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Digital Self-Management of Long Covid: A Preliminary Review of Existing Tools and Needs

Solutions digitales pour l'auto-gestion du covid long : Une revue préliminaire des outils existants et des besoins

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Abstract

Long Covid (LC) is a chronic, energy-limiting condition characterized by multisystemic, fluctuating, and disabling symptoms, with a major impact on the daily lives of those affected. Despite its prevalence, LC remains poorly recognized, with no specific treatment or accessible care pathway. In this context, patients are left to manage their condition largely on their own and are in need of tools to support day-to-day self-management. Digital solutions can play a valuable role by helping patients monitor and manage symptoms, as well as implement pacing strategies—currently recommended to manage energy and prevent post-exertional malaise. This preliminary review is intended to shed some light on digital solutions that are currently available to LC patients –be it specifically designed for them or appropriated, as well as solutions that are yet to be designed.

Résumé

Le Covid Long (CL) est une affection chronique limitant l'énergie, caractérisée par des symptômes multisystémiques, fluctuants et invalidants, qui ont un impact majeur sur la vie quotidienne des personnes touchées. Malgré sa prévalence, le CL reste mal reconnu, sans traitement spécifique ni parcours de soins accessible. Dans ce contexte, les patients doivent gérer leur maladie en grande partie par eux-mêmes et sont demandeurs d'outils pour les aider à s'autogérer au quotidien. Les solutions numériques peuvent jouer un rôle important en aidant les patients à surveiller et à gérer leurs symptômes, ainsi qu'à mettre en œuvre des stratégies de pacing - actuellement recommandées pour gérer l'énergie et prévenir les malaises post-effort. Cette étude préliminaire vise à faire la lumière sur les solutions numériques actuellement disponibles pour les patients atteints de CL, qu'elles soient spécifiquement conçues pour eux ou détournées, ainsi que sur les solutions qu'il reste à concevoir.

CCS Concepts

• **Human-centered computing** → **Interaction devices; Accessibility;**

Keywords

Digital Tools, Long Covid, Pacing, Logbooks

Mots clés

Outils Digitaux, Covid Long, Pacing, Livres de bord

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1 Introduction

In 2021, the OECD (Organisation for Economic Co-operation and Development) reported that more than one-third of adults of 24 OCDE countries live with a chronic illness [28]. Among these chronic illnesses are non-infectious diseases such as diabetes, cancer, multiple sclerosis, chronic kidney disease, and rheumatoid arthritis, as well as post-infectious syndromes such as Fibromyalgia Syndrome (FMS), Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME), and a recent addition: Long COVID (LC) [26]. The definition of Long COVID evolved with time and the latest one was defined in July 2024 by the “National Academies of Sciences, Engineering, and Medicine Committee on Examining the Working Definition for Long Covid” (NASEM) which states that “Long COVID is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems” [8]. LC includes more than 200 symptoms that affect multiple organs [5]: fatigue, brain fog, loss of taste and smell, and insomnia are some common symptoms. However, the multisystemic condition spans cardio-respiratory,

neurocognitive, musculoskeletal, psychological, circulatory, dermatological and gastrointestinal problems.

Fatigue is the most frequently reported symptom [30]. LC has therefore joined the rank of the Energy Limiting Conditions (ELC), a term that emphasizes the specific aspect of reduced energy availability [15, 21]. Fatigue can be defined as "an overwhelming, debilitating, and sustained sense of exhaustion that decreases the ability to function and carry out daily activities" [26]. Fatigue is invisible and negatively impacts all aspects of life, making every chronic illness such as LC an invisible or hidden disability [11]. It is also difficult to measure and objectify. Researchers have developed and refined scales for patients to report their level of fatigue, and research is also striving to find biomarkers that could help diagnose and monitor fatigue [6, 19, 24, 25, 34]. We should distinguish chronic fatigue, characterized by a constant lack of energy, from Post-Exertional Malaise (PEM), which corresponds to a severe symptom exacerbation after physical, mental, cognitive or emotional exertions starting 6-24 hours after activity and can last for days or even weeks [32].

