"A Switch Went off in my Whole Body": Lived Experiences of Fatigue and Post-Exertional Malaise in Long Covid

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ABSTRACT

The growing HCI agenda on health has focused on different chronic conditions but less so on Long Covid, despite its severe impact on the quality of life. We report findings from 2 workshops with 13 people living with Long Covid, indicating the challenges of making sense of their physical, cognitive, and emotional symptoms, and of monitoring the triggers of post-exertional malaise. While most participants engage in pacing activities for the self-management of fatigue, only a few are aware of the importance of planning all their daily activities and routines in order to avoid post-exertional malaise. We conclude with design implications to support light-weight tracking and sensemaking of fatigue symptoms, novel data analytics for monitoring the triggers of post-exertional malaise and the worsening of symptoms, and support for self-management in order to prevent post-exertional malaise.

CCS CONCEPTS

• **Human-centered computing**; • **Human computer interaction (HCI)**; • **Empirical studies in HCI**;

KEYWORDS

Fatigue, Long Covid, Post-Covid Syndrome, Post-exertional malaise, PEM, Lived experiences, Triggers, Cognitive Exertion, Stress, Over-stimulation, Body awareness

1 INTRODUCTION

The global impact of Covid-19 pandemic has motivated significant research across diverse disciplines with a predominant focus on the acute infection stage. A growing body of findings however has consistently indicated that in about 10% of cases [54], the infection is followed by Long Covid or Post-Covid Syndrome consisting of viral persistence longer than 12 weeks and up to 6 months [34]. Long Covid is characterized by many fluctuating and relapsing symptoms [18] that vary among patients [34], with the most prevalent and debilitating one being fatigue [23] [37], defined as "unrelenting exhaustion and a constant state of weariness that reduces a person's energy, motivation, and concentration" [13]. In some cases, the worsening of fatigue symptoms can last for days or weeks even after minor physical or cognitive effort, which has been described as post-exertional malaise (PEM) [53]. Despite the substantial medical research on Long Covid, people's lived experiences of fatigue have been less explored, with findings conforming the challenges of recognizing the symptoms [26] [31].

Designing health technologies is a key area of HCI research targeting a range of physical [22] and mental health conditions [38] including chronic ones such as chronic pain [43] [44], together with interventions for their management through increasing activity level despite pain [5] [44]. However the topic of fatigue [17], particularly related to Covid-19, has been limitedly investigated. To address this, we employed a phenomenological approach to the exploration of people's lived experiences with Long Covid and how such subjective experiences are grounded in the body. We report findings from 2 workshops with 13 people living with Long Covid, half of them for the last 2 years, indicating many and diverse fluctuating symptoms that people struggle to understand and manage. Our contributions include richer accounts of the lived experiences of Long Covid, a vocabulary to better describe post-exertional malaise, and a cycle model for self-management of energy levels: before, approaching, during, and after PEM, tailored to the specific needs that people living with Long Covid may have at each of these four stages.

2 BACKGROUND

2.1 HCI Research on Chronic Conditions: Fatigue and Pain

We draw from HCI work on chronic conditions including the care values for people living with multiple chronic conditions, the needs and physical rehabilitation technologies for those living with chronic pain, and on the limited work for the needs of people living with chronic fatigue. Regarding the latter, a noticeable exception is Davies and colleagues' studies exploring symptoms that people living with chronic fatigue would like to be supported by technologies, the challenges and approaches to self-management and the use of commercial mobile apps for this [17]. Their findings indicate the variety of daily symptoms with post-exertional malaise and brain fog having the strongest negative impact on daily life, reduced autonomy and social relationships. Their findings also show that the main form of self-management is activity pacing or planed and gradual increase of one's energy level to avoid PEM. Davies and colleagues generated design implications for chronic fatigue technologies such as supporting people to identify their energy thresholds to avoid PEM, to plan their daily activities and routines within these thresholds as informed by energy envelope theory [35], while accounting for daily variations, to better track both physical and cognitive fatigue with limited user's effort, and to support motivation for self-management despite others' feelings of illness-invalidation.

Other strand of HCI work has focused on chronic pain and self-management technologies for rehabilitation to support much needed physical activity despite patients' fear of exacerbated pain [43]. Their findings indicate the value of accepting and understanding the pain, adjusting expectations, and assuming responsibility for their self-management by building gradually, slowly, and maintaining gains in their capabilities. In follow-up work authors designed and evaluated a wearable technology with audio feedback for sonifying real time movement during functional activities which led to increased body movement awareness and better self-managing through pacing [44]. Other scholars explored novel smartphone-based tools for momentary self-assessment of pain aimed to support engagement and reduce effort of quantifying the subjective experience of pain [1]. Healthcare for chronic conditions is particularly challenging involving lifelong non-linear trajectory consisting of repeated cycles of care alternating between home and clinical settings [12]. Researchers have also explored the values about self-care practices of people living with multiple chronic conditions [28], spouses' values impacting collaborative practices of care [6], and communication of such values to healthcare providers [5].

To summarize, much HCI research on health has looked at chronic conditions, but limited work has explored those similar to Long Covid. Some design implications for the management for instance of chronic fatigue and chronic pain may be also relevant for Long Covid, given that they encourage pacing of activity. However, we know less about how such strategy can support the self-management of the various symptoms of Long Covid and particularly post-exertional malaise.

