy. This is in line with the goal of crip approaches and accessibility guidelines in developing research methods that “cost” less for research participants without impacting the quality of their contributions through supporting flexibility [73, 75, 93].

The community aspect of the ARC method proved to be beneficial for people with ELC. Online, communal approaches to HCI co-design methodology are proven to work especially well within stigmatised topics [51, 71], helping individuals to navigate chronic illness collectively [125]. The ARCs cultivated a social environment that encouraged participation, as well as providing a positive experience of participating in the research study. From a researcher perspective, inter-participant interactions also added a layer of rich detail, which likely would have been missed in a traditional one-to-one interview format, particularly if the interviewer did not have experience with an energy-limiting condition. In some cases, the participants themselves became researchers, asking the other group members for their thoughts on certain questions around pacing. The other potential benefit of the group dynamic was that it may have shifted the power dynamic between researchers and subjects. In research studies, the researcher can often appear as the authority figure, which shapes the responses that participants give [35, 115]. In an ARC, the support of peers may empower the participants to feel more like an authority themselves. For example, in one-on-one interviews, some participants may not have felt comfortable bringing up that they took issue with our use of the word “tired” to describe fatigue symptoms.

6.1.2 The Cost of Co-Design. The *crip technoscience manifesto* instructs that people with chronic illness and disability should be included as “designers and world-builders” [49]. However, our results present some challenges in relation to participants becoming co-designers. Many participants reported that activity 3, where participants were asked to imagine new technologies, required too much energy to complete, and this activity had the lowest participation rate. One potential approach to reduce the energy cost of creative tasks could be to break large design tasks into smaller, more specific tasks given over the duration of the ARC. This could relieve the mental load of developing ideas for all aspects of the design concept at once. However, this approach of breaking the activity into smaller tasks does risk missing some valuable insights, since the ideas discussed would be boxed in by the more specific prompts given, and being influenced by one another’s ideas over a longer period than typical co-design activities might result in the group developing more homogeneous design concepts overall.

One draw-back of our co-design methods was that they bracketed out more embodied ways of collecting and communicating data due to the fact that data had to be delivered digitally, rather than in person. This is at odds with the fact that an ELC, and chronic illnesses more generally, are intensively embodied experiences [23]. An attempt to compensate for this was to encourage participants to engage with a range of mediums, e.g. sketching, making videos and voice recordings and physical prototyping. However, it was these activities and mediums that were critiqued by participants in relation to energy expenditure. The question of how we can make more hands-on, non-textually-based ideation feasible for people with an ELC might be addressed through adopting techniques that minimize effort and scaffold creativity. For example, asking participants to search online for images that relate to their ideas, similar to the prompt in Activity 2. AI programs that generate images from natural language prompts have also recently been integrated into co-design and could represent valuable directions to explore, how-

ever these tools still require some on-boarding and effort to produce effective images [27, 108, 114]. Additionally, the more traditional co-design approach of shifting some of the creative work to the research team, similar to the approach taken by Hong et al. to create a library of images which their study participants could use to construct storyboards, could also support creativity, but would risk closing down the directions participants might want to take their design concepts [60].

Rather than imposing methods on participants that risk discomfort, a valuable future direction seems to be following what our participants were already more naturally inclined towards. This might include integrating the energy management strategies described by our participants in the structure of the research project itself. For example, to “octopus” activities so that the minimum amount of interactions with the research project are required for the maximum effect. As we have described, textual descriptions of prototypes were by far the most common medium used by our participants to respond to ARC activities. Writing is described as an important resource for people with chronic illness and disabilities as it supports therapeutic reflection during an emotionally challenging experience and allows for the sharing and validation of experiences often under-valued or disbelieved in society [20, 79, 84]. Building on our participants’ existing affinities with writing and building on existing research that used creative writing tools as co-design methods with older adults e.g. [63], *crip* approaches to co-designing with people with ELC might therefore adopt literary methods such as storytelling and poetry in the co-design process.

6.1.3 Failing to Co-Design with People with an ELC? As outlined above, our study resulted in many examples of “failure”. Only 7 of our 19 participants completed the magic machine activity and our participants articulated their dissatisfaction with this activity and other elements of the research in the post-study survey as well as throughout the ARC itself. However, we are not surprised by these results since our motivation behind embarking on this research was to explore how to co-design with a group of people who are notoriously challenging to conduct research with [75, 90].