In addition to the strain and frustration of not being recognized as disabled in society due to the invisible nature of the symptom/syndrome we are discussing, another challenge for LC patients is the management of their symptoms, including the management of fatigue. This management is vital for patients to limit exertion and try and avoid post-exertion malaise, as well as to try and find an appropriate pace throughout the day, the week, etc. Pacing is critical to maintain minimal functioning to allow performing at least a few everyday life tasks such as showering, eating, and some basic tasks such as reading, interacting with family, house chores, even possibly some level of work, depending on the severity of the fatigue and symptoms. To help manage their symptoms, many people living with LC (as well as other ELCs) use digital tools, such as mobile apps and smartwatches. The management of fatigue is highly dependent on the individual's ability to use self-care actions, but also on their available tools. Digital tools have proven useful for the evaluation of fatigue in health and disease [1]. This also applies to the history and management of other symptoms such as insomnia, digestive issues, or palpitations, and POTS (Postural Orthostatic Tachycardia Syndrome) [3].

This short and preliminary review assesses the current landscape of digital tools for managing LC symptoms. In our digital area, it is important to assess which digital tools are available for patient self-management of LC symptoms, which ones are lacking, and which ones could be useful to increase their quality of life and inclusion, as well as, if possible, help with their rehabilitation and healing. Our review highlights that many of these tools were not expressly designed for LC management, but have been appropriated and adapted by patients to meet their needs. We present a non-exhaustive list of available and/or appropriated tools such as digital logbooks and pacing tools, then identify the unmet needs and opportunities for development, before concluding.

2 Available Digital solutions

To begin, we identified several categories of self-management tools: digital logbooks, pacing/activity tracking tools, stress/breathing/-cardiac coherence tools, and nutrition management tools (see Figure

1). Table 1 presents examples of digital tools in each category, indicating which tools were purposefully designed for LC patients and which tools were appropriated by them. As mentioned, this short paper intends to present a non-exhaustive list of digital tools designed to perform LC symptoms self-management. Some of these tools were designed for this express purpose, while others were appropriated. Our goal is to raise awareness in the HCI community as to which categories of tools are in use, and which ones are needed by LC patients.

The list of digital tools was created by compiling feedbacks from LC patients: three of the authors and 10 LC patients from the #ApresJ20 Association Covid Long France ¹ who were solicited via the Slack chat of the association. They had to answer the following questions:

- What tools do you know or use to help you better manage your symptoms?
- What are you missing in terms of digital solutions?

The categories were created by the authors on the basis of the list of tools.



Figure 1: Digital tools categories as created from tool list gathered from LC patients.

While we further discuss these tools in the following subsections, the table shows that only a few tools have been designed for LC symptoms per se, and a large majority of digital tools used by LC patients were actually designed for other conditions, and appropriated by patients (i.e., diverted from their original purpose) for lack of available, adequate, and comprehensive tools. It should be noted that the table is not comprehensive and neither are the categories as they are based only on a small sample of patient feedback. In addition to managing LC symptoms, LC patients also make use of digital tools to stay connected with their family and friends (e.g., thanks to smartphones and videoconferencing tools), work from home, practice sport at home (e.g., via YouTube channels or sport apps), or get reminders of medications to take (e.g., My Therapy app).

¹<https://www.apresj20.fr/>

Tool	Logbooks	Pacing/Activity	Stress/Anxiety	Nutrition
Long Covid Companion	x			
Living With COVID Recovery	x			
Visible	x	x		
Agenda/calendar	x			
Bearable	x			
Pacing apps (e.g. ME/CFS Pacing, Pomodoro)		x		
Health apps for Smartwatch (e.g. Samsung, Garmin, Decathlon)		x		
Website & apps for Fodmap diet (e.g. Monash University FODMAP Diet, Fodmapedia)				x
Respirelax+			x	
Meditation videos (Youtube)			x	

Table 1: Examples of digital tools used by Long COVID patients. Grey: Tools specifically designed for LC symptom management. White: Tools appropriated by LC patients.