2.2 Long Covid

A systematic review of 81 studies on symptoms and management of Long Covid indicated the prevalence of fatigue, low energy, muscular weakness, malaise, and cognitive impairment including brain fog, deficit in attention, articulation, psychomotor coordination, memory and learning which lasted at least 12 weeks after the confirmed diagnosis, with impact on quality of life consisting of limitations on activity like daily tasks, self-care and mobility; work like reduced work or inability to resume work; or social impairment like taking part in sport or leisure activities [9]. These symptoms appear to be more prevalent among female [13] with preexisting conditions especially depression or anxiety [9] [23] [36] [54], and for some individuals they could worsen in time [9], while healthcare inequities impacting particularly on vulnerable people living with Long Covid [34].

Health researchers have also suggested that Long Covid has similarities with chronic fatigue syndrome, characterized also by enduring symptoms, PEM, and reduce daily activity [13], headache, muscle pain, PEM, unrefreshing sleep and cognitive impairment [54]. Given the limited knowledge of Long Covid, recommendations have been made towards self-management approaches used for chronic fatigue, such as those involving pacing for managing PEM, while cognitive impairment can benefit from occupational and speech therapy, stress and relief therapy [13]. Health researchers have also explored the experiences of people living with Long Covid showing the fluctuations of their symptoms and their debilitating impact, since these are not easily recognized and are further worsened by the lack of diagnosis [31]. Further studies with health professionals also emphasized the uncertain prognosis of the condition, challenging loss and stigma, suggesting the value of listening to patients' voice, document monitor symptoms' fluctuation, educate patients, and encourage self-management of fatigue [26].

To conclude, despite the growing body of work on health research and social science on the lived experiences of Long Covid, there has been limited consideration of how findings my inform the design of novel technologies.

3 METHOD

In order to explore the phenomenological experiences of Long Covid we conducted a study which received institutional ethics approval. For this, we recruited participants through adverts on social media, who self-identified as having experienced fatigue for at least 3 months following Covid-19 infection. We recruited 15 participants and ran 2 online workshops with 6 and 9 participants, respectively, each lasting 2 hours focusing on participants sharing and discussing their individual experiences of fatigue. We asked questions about fatigue's symptoms, triggers, challenges and participants' self-management. Due to internet connectivity issues we excluded the inaudible input from 2 participants, so that the analysis was completed on data from 13 participants: 6 female, 6 male, 1 not disclosed, age range 25-62, average age 39. Regarding education, 3 participants have Diploma, 3 have BSc degree, and 6 Postgraduate degree, while 1 did not disclose. Each participant was compensated with gift voucher equivalent of 50 USD. The workshops were audio recorded and fully transcribed.

Our study draws from the growing HCI interest in the body [16] [49] and phenomenology studying phenomena or experiences [3] [24] that challenges the Cartesian body-mind dualism depicting that the body and mind are separated and distinct [32], in order to explore the lived experiences such as those of designers [40], of people living with HIV [4], depression [41], stress [39] [50], or of those engaged in meditation [15]. We employed a phenomenological approach to the exploration of people's lived experiences with Long Covid and how such subjective experiences are grounded in bodily senses. This approach is reflected in our gathered data reflecting lived experiences of fatigue as well as in the Interpretative Phenomenological Analysis (IPA) for analyzing participants' personal accounts for describing and making sense of their felt fatigue experiences involving three steps [45]. In the first step, two authors independently read each transcript and annotated significant parts by capturing their interpretation in the light of study aim, while looking also for differences and similarities across participants' accounts. In the second step, the authors used their annotations to inform the development of emerging themes and the selection of the most relevant ones for the study aim, with the connections between the themes and their excerpts from transcripts being explored in the third step.

4   FINDINGS

We report the identified types of Long Covid's symptoms, rich descriptions of the lived experiences of post-exertional malaise and its triggers, and people's efforts to self-manage their symptoms. We also highlight the key challenges of both identifying and monitoring the PEM's triggers, and of limited use of energy envelopes [35] as self-managing strategy, with energy envelopes reflecting the planned amount of energy to be spent as being within the limits of one's available energy.

4.1   Long Covid Symptoms: Physical, Cognitive and Emotional

Findings indicate that half of participants have struggled with Long Covid for over 2 years, and all participants reported many and diverse physical, cognitive and emotional symptoms of fatigue which are challenging to keep track, make sense of, and communicate, bearing massive impact on their quality of life.

Physical symptoms were reported by all participants and include pain in muscle and joints and unrestful sleep or unrefreshing rest, headache, dizziness, and high heart rate, as shown in this illustrative quote: "*it takes a number of forms on day to day. Some days can be absolutely horrendous [. . .] when I wake up, it will feel like I'm being pushed into that like gravity is kind of wrapped it up and I'm being kind of sucked, pulled into the bed aches and pains. A lot of. Because of my fine motor control, I struggle to do up buttons, zip up shirts [. . .] hold a knife. legs are heavy almost. It's like dragging feet across the floor, and every small [. . .] effort and heart rate [spikes]. I'm an avid runner [. . .] before I got sick, I had two marathons in two days [and] was training for another [. . .] when I got my viral infection and COVID [. . .] it was different end of the scale [. . .] from relatively fit to unable to work, walk, cognitively function*" [P1].