Crip, feminist and queer theories do not view failure as a negative outcome but, rather, as a powerful tool for challenging and redefining societal and systemic norms. This is due to the fact that queer people, women and gender minorities and people with disabilities are all positioned as “failing” to live up to the male, heterosexual, able-bodied ideal in society [41, 46, 103]. Within an ableist society, disabled bodies are always framed as “failing” [41]. This has led to crip theorists embracing and reframing failure as an inherent aspect of being crip and a way of questioning sociopolitical norms around which bodies can be celebrated [67]. Above, we have outlined further improvements that could further support the inclusion of people with ELC in co-design research, but this is only to improve the experience of participants, rather than improving the validity or “success” of our findings through increased participation. Conducting co-design research with people with ELC was a deliberately high risk pursuit and we propose that a crip approach to research should hold that any level of participation with hard to reach groups, such as people with ELC, is better than no participation at all [36, 113]. Embracing failure in design methods might therefore require an expansion of norms around co-design methods

to include partial participation. For example, increased participant drop outs, episodic participation, and minimal participation. This reflects similar calls in HCI to avoid extractive and costly labour from participants by understanding and working with participants' own motivations to contribute to research, as well as supporting them in leaving or pausing the research project when necessary [61]. Rather than success being measured by the amount of contribution a participant provides a research project, crippled co-design would instead measure success by the wellbeing of the participants involved.

Taking up a *crip* approach not only means allowing for different definitions of failure in terms of levels of participation, but also in relation to participant contestations. Contestation is a key aspect of critical theories such as *crip*, queer and feminist theory [6, 49]. Rather than seeing negative feedback from our participants as evidence of the failure of our attempts to provide suitable methods, we can see it as an integral aspect of crippled co-design methods. To this aim, we integrated methods in order to gather participant feedback on the activities through the exit survey, but, as we have described, participants did not wait for this and provided unprompted feedback all the way through the five-week ARC study. What our study supports is the integration of reflexive and discursive methods into co-design methods. This would allow for participants to suggest adaptations to the methods as they were presented in real time. Building on the survey model we employed, a range of options could be presented to participants to vote on to determine which methods would be most appropriate and preferable. Therefore, crippled co-design methods could integrate contestation and prioritise participants' subjective knowing into designing the research methods themselves.

6.2 Crippling Future Pacing Technologies

As well as attending to questions around inclusion and definitions of success and failure, we propose that taking up a *crip* approach demands that we radically question our understandings of ELC, pacing, and even designing technologies for chronic conditions.

6.2.1 Communities of Care Networks. In line with *crip* theories on interdependence and the importance of community in living with disabilities and chronic conditions, our participants imagined preferable futures for living with pacing technologies that built upon the care networks they currently have [13, 67]. Our findings reflect the significance of social factors in the overall experience and management of an ELC, as well as for chronic conditions more generally [31, 58, 118]. As represented in activity 3, our participants imagined smart-home devices, such as the Birdie concept, that could indirectly alert others to their health status through ambient forms of data that did not require explicit communication [1]. Several other design concepts supported the delivery of messages of encouragement and support from healthcare professionals and friends and family. The motivation behind this was the fact that the enigmatic and under-understood nature of chronic conditions, and particularly ELC, leads to stigma in society and a lack of understanding of the condition [22, 101]. It is not surprising that self-tracked data is desirable as "proof" of an ELC to share with care networks and healthcare providers, since healthcare systems make it challenging for people with ELC to receive recognition and

even state benefits due to the fact that there is not yet a medically validated pathology or treatment for ELC [54, 58]. However, although supporting data sharing through design can be beneficial in improving understanding and emotional support, there is a risk of perpetuating the belief that quantitative tracked data is required to provide objective validity to the condition [88, 106, 120]. This risks re-enforcing the invalidity of subjective and qualitative accounts of ELC [33, 58]. In our future research, we will need to negotiate these tensions through our designs of pacing technologies in relation to what kinds of data is shared and how it is shared with others.

6.2.2 Can Pacing Technologies Be Crip? As mentioned, applying *crip* theories to the topic of pacing results in certain tensions. These tensions related to *crip* commitments to not "fixing" the disabled body through technologies and medical interventions, but rather exploring how societal and political factors shape disability. A frustration described by many of our participants throughout the ARC study was how ELCs do not have a biomarker that could be used to provide an objective "truth" about the state of their body. Most of the magic machine design concepts produced by our participants imagined such a biomarker and how it could be used in an automated system where no work was required from the user to parse tracked data into pacing strategies. Many of the design concepts also integrated therapeutic devices that would also provide some kind of automated service to alleviate symptoms. Similar to the artificial pancreas used to treat type 1 diabetes that combines a glucose sensor, a control algorithm, and an insulin infusion device, what was most desired was a closed loop system that offers total medical well-being in order to transcend the ELC without the "work" of pacing. However, despite their wish for automation in future pacing devices, participants also described frustrations with current self-tracking technologies in relation to their inability to provide an accurate portrayal of their illness or energy levels. This information had to be augmented through using their bodily senses. Our findings support and nuance previous research illustrating that tracking technologies are useful to outsource and enhance our bodily knowing, but that they often fail in capturing the full richness or accurate reality of chronic illness [9, 58, 59, 86].