2.1 Digital Logbooks

Logging symptoms is a practice that is strongly encouraged by medical professionals in order to better assess the prevalence and evolution of symptoms. Although many patients still use manual logbooks, digital logbooks are now available to facilitate the process. In addition to logging symptoms, LC patients report using these logbooks to record medication intake, as well as any information that may be relevant to the current state, such as particular events that could drain the patient's energy (e.g., medical appointment, on-site work, grocery shopping). Examples of digital logbooks used by LC patients are given in table 1, they include digital agendas and calendars, the Bearable app² which allows to log a great variety of symptoms, the Living with COVID recovery app (only in UK and on invitation)³, the Visible app (not available in every county) designed specifically for invisible illnesses⁴, as well as a recent example of a tool designed specifically for LC patients: the Long Covid Companion⁵.

2.1.1 Visible. The Visible app is designed to record daily symptoms, sleep quality, energy demands, and the presence of a crash (PEM). The symptom list can be personalized. For each, the user can input how their symptoms were at their worst, between None, Mild, Moderate, and Severe. The energy demands are divided into physical, mental, emotional, and social, with a scale of exertion varying from None, A little, Somewhat, and A lot. The app offers some trend visualization.

2.1.2 Long COVID Companion. The Long COVID Companion app has been co-developed following patient's needs, based on the results of a mixed method study [10]. The app has been intended as a

²<https://bearable.app/>

³<https://livingwithhealth/covid-recovery/>

⁴<https://www.makevisible.com/>

⁵<https://app.longcovidcompanion.org>

companion to support patients in their daily lives. The main expectations raised by Long COVID patients regarding a digital health solution were to be able to monitor their symptoms in-between consultations, to improve communication with their healthcare professionals, to improve their care and access to care, and to potentially limit medical appointments. In brief, the daily data collection process is structured around three key functionalities: 1/ A self-assessment of overall health using a 0–10 Likert scale, 2/ a symptom tracking feature in which users select symptoms from an extensive list and rate their perceived intensity on a 0–5 scale, and 3/ a voice diary, enabling users to record personal notes about their daily experiences and emotions. Additional features include access to validated questionnaires that target specific symptoms or quality of life domains, and a diary to enter medical and daily life information. Visualization tools allow users to monitor the progression of each recorded symptom and questionnaire score over time, and to overlay medical and daily life events to identify potential correlations. Downloadable PDF reports summarizing all collected data over a selected time period can be generated and shared with healthcare professionals to facilitate communication and help patients provide a more objective view of what happened since the last consultation.

2.2 Pacing Tools

Pacing strategies "consist of adapting and adjusting the different patients' activities in terms of physical, cognitive and emotional effort within the limits imposed by the illness" [12, 14]. It is the only symptom management strategy shown to reduce the impact of PEM and help with day-to-day-life, such as return to work [12]. Pacing can be implemented without digital tools, such as by checking the time on a clock, or being reminded by close ones to take medications or rest, or using a timer to force oneself to take breaks. Digital

tools that enable activity tracking and cardiac monitoring –such as provided in health apps for Smartwatches– can also help by providing visualizations that can help plan breaks. Recent work by Homewood and collaborators stresses the usefulness of these tracking technologies for pacing [20, 22]. Appropriation of these solutions by LC patients is quite common these days, as is the use of digital agendas and calendars that can also be used to implement reminders.

Some tools are even designed for pacing strategies. In particular, these solutions provide automated activity and energy assessment with reminders to rest. This can help LC patients by reducing the mental load of implementing such reminders or relying on others to do so. Examples of digital tools designed to enable pacing strategies include the Pomodoro app⁶ (originally designed to enhance attentional focus), the ME/CFS Pacing app⁷, the Bearable app which also offers to set reminders, and the Visible app⁸.

In more details, in addition to the digital logbook app, Visible offers an armband that measures biosignals and additional app features that support users in budgeting their energy to avoid overdoing it. It includes notifications when to rest. However, the tool is not available in every country yet (including the authors' countries). There is also a lack of scientific research articles to support their claims, as with most solutions currently on the market.