Cognitive symptoms include long term impairments such as brain fog impacting reading, writing and speech abilities: "*I've*

gone from being a normal functional person to, well, nothing. I hate it. I can't read anymore. My concentration won't let me read. I've just listened to audiobooks, but I can't read books. I can't read news, newspaper articles very well. Things have to be in bullet points for me to understand them. I can't fill in paperwork" [P2]. Cognitive symptoms are perceived by participants as more challenging to manage, and more debilitating than physical ones: "*I think that one of the hardest things [was] trusting [your judgement], because you can't think things through clearly [. . .] Difficult [as] I don't know if my brain doesn't work like it did before or it works just as well as it did before, but just for short periods, I still don't know that [. . .] Help? Not much, but there's some kind of help and guidance for people with their physical symptoms [. . .] but I can't find anybody that will help me understand whether it's my brain still working OK and I could go back to my job, or whether I can only do it for short periods. I've just got to try and work it out for myself, which is really hard to do*" [P7].

Emotional aspects of Long Covid are characterized by heightened distress and anxiety for the future expressed by most participants: "*I just wonder how long this is going to go on for [. . .] Is this for life? This is my worry. And this is where it's affected my mind really, cause you know, we all want our life back and we don't mind if we get if we know we're going to get better, our bodies can recover. Or is this for life?*" [P6], as well as grief for the profound losses experienced by all participants: "*my life is quite empty [. . .] You are not having a life*" [P4].

Such significant impact on the quality of life ranges from daily activities such as cooking, cleaning, washing or dressing oneself, to social life and leisure activities, to reduced ability to work and livelihood implications: "*there is definitely a massive impact [. . .] what I'm able to do [. . .] see people [as] talking to others [. . .] is definitely draining [. . .] But also, I've had to reduce the number of hours I work [. . .] I'll turn on alternate days, so that I can rest in between [. . .] it's very difficult to do much else, while also working and dealing with all other symptoms*" [P8].

4.2   Lived Experiences of Post-Exertional Malaise and its Triggers

A significant outcome is the rich accounts of participants' lived experiences of PEM described in different terms and metaphors such as: "*shutdown*", "*crash*", "*being tipped over the edge*", "*standstill*", "*complete stillness*", or "*completely drained battery*". Findings indicate that PEM can be triggered by physical moderate or gentle activities, cognitive activities such as driving or work, emotional activities such as conversations, or stress, as well as overstimulation:

"*A few months ago, I went to a therapy pool which was heaven getting in, but once I got home I just about made it up the stairs and it was like a switch went off in my whole body and I face planted on the landing [. . .] couldn't move anything in and my body felt like it shut down [. . .] And I just had to lie there for half an hour [. . .] I couldn't cope with anything. I couldn't speak. I couldn't look at anything. I was just faced down eyes shut for half an hour, and it is like a total sensory overload*" [P3].

Many participants reported several triggers, while a few reported all four types: physical, cognitive, emotional and overstimulation: "*anything from a loud noise to a bright light, to trying to speak to someone for too long, not just the physical exertion or emotional*

exertion [but also] cognitive exertion [. . .] it tends to be a delayed reaction when it comes to the physical [. . .] if I do a workout, I feel pretty good at the time and then two-three days later it will be off a cliff. In regard to [. . .] noise and light, it really kind of just sends me crashing down. [. . .] some weeks will be better than others [. . .] could feel my battery is draining [and I was] going into to work one day and feeling very unbalanced, very shaky, very heavy, and quite sea-sick [. . .] unable to focus on anything and I think I tipped myself over the edge at that point, then spent the next two weeks in bed in a dark room [. . .] any kind of stimulation noise, lights, mental, physical stimulation just left me unable to do anything" [P1]. Stress in particular also triggers PEM as: "it can compound [other symptoms] and make it worse [. . .] one of my school friends passed away [and] I would have been upset anyway, but actually it just completely floored me [. . .] because we are running you know with very little reserves so that little added extra you just can't cope with" [P6].

An important outcome is the different impact of the lived experiences associated with the physical, cognitive, emotional and overstimulation triggers. Several participants mentioned that cognitive triggers have immediate impact but are more challenging to manage, than physical ones whose impact may be both immediate or delayed; "I think I could maybe find ways to work and manage the physical fatigue sometimes, but then the cognitive fatigue I don't. That seems to be one of the biggest barriers for me" [P12].

4.2.1 Challenges: Identifying PEM Triggers, Communicating about Fatigue. A significant finding is the challenges of identifying and recognizing one's PEM triggers among the many symptoms fluctuating daily or weekly: "there are so many symptoms, so many, and they come and go randomly without any particular reason for them" [P4]. Findings also show that people's effort to track and reflect on in order to recognize the combination and intensity of their symptoms leading to PEM: "my whole body feels like it's wading through treacle, and then and I feel increasingly weak as I get more fatigued and I might start to become a bit more uncoordinated and drop things [. . .] start to get balance problems as well [. . .] brain fog and my cognitive problems will get worse [. . .] looking back now, I realized it was because I was in a big crash" [P12].

Another important challenge regards the invisibility of the condition hindering people's efforts to communicate its massive debilitating impact: "cannot be explained" [P5], "most times when I explain it to others like this, they [do not] understand.; they feel I'm saying things like that's not possible" [P9], "I try to explain and [family, friends] just don't understand sometimes [and] affects some relationships [. . .] it often gives off the vibe that I'm a bad student who I'm really not" [P10], which in turn leads to reduced social support: "a lot of my friends [and family] have been very supportive [. . .] especially in that initial stage [but if I say] I'm fatigued I know. Well, just get over it [. . .] it is socially quite challenging [. . .] the stigma around that" [P1].