Interestingly, our participants' magic machines contrast with *crip* approaches that reject the dominance of techno-centrism. In line with arguments against transhumanism, *crip* theorists could critique our participants' desire for a closed loop system as being an attempt to "transcend" their ELC through technological and medical augmentations in pursuit of emulating a "normal" "healthy" person's experience [119]. This is an example of what Shew calls "technoableism"; technology is positioned as a fix to the problem of disability [102]. In contrast, *crip* approaches are instead typically orientated towards an interdependent relationality between humans and assistive technology [38, 40, 66, 121]. However, there are life-altering realities of ELC - chronic fatigue, pain, brain fog - that mean that it is not surprising that our participants' ideal future is one where they simply feel better.

Critiquing *how* we frame the body when designing *crip* technologies, raises the larger issue of *whether* we should be designing *crip* technologies at all. Another critique *crip* theorists could have of our participants' design concepts is that they predominantly address ELC from a medical perspective, rather than addressing systemic,

political and societal factors [37, 39, 109]. As mentioned, applying a *crip* approach to improve the experience of chronic conditions by designing self-tracking technologies sits in tension with *crip* theory's rejection of using medical models to address disability and chronic conditions [67]. On the other hand, using a solely social and political model to design pacing technologies would stop us from being able to account for the physiological realities of living with an ELC [69]. As feminist theorist Elizabeth Grosz says, someone with an amputated limb cannot simply grow it back through changing their social conditions [45]. People with ELC have long had to fight for the physiological reality of their condition to be accepted, and it seems troubling to not be able to address them through the design of technologies [22, 54, 58].

So how might we walk this middle road when designing *crip* pacing technologies? As an alternative to social constructivism, Grosz proposes that the way in which we experience the world is not only made up by our mental subjectivities informed by social and cultural aspects, but also the physiological reality of the bodies we live in [45]. Similarly, as a solution to a lack of embodiment in social models of disability, Toro et al. offer an ecological-enactive model of disability. This model rejects that somebody is made disabled by social and political factors alone. Instead, they propose that each individual's experience of their disability is determined by their ability to find their way to "affordances that allow them to act adequately within the constraints of their impairment." [116]. These affordances are still informed by social and political factors (i.e. what accessibility aids they have access to), but the individual also has agency in adopting tools and developing skills in response to the changing conditions of the world around them [69]. Dokumaci even extends this approach and proposes with his concept of "activist affordances" that people with disabilities create *new* affordances, beyond the capabilities of able people, in order to obtain their goals [34].

In our future design work, adopting approaches such as Grosz's theory of embodied subjectivities, Toro et al.'s ecological-enactive model and Dokumaci's activist affordances approach to designing pacing technologies might allow us to integrate a *crip* approach to pacing energy levels that still allows for the changing realities of the material body to be acknowledged. An approach to the body in ELC as both "embedded and embodied" [104]. This might be through avoiding prescriptive pacing technologies that dictate which activities are appropriate and when to rest. Instead, we might explore co-evolving and co-constructed models of pacing that represents a constant coupling and mutual re-tuning of human subjects and their technological companions [57, 59, 72]. We can build on the approach represented by P2's "Color App" design concept that illustrated that it is important to not only consider the physiological events that make up an ELC, but rather a combination of the "physical, cognitive and emotional" aspects of their daily lives. Since these tensions exist when applying *crip* theory in this project, future research will not only involve designing new pacing technologies, but will also "talk-back" to *crip* theories themselves by generating knowledge on the question of the body in *crip* theory [94].

6.2.3 Validating Rest Through Design. As mentioned previously, the act of pacing can both be framed as an ableist and curative attempt to erase the "problem" of ELC, but also as a *crip* act of

resistance in saying "no" and prioritising rest and wellbeing over productivity [101]. To address this tension, Sheppard proposes a "*crip* pacing" that is "an active statement of self-worth, rather than an attempt at rehabilitation." [101]. This is an especially important aspect of managing chronic illness, which are inherently long-term, where decision making around what activities are appropriate, or as Mack et al. name it, "consequence calculus" [76], is informed by both maintaining quality of life as well as physiological health [11, 56]. Our participants described a wide range of restorative activities that troubled the binaries of exertion and rest due to the fact that energy was being expended, but that they were restorative in relation to quality of life. The only drawback to these activities, such as gardening, was that they could tempt the individual to over-exert themselves and, reluctantly, pacing strategies were required to avoid this. Though, as Sheppard describes, making the choice to cause over-exertion could also be framed as a self-care and self-worth strategy outside of normative understandings of health and quality of life [101]. Again, it is believed that it is through agency, choice, and access to affordances that people with disabilities are believed to be given the best *crip* futures.