2.3 Stress/Anxiety

Symptoms such as anxiety/stress, and symptoms directly related to these states, such as cardiac palpitations, can be managed by breathing exercises, as well as yoga and meditation exercises [17, 27]. These exercises can be learned during a session with a medical professional, but can also be performed thanks to digital tools now available online (e.g. Youtube videos), and via health applications on smartphones and smartwatches. An example of a breathing exercise tool is the RespiRelax app⁹.

2.4 Nutrition

A non-negligible proportion of LC patients suffer from digestive problems (about 22% [4]). In order to manage their symptoms, they usually have to drastically change their diet. LC patients are generally advised to log their water and food intake to better assess which food is tolerated and which will trigger pain, bloating, or other invalidating symptoms. In particular, the low FODMAP (Fermentable Oligo-, Di-, Monosaccharides And Polyols) diet is often recommended by practitioners [16]. This diet is originally recommended for patients who suffer from Irritable Bowel Syndrome (IBS). Hence, in addition to water intake monitoring that can be performed using smartwatches and health apps, digital tools developed for IBS patients can be used by LC patients to manage their digestive symptoms. A first example is the Monash University FODMAP Diet app¹⁰ developed by Monash University based on its in-depth research on the topic. The application allows to select individualized FODMAP parameters as well as log daily symptoms, perform food reintroduction, and receive personalized recommendations. It

is not expensive, however may lack some food and culinary specialties from various countries. Hence, local solutions have started to develop; one example of such is the Fodmapedia¹¹ online encyclopedia which also exists as an application. It provides FODMAP information regarding French food; however, it does not provide personalized recommendations as no parameters can be selected.

3 Unmet needs

Despite the availability of some digital tools, as listed above, important unmet needs still remain for Long COVID patients in terms of comprehensive, integrated, and locally adapted self-management solutions. Patients of the #ApresJ20 Association Covid Long France express the need for a smart calendar that can assist with pacing and daily management, including reminders to rest, eat, and take medications, as well as a color-coded visualization of care, rest, and activity over time. Far from exhaustive, the subsections below provide ideas and insights on needs regarding personalized pacing, new biomarkers that could be useful, as well as social support through virtual assistants and robotic companions.

3.1 Personalized pacing

As seen earlier, current tools used for pacing are usually diverted from their original design, that is promote exercise. Hence, activity/physiological monitoring solutions provide reminders to move and perform physical activity, while LC patients usually require the exact opposite. Personalized pacing should be provided with respect to long COVID, i.e., encourage rest based on current and past activity and physiological state. The Visible arm band does provide this solution, however, it is still unavailable in most countries.

Also, current pacing tools lack personalized guidance, audio or visual reminders, and practical step-by-step support adapted from patient associations. An ideal solution would integrate symptom-tracking apps with wearable data, medication schedules, and physiological monitoring (e.g., heart rate variability). Similar to the Visible arm band, the Long Covid Companion app has planned evolutions that include the option to integrate health data from connected devices (physical activity, sleep, heart rate), to complete symptom history a-posteriori in case of crash, and to do some cardiac coherence exercises, which is an important step towards providing an integrative digital solution.

Patients also highlight the need for a feature to scan and digitize prescriptions, helping those with cognitive issues to manage complex treatment regimens more effectively. Finally, tools should be nonjudgmental and avoid promoting unrealistic activity goals. Ultimately, the dream solution would be an all-in-one app, calm, intuitive, and customizable, that supports self-monitoring, personalized pacing, well-being journaling, and positive feedback without increasing cognitive burden.