4.3 Self-Management of Long Covid: Preventing Post-Exertional Malaise

Given the limited support from healthcare providers for the management and treatment of their condition, most participants have to rely on their own effort to manage their symptoms. Interestingly,

despite the abundant accounts of PEM, no participant called it using the medical term, and even fewer articulated the focus of their self-management to prevent PEM like in this example: "I am much better than I was a year ago, but I don't know if I'm recovered or just start to learn to manage the fatigue more, and avoid the crashes" [P12]. Activity pacing was perceived as also empowering, as well as accepting and working within one's limited energy: "[before] you would have battled through and making things worse, [planning means] taking that control back, and saying I will do this, this, and this, and this will have to go by the wayside, was actually quite liberating [. . .] act proactively [. . .] rather than actively just destroying yourself by trying to do too much" [P1].

4.3.1 Challenges: Limited Use of Energy Envelopes, Limited Monitoring of PEM Triggers. While many participants reported pacing as a self-management strategy, their understanding and implementation of pacing reflected limited use of energy envelopes, varying greatly among them from (i) awareness of the need to avoid behaviors triggering PEM: "I attend CBT workshops, and I sort of became aware of some of my behaviors, and [now] I tend to avoid stuff because I know that if I just do nothing, I feel better. If I do stuff, it makes me fatigued" [P4]; (ii) resting and taking breaks: "more manageable if I rest enough and pace [and] take regular breaks when I undertake activities" [P8]; (iii) planning without energy envelopes: "you have to pace absolutely everything [. . .] when you're going to cook and what [or] I can't clean a bathroom all in one go [. . .] one day I'll clean the sink the next [the] bath [and] make sure [. . .] you're not going to totally exhaust yourself, planning the whole time" [P3].

Participants acknowledged the low cognitive load of such planning, for which they used units of time, while the energy required by each activity remains tacit: "that's not a huge cognitive load [rather] simple calculation [like] I can do an hour exercise a day maximum;. [. . .] if I'm meeting with friends, I keep that to one hour [. . .] I actually like planning [. . .]I feel like I've got a bit of control" [P5]. Findings also indicate (iv) active planning of activities with energy envelopes, as mentioned by only one participant: "counting how many spoons I would need for each activity [. . .] do I have enough for the day? Overtime that has really helped scheduling the activities [. . .] use a wheelchair [as I] struggle to walk more than 1015 steps [. . .] live a sort of normal life, but with these additional tools" [P8].

Study outcomes also reveal limited use of analog or digital tools for tracking their fatigue symptoms and monitoring PEM triggers. We have seen any instance of diaries or mobile apps, and only two participants reported the value of heart rate monitoring within wearable devices: "I found really helpful having a heart rate Fitbit to check [heart rate over 100 bpm] because then I know that I need to slow down" [P8], and "I have [also] found that there is a relationship between my heart rate and my fatigue, so definitely my heart rate will go up when I've kind of reached, reaching the limits of it, and if I don't respond to that, then I definitely have a much bigger, bigger crash" [P12]. These quotes further illustrate the value of body awareness and of automatic tracking of bodily cues for preventing PEM.

Interestingly, for some participant, unlike physical exertion with more visible cues, the cognitive one appears to be more subtle and hence more difficult to understand and manage: "I think I could maybe find ways to work and manage the physical fatigue sometimes, but then the cognitive fatigue I don't. That seems to be one of the

biggest barriers for me" [P12]. Findings also suggest limited support for monitoring emotional and triggers which may be difficult to anticipate and manage given that they tend to involve social or work activities which are less in one's full control. In addition, we have also seen limited accounts of participants anticipating overstimulation and planning for limiting its impact, with most of them limited overstimulation after they have reached PEM, i.e., dark room.

5 DESIGN IMPLICATIONS

Our study aims to explore the lived experiences of Long Covid. Our findings confirming those from health research regarding the numerous and varied symptoms of this syndrome [18] [23] [34] [37] [53], as well as their fluctuation impacting the lived experience of Long Covid making them difficult to recognize [31] or manage [26]. Our findings also highlight two important additional insights. The first is that such physical, cognitive and emotional symptoms can last beyond 2 years rather than up until 6 months as previously suggested [34]. The second, concerns PEM. This has been suggested as the most significant and unique symptom of chronic fatigue syndrome [14] [25], and our findings highlight that PEM characterizes also Long Covid.

Regarding PEM, we provide a richer vocabulary to articulate the lived experience of PEM through metaphors related to *shutting down, complete energy drain, complete stillness, crashing*, or *falling* which extend the previously limited reports of lived experience of PEM. A noticeable exception here is poignant first person account of PEM in extremely severe chronic fatigue suggesting the importance of avoiding going over one's energy limit as the worsening of the symptoms may become permanent, and energy limit further reduced [14]. Vocabularies have been previously proposed as HCI contributions [20] [42]. The vocabulary we propose is important given participants' various idiographic accounts of PEM which may be difficult to recognize as such by healthcare providers, in addition to participants' challenges of making sense of their fatigue symptoms, and of monitoring the triggers and the worsening of their symptoms in order to anticipate and avoid the occurrence of PEM. However, preventing PEM has been suggested as crucial for self-management of chronic fatigue [14] through activity pacing as the key strategy [10]. Regarding self-management, findings indicate participants' willingness to engage in planning as means to reclaim agency for the self-management of their condition, also suggested as important in the self-management of chronic pain [43]. To address these challenges, we articulate the following design implications.