Due to their conditions being misunderstood and disbelieved, people with an ELC are often criticised as being "work shy" and unproductive members of society [22]. An important concept within *crip* theory that is particularly relevant to consider in the context of energy-limiting conditions is *crip* time. *Crip* time emerged as a term within the disability community to refer to the fact that people with disabilities and chronic conditions may require extra time to accomplish tasks as a result of symptoms, and that they might even experience time differently due to not living "normal" lives with daily rhythms such as full-time work [96]. *Crip* time and *crip* theories in general question normative assumptions about productivity since, as Janicki et al. states in their *crip* exploration of work-related technologies, *cripping* "might also include resting, pausing, and slowing down" [66]. As author Alice Hattrick, who herself has ME/CFS, writes "*Crip* time is failed productive time - the time of not doing, and potential undoing... *Crip* time is failing to make the most of your time, it is failing to fulfil normative expectations, of using your time wisely." [54, p. 82]. Taking a *crip* approach to pacing means rejecting normative and ableist assumptions about energy allocation. Rather than using rest to save up energy to spend in normatively productive ways such as by working or completing household chores, restorative activities can be framed as a form of activism [54, 96]. This echoes the ethos of Tricia Hersey's "Rest as Resistance" and the consequent "Nap Ministry" movement that is rooted in racial justice and proposes rest as an act against capitalism and white supremacy [55].

Although resting is an important aspect of life, whether or not you have an ELC, it is still an unexplored design space within HCI. Our study highlights the potential in exploring how technologies might be designed to support *crip* approaches to facilitating defiantly non-productive rest and restorative activities. Since resting often means time away from technologies, this will also be taken into account [90]. Rather than pacing being a strategy to maintain a normative life, we will explore what challenging the structures that shape pacing and temporality more radically might mean. As Kafer describes, "I'm thinking, too, of slowness. Of how easily *crip* time has been reduced to, narrowed to, more time—more time as a way of

mobilizing disabled people into productivity rather than transforming systems” [67, p. 421]. Our future design work will address the nuances between different kinds of rest activities outlined by our participants, and, in line with Sheppard, explore what technologies designed with a definition of pacing as an act of self-worth might look like [101].

7 Future work

As previously mentioned, this study will inform a future ideating and prototyping process that will be reported upon in future publications. The contribution our research makes to HCI and the topic of pacing technologies will act as design openings that we will explore further in the process of developing a crippled pacing technology prototype. We will then conduct user research with this device with people with ELC in order to understand the value and limitations of adopting the cripp approach in relation to the topic of pacing technologies. We will also address how our research “talks-back” to cripp theory through our research through design process.

8 Conclusion

Our research explored how we can reduce accessibility barriers for people with ELC to participate in co-design research, and what major challenges may persist despite these efforts. To this aim, cripp approaches were used in two ways to develop accessible and inclusive co-design research methods and reject normative definitions of productivity and quality of life in our approach to the topic of pacing. We conducted a five-week co-design study with people with ELC using the Asynchronous Remote Community method, which advocates for using private social media groups as a site to conduct research with populations that are otherwise difficult to reach [77]. We then analysed both the content from the activities within this study and the participants’ evaluations of their experience of taking part in this research.

Our study contributes knowledge on the tensions inherently present when conducting co-design with people with an ELC. We found that co-design activities allowed for participants to think differently about their experiences of managing an ELC, and that the community aspect of the ARC was successful, but that creative thinking and physical prototyping were experienced as particularly challenging in relation to energy exertion. Although our aim is to understand, rather than solve, the accessibility issues inherent in involving people with an ELC in HCI research, we propose some seemingly fruitful adaptations improving on our own methods, such as breaking creative tasks down over time, scaffolding creativity by using existing tools, integrating participant giving feedback into co-design methods and building on existing competencies by using creative writing tools. We discuss how adopting a cripp approach requires redefining “failure” in relation to participant contribution and contestation, and suggest that success should instead be measured by patient wellbeing.

Adopting cripp commitments demanded a non-curative and non-medicalising approach to the topic of ELC. In relation to the design of future pacing technologies, our findings support and extend existing research on the importance of care networks and data

sharing during chronic conditions. Our findings also extend current research through proposing alternative and more therapeutic forms of pacing technologies beyond the fitness watch. Taking a non-medicalising approach to the topic of ELC also surfaced societal and political norms related both to ELC as well as chronic conditions more generally, such as how future closed-loop pacing technologies that removed the “work” of pacing were understood to provide the solution to transcend and solve the problem of ELC, despite current self-tracking technologies being erratic and redundant for many participants. Our research points to future cripp pacing technologies that acknowledge that pacing is not only used to store up energy for tasks related to normative and ableist understandings of productivity, but could also be used to maintain and improve quality of life through supporting restorative activities.

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