3.2 New biomarkers

Current physiological monitoring in available solutions includes only assessment of cardiac activity, usually based on heart rate measurements. Other modalities could be integrated into LC patients' monitoring solutions. Among those, one could imagine adding a variety of measurements that can be gathered from wearable sensors,

⁶<https://pomofocus.io/>

⁷<https://www.emerge.org.au/news/mecfs-pacing-app-2/>

⁸<https://www.makevisible.com/>

⁹<https://www.thermes-allevard.com/content/respirelax-0>

¹⁰<https://www.monashfodmap.com/ibs-central/i-have-ibs/get-the-app/>

¹¹<https://fodmapedia.com>

such as electro-dermal, electroencephalographic, and electro-ocular activities. Indeed, such electrophysiological measurements are particularly relevant for assessing cognitive and affective states both in disease and in health.

Voice is also an interesting media for health assessment as voice collection is fast and easy to do, and voice production and audio signal are affected by diseases or symptoms. A vocal biomarker (VB) is a feature, or a combination of features from the audio signal of the voice that is associated with a clinical outcome. Vocal biomarkers can be used in clinical practice or research for monitoring purposes, for patient screening, or as a secondary endpoint to evaluate the efficacy of a treatment strategy for example [9]. A vocal biomarker candidate for fatigue has been previously developed based on the data from the Predi-COVID cohort study in Luxembourg, allowing to discriminate people with fatigue from people without fatigue with AUC comprised between 79% and 86%, depending on the sex of the participant and of the type of smartphone's operating system (IOs or Android) [7]. A digital cohort study will be implemented within Long COVID Companion users to refine and validate the existing VB candidate of fatigue available, and to develop VB for other main symptoms of people living with LC (brain fog, respiratory problems, mental health issues, etc.).

3.3 Social and medical support

Currently, the digital tools designed for LC patients do not specifically provide social support. Social support is gained via chats, forums, social networks. Since the first outburst of COVID, people with Long COVID have formed online communities thanks to existing digital tools, mostly on social media. These communities and tools help people with LC shape many aspects of their lives, including their diagnosis [2]. Moreover, 60% of LC patients who participated in the co-design study of the Long COVID Companion app declared that they would like to communicate with other patients via a forum or a secured mailing system integrated in the app. Finally, due to time and complexity constraints, these features were not integrated in the app but social support is provided in the app by providing contacts of patient's associations and of specialized LC healthcare networks. A new path to providing LC patients with social support as well as medical support could be taking advantage of the current research into the field of telehealth and virtual care that include the design of virtual assistants and robotic solutions. Virtual assistants and interventions are in particular currently evaluated for at home rehabilitation of LC patients [23]. Moreover, robot companions have been shown to support well-being for a variety of applications, including hospitalization but also home based support (for a review see [33]). Further, building on the fact that telepresence robots have been successfully used to support the remote inclusion of people with chronic illnesses, Ghosh and collaborators have recently evaluated the possibility of developing telemanipulator robots for LC patients and have proposed design recommendations for future developments [13].

4 Conclusion

This preliminary review performed by the authors with the help of patients from the #AprèsJ20 Association Covid Long France was intended to shed some light on the digital tools used by Long COVID

patients, as well as to propose avenues for improving these tools or the creation of new tools. It is far from exhaustive and should be pursued by a systematic review in the future. What's more, LC patients should also be included in the design process (co-design) in order to better meet their needs, as initiated by Homewood and collaborators for pacing technology [21]. Moreover, it would be particularly interesting to assess fluctuations of LC technology use depending on patients symptoms per digital tool category. Indeed, it was shown recently that on bad days, LC patients could increase their use of technology or, on the contrary, abandon it entirely due to cognitive or sensory limitations [29]. Lastly, digital tools based on wearables can help researchers and clinicians identify markers to better assess LC patients' state; an example is autonomic dysfunction monitoring using heart rate variability measurements [31]. They could also be designed with incorporating counter-measures for degraded states, as is currently developed for non-clinical applications [18]. Hence, the design of digital tools that would both increase LC patients' ability to self-manage their symptoms while providing data for research purposes is a major prospect. It should be noted that for some patients the use of digital technology is impossible or undesired and it cannot substitute for medical support and advancements in research. And, of course, beyond the need for symptom self-management tools, LC patients still have a dire need for medical and social recognition, which researchers can hope to help by undertaking to address their needs and communicate about them.

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