5.1 Support for Lightweight Tracking of and Sensemaking of Fatigue Symptoms

Findings indicate that the numerous, fluctuating and apparently random symptoms challenge people's efforts to remember, communicate, and make sense of them, while the need for capturing Long Covid symptoms through patients' voices has also been also advocated by health researchers to better understand the condition and support its diagnosis [26] [31]. Here we can think of lightweight tracking tools such as ecological momentary assessment (EMA) on smartphones or watches for capturing self-reports of fatigue symptoms through validated scales with few items in order

to limit users' burden and prevent worsening of symptoms. Similar caution for users' low burden has been suggested for capturing the subjective experience of pain [1]. Our findings indicate that unlike physical exertion, cognitive or emotional one is more challenging to make sense of. To sensitively address this need, we suggest careful selection of measuring scales for all three categories of identified symptoms: physical, cognitive and emotional exertion. These can include both mental effort scales [33] [52], or emotional exertion scale of Maslach Burnout Inventory [30]. Self-reports should also include few, carefully curated items to capture contextual information that can support users understand the reason of their exertion: activity name, its social context, and environmental stimuli, i.e., noise, light. In addition, self-reports can be augmented with both environmental sensors, as well as wearable sensors for capturing data on users' activity, interaction with their environment, as well as heart rate variability (HRV). The latter is important, given consistent findings showing HRV as promising biomarker for stress [26], cognitive load [46] and cognitive impairment [19], as well those indicating the association of Long Covid with dysregulation of autonomous nervous system, particularly HRV dysregulation [4]. HRV could be recorded through integrated biosensors [11] such as electrocardiography (ECG) chest strap or photoplethysmography (PPG) wristband, while sensitively balancing the accuracy of the former with the wearability of the latter [51].

5.2 Data Analytics for Monitoring PEM Triggers and Worsening of Fatigue Symptoms

Study outcomes indicate participants' efforts to recognize when they are approaching PEM and the various triggers that can cumulatively push them over the edge of their energy limits, be them physical, cognitive, emotional or sensory triggers. To address this challenge and its additional cognitive burden, we can envisage novel set of analytics based on machine learning and federated learning algorithms to provide privacy/security on patient data. Many ML techniques have been used for classifying the severity of chronic fatigue based for instance on immune biomarkers captured through invasive tools [48]. In contrast, less work has focused on non-invasive tools such as mobile health technologies [8] integrating multimodal sensing data and self-reports for fatigue assessment [29], or HRV and accelerometer data for detecting fatigue severity [21]. We can imagine new algorithms taking as input the data from the EMA, wearables, or less explored environmental sensors to predict the worsening of the symptoms and the likelihood of PEM occurring. Such technologies may be used to evaluate the impact of novel interventions or make AI-based recommendations for self-management as further detailed.

5.3 Supporting Self-Management of Fatigue Symptoms and Prevention of PEM

Findings indicate a cyclic journey of Long Covid, marked by the problematic occurrences of PEM. This suggests the need for more nuanced self-management tools, tailored to where people are within the cycle of energy management with regard to PEM: before, approaching, during, or after. *Before PEM stage*, if people are comfortably within their energy limits, they can be helped to maintain it by engaging in pacing and activity planning as previously suggested by

HCI work on chronic fatigue [17]. Ours extend previous findings by highlighting the added value of personalized feedback for activity pacing, together with psychoeducation on activity planning, since most of our participants engaged in taking breaks, albeit only a few were aware of the importance of planning all their daily activities and routines as informed by the energy envelope theory [35]. Here we can imagine for example lightweight screen-based interactions either on smartphones or smartwatches from which people select key daily activities from a list, together with estimated energy levels required by each one, against their estimated overall daily energy.

Approaching PEM stage requires careful reduction in the daily energy expenditure as well as replenishing it through rest. We also suggest the value of personalized recommendations for respite microinterventions, both analog or digital, involving for instance the nature's restorative value or progressive muscle relaxation [47]. The latter can include for example body scan presenting additional benefit for increasing body awareness.

During PEM stage people require complete rest and no stimuli, for which dark rooms and white noise [14] may be preferable. In terms of design implications, we can think of understimulation bubbles such as smart spaces with limited external stimuli such as images or sounds.

After PEM stage people can be supported to gradually increase exposure to sensory stimulation, by planning for activities with minimal energy demands in order to not exceed their low level of daily energy. Here we can imaging novel technologies such as interfaces for sonification of movement used for pacing activities in the self-management of chronic pain [44]. These can be extended with rest and respite microinterventions to encourage replenishing of energy.

6 CONCLUSIONS

To better understand the lived experiences of Long Covid, we conducted workshops with 13 people, half of whom have lived with this condition for the last two years. Findings indicate people's challenges of making sense of their diverse and fluctuating symptoms, and of monitoring the physical, cognitive, emotional, and perceptual triggers of post-exertional malaise. We contributed with richer accounts of lived experiences of Long Covid, a vocabulary to describe PEM, and a cycle model for self-management of energy levels: before, approaching, during, and after PEM. We articulated design implications for lightweight tracking and sensemaking of symptoms, novel data analytics for monitoring PEM triggers, and support for self-management to prevent PEM.

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REFERENCES

[1] Phil Adams, Elizabeth L. Murnane, Michael Elfenbein, Elaine Wethington, and Geri Gay. 2017. Supporting the Self-Management of Chronic Pain Conditions with Tailored Momentary Self-Assessments. In *Proc. Conference on Human Factors in Computing Systems (CHI '17)*. ACM, New York, NY, USA, 1065–1077. https://doi.org/10.1145/3025453.3025832
[2] Patricia Albulescu, Irina Macsinga, Andrei Rusu, Coralia Sulea, Alexandra Bodnaru, and Bogdan Tudor Tulbure. 2020. "Give me a break!" A systematic review and meta-analysis on the efficacy of micro-breaks for increasing well-being and performance. *Plos one* 17, no. 8: e0272460
[3] Miquel Alfaras, Vasiliki Tsaknaki, Pedro Sanches, Charles Windlin, Muhammad Umair, Corina Sas, and Kristina Höök. 2020. From Biodata to Somadata. In *Proc. Conference on Human Factors in Computing Systems*. ACM, 1–14. https://doi.org/10.1145/3313831.3376684
[4] Nicolas Barizien, Morgan Le Guen, Stéphanie Russel, Pauline Touche, Florent Huang, and Alexandre Vallée. 2021. Clinical characterization of dysautonomia in long COVID-19 patients. *Scientific reports* 11(1): 1-7
[5] Andrew Berry, Catherine Y. Lim, Tad Hirsch, Andrea L. Hartzler, Linda M. Kiel, Zoë A. Bermet, and James D. Ralston. 2019. Supporting Communication About Values Between People with Multiple Chronic Conditions and their Providers. In Proc. *Conference on Human Factors in Computing Systems (CHI '19)*. ACM, New York, NY, USA, Paper 470, 1–14. https://doi.org/10.1145/3290605.3300700
[6] Andrew Berry, Catherine Lim, Andrea L. Hartzler, Tad Hirsch, Edward H. Wagner, Evette Ludman, and James D. Ralston. 2017. How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal Caregivers. *In Proc. Conference on Human Factors in Computing Systems (CHI '17)*. ACM, New York, NY, USA, 5257–5270. https://doi.org/10.1145/3025453.3025923
[7] Alemitu Mequanint Bezabih, Kathrin Gerling, Workeabeba Abebe, and Vero Vanden Abeele. 2022. The Challenge of (Non-)Disclosure: Exploring the Lived Experience of Ethiopian Adolescents with HIV and Their Attitudes Toward Technology. In *Proc. CHI Conference on Human Factors in Computing Systems (CHI '22)*. ACM, New York, NY, USA, Article 525, 1–19. https://doi.org/10.1145/3491102.3502132
[8] Lluis Capdevila, Jesús Castro-Marrero, José Alegre, Juan Ramos-Castro, and Rosa M. Escorihuela. 2021. Analysis of gender differences in hrv of patients with myalgic encephalomyelitis/chronic fatigue syndrome using mobile-health technology. *Sensors* 21, no. 11 : 3746
[9] Felicia Ceban, Susan Ling, Leanna MW Lui, Yena Lee, Hartej Gill, Kayla M. Teopiz, Nelson B. Rodrigues *et al.* 2022. Fatigue and cognitive impairment in Post-COVID-19 Syndrome: A systematic review and meta-analysis. *Brain, behavior, and immunity* 101: 93-135.
[10] Centers for Disease Control and Prevention. 2019. Treating the most disruptive symptoms first and preventing worsening of symptoms. Available only: https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/treating-most-disruptive-symptoms.htm
[11] Niaz Chalabianloo, Can, Y. S., Muhammad Umair, Corina Sas, Cem Ersoy. 2022. Application level performance evaluation of wearable devices for stress classification with explainable AI. *Pervasive and Mobile Computing, 87*, 101703.l
[12] Yunan Chen. 2011. Health information use in chronic care cycles. In Proceedings of the ACM 2011 conference on Computer supported cooperative work (CSCW '11). ACM, New York, NY, USA, 485–488. https://doi.org/10.1145/1958824.1958898
[13] Harry Crook, Sanara Raza, Joseph Nowell, Megan Young, Paul Edison. 2021. Long covid—mechanisms, risk factors, and management. *BMJl* 374.
[14] Whitney Dafoe. 2021. Extremely severe ME/CFS—a personal account. *Healthcare*, 9(5), p. 504. Multidisciplinary Digital Publishing Institute.
[15] Claudia Daudén Roquet, Corina Sas. 2020. Body Matters: Exploration of the Human Body as a Resource for the Design of Technologies for Meditation. In *Proc. Designing Interactive Systems Conference (DIS '20)*. ACM, NY, USA, 533–546. https://doi.org/10.1145/3357236.3395499
[16] Claudia Daudén Roquet, Corina Sas. 2021. Interoceptive Interaction: An Embodied Metaphor Inspired Approach to Designing for Meditation. In *Proc. Conference on Human Factors in Computing Systems (CHI '21)*. ACM, NY, Article 265, 1–17. https://doi.org/10.1145/3411764.3445137
[17] Tabby Davies, Simon L. Jones, and Ryan M. Kelly. 2019. Patient Perspectives on Self-Management Technologies for Chronic Fatigue Syndrome. Proc. *CHI Conference on Human Factors in Computing Systems (CHI '19)*. ACM, NY, Paper 222, 1–13. https://doi.org/10.1145/3290605.3300452
[18] César Fernández-de-Las-Peñas. 2022. Long COVID: current definition. *Infection* 50, no. 1: 285-286.
[19] Forte, Giuseppe, Francesca Favieri, and Maria Casagrande. 2019. Heart rate variability and cognitive function: A systematic review. *Frontiers in neuroscience* 13: 710.
[20] Elisa Giaccardi, Elvin Karana. 2015. Foundations of Materials Experience: An Approach for HCI. In *Proc. Conference on Human Factors in Computing Systems (CHI '15)*. ACM, New York, NY, USA, 2447–2456. https://doi.org/10.1145/2702123.2702337
[21] Karla Gonzalez, Farzan Sasangohar, Ranjana K. Mehta, Mark Lawley, and Madhav Erraguntla. "Measuring fatigue through heart rate variability and activity recognition: A scoping literature review of machine learning techniques." In *Proceedings of the human factors and ergonomics society annual meeting*, vol. 61, no. 1, pp. 1748-1752. Sage CA: Los Angeles, CA: SAGE Publications, 2017.
[22] Kirsi Halttu, Harri Oinas-Kukkonen. 2017. Persuading to reflect: role of reflection and insight in persuasive systems design for physical health. *Human–Computer Interaction* 32, no. 5-6: 381-412.
[23] Tim Hartung, Christian Neumann, Thomas Bahmer, Irina Chaplinskaya-Sobol, Matthias Endres, Johanna Geritz, Karl Georg Haeusler *et al.* 2022. Fatigue and

cognitive impairment after COVID-19: A prospective multicentre study. *EClinicalMedicine* 53: 101651.

[24] Leonard Jason, Anna Vallgårda. 2020. Putting Phenomenological Theories to Work in the Design of Self-Tracking Technologies. *In Proc. Designing Interactive Systems Conference (DIS '20).* ACM, New York, NY, USA, 1833–1846. https://doi.org/10.1145/3357236.3395550

[25] Leonard Jason, Meredyth Evans, Suzanna So, Jilian Scott, and Abigail Brown. 2015. Problems in defining post-exertional malaise. *Journal of Prevention & Intervention in the Community* 43(1): 20–31.

[26] Hye-Geum Kim, Eun-Jin Cheon, Dai-Seg Bai, Young Hwan Lee, and Bon-Hoon Koo. 2018. Stress and heart rate variability: A meta-analysis and review of the literature. *Psychiatry investigation* 15(3): 235.

[27] Emma Ladds, Alex Rushforth, Sietse Wieringa, Sharon Taylor, Clare Rayner, Laiba Husain, Trisha Greenhalgh. 2020. Persistent symptoms after Covid-19: qualitative study of 114 "long Covid" patients and draft quality principles for services. *BMC health services research* 20(1): 1-13.

[28] Catherine Lim, Andrew B.L. Berry, Andrea L. Hartzler, Tad Hirsch, David S. Carrell, Zoë A. Bermet, and James D. Ralston. 2019. Facilitating Self-reflection about Values and Self-care Among Individuals with Chronic Conditions. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19). ACM, Paper 655, 1–12. https://doi.org/10.1145/3290605.3300885

[29] Hongyu Luo, Pierre-Alexandre Lee, Ieuan Clay, Martin Jaggi, and Valeria De Luca. 2020. Assessment of fatigue using wearable sensors: a pilot study. *Digital biomarkers* 4(1): 59-72.

[30] Christina Maslach, Jackson, Susan. 1986. *The Maslach Burnout Inventory. Manual*, 2nd Edn. Sage, Palo Alto,CA.

[31] Elaine Maxwell. 2020. National Institute for Health Research. Living with Covid-19: a dynamic review of the evidence around ongoing Covid-19 symptoms (often called Long Covid). https://evidence.nihr.ac.uk/wp-content/uploads/2020/10/Living-with-Covid-Themed-Review-October-2020.pdf

[32] Maurice Merleau-Ponty. 1962. *Phenomenology of perception*. Routledge.

[33] Fred Paas, Juhani E. Tuovinen, Huib Tabbers, and Pascal WM Van Gerven. 2016. Cognitive load measurement as a means to advance cognitive load theory. In *Educational psychologist*, pp. 63-71. Routledge.

[34] Joseph Pergolizzi, Jo Ann LeQuang, Peter Magnusson, Dariusz Myrcik, and Giustino Varrassi. 2021. It's not over till it's over: a narrative review of Long COVID. *Signa Vitae* 17, no. 3: 21-30.

[35] Pesek, Julia R., Leonard A. Jason, and Renee R. Taylor. 2000. An empirical investigation of the envelope theory. *Journal of Human Behavior in the Social Environment* 3, no. 1: 59-77

[36] Arkiath Raveendran, Rajeev Jayadevan, and S. Sashidharan. 2021. Long COVID: an overview. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews* 15, no. 3: 869-875.

[37] Thorsten Rudroff, Alexandra C. Fietsam, Justin R. Deters, Andrew D. Bryant, and John Kamholz. 2020. Post-COVID-19 fatigue: potential contributing factors. Brain sciences 10, no. 12: 1012.

[38] Pedro Sanches, Axel Janson, Pavel Karpashevich, Camille Nadal, Chengcheng Qu, Claudia Daudén Roquet, Muhammad Umair, Charles Windlin, Gavin Doherty, Kristina Höök, and Corina Sas. 2019. HCI and Affective Health: Taking stock of a decade of studies and charting future research directions. In *Proc. Conf. on Human Factors in Computing Systems (CHI '19).* ACM, Paper 245, 1–17. https://doi.org/10.1145/3290605.3300475

[39] Pedro Sanches, Kristina Höök, Corina Sas, and Anna Ståhl. 2019. Ambiguity as a Resource to Inform Proto-Practices: The Case of Skin Conductance. *ACM Trans. Comput.-Hum. Interact.* 26(4), Article 21, 32 pages. https://doi.org/10.1145/3318143

[40] Corina Sas, Chenyan Zhang. 2010. Do emotions matter in creative design? In *Proc. Conference on Designing Interactive Systems (DIS '10).* ACM, New York, NY,

USA, 372–375. https://doi.org/10.1145/1858171.1858241

[41] Corina Sas, Kobi Hartley, and Muhammad Umair. 2020. ManneqKit Cards: A Kinesthetic Empathic Design Tool Communicating Depression Experiences. In *Proc. Designing Interactive Systems Conference (DIS '20).* ACM, 1479–1493. https://doi.org/10.1145/3357236.3395556

[42] Corina Sas, Steve Whittaker, Steven Dow, Jodi Forlizzi, and John Zimmerman. 2014. Generating implications for design through design research. In *Proc. Conf. on Human Factors in Computing Systems (CHI'14).* ACM, NY, 1971–1980. https://doi.org/10.1145/2556288.2557357

[43] Aneesha Singh, Annina Klapper, Jinni Jia, Antonio Fidalgo, Ana Tajadura-Jiménez, Natalie Kanakam, Nadia Bianchi-Berthouze, and Amanda Williams. 2014. Motivating people with chronic pain to do physical activity: opportunities for technology design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '14).* ACM, NY, USA, 2803–2812. https://doi.org/10.1145/2556288.2557268

[44] Aneesha Singh, Nadia Bianchi-Berthouze, and Amanda CdeC Williams. 2017. Supporting Everyday Function in Chronic Pain Using Wearable Technology. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17).* Association for Computing Machinery, New York, NY, USA, 3903–3915. https://doi.org/10.1145/3025453.3025947

[45] Jonathan Smith, Megumi Fieldsend. 2021. *Interpretative phenomenological analysis.* American Psychological Association.

[46] Soroosh Solhjoo, Mark C. Haigney, Elexis McBee, Jeroen JG van Merrienboer, Lambert Schuwirth, Anthony R. Artino, Alexis Battista, Temple A. Ratcliffe, Howard D. Lee, and Steven J. Durning. 2019. Heart rate and heart rate variability correlate with clinical reasoning performance and self-reported measures of cognitive load. *Scientific reports* 9(1): 1-9.

[47] Anna Steidle, Gloria Gonzalez-Morales, Annekatrin Hoppe, Alexandra Michel, and Deirdre O'shea. 2017. Energizing respites from work: a randomized controlled study on respite interventions. *European Journal of Work and Organizational Psychology* 26, no. 5: 650-662

[48] Elizabeth Ann Stringer, Katharine Susanne Baker, Ian R. Carroll, Jose G. Montoya, Lily Chu, Holden T. Maecker, and Jarred W. Younger. 2013. Daily cytokine fluctuations, driven by leptin, are associated with fatigue severity in chronic fatigue syndrome: evidence of inflammatory pathology. *Journal of translational medicine* 11(1): 1-11.

[49] Muhammad Umair, Corina Sas, and Muhammad Hamza Latif. 2019. Towards Affective Chronometry: Exploring Smart Materials and Actuators for Real-time Representations of Changes in Arousal. In *Proceedings of Designing Interactive Systems Conference (DIS '19).* Association for Computing Machinery, New York, NY, USA, 1479–1494. https://doi.org/10.1145/3322276.3322367

[50] Muhammad Umair, Muhammad Hamza Latif, and Corina Sas. 2018. Dynamic Displays at Wrist for Real Time Visualization of Affective Data. In *Proceedings of the 2018 ACM Conference Companion Publication on Designing Interactive Systems (DIS '18 Companion).* Association for Computing Machinery, New York, NY, USA, 201–205. https://doi.org/10.1145/3197391.3205436

[51] Muhammad Umair, Niaz Chalabianloo, Corina Sas, and Cem Ersoy. 2021. HRV and stress: a mixed-methods approach for comparison of wearable heart rate sensors for biofeedback. *IEEE Access* 9: 14005-14024.

[52] Tamara Van Gog, Fred Paas. 2008. Instructional efficiency: Revisiting the original construct in educational research. *Educational psychologist* 43(1): 16-26.

[53] Timothy Wong, Danielle J. Weitzer. 2021. Long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)—a systemic review and comparison of clinical presentation and symptomatology. *Medicina* 57(5) 5: 418.

[54] Shin Jie Yong. 2021. Long COVID or post-COVID-19 syndrome: putative pathophysiology, risk factors, and treatments. *Infectious diseases* 53(10): 737-754.