Digital Health and Informatics Innovations for Sustainable Health Care Systems
J. Mantas et al. (Eds.)

doi:10.3233/SHTI240815

Challenges in Daily Computerized Assessment of Cognitive Functions of Post-COVID Patients

Ann-Kathrin KNAK[a,b,1], Mandy ROHEGER[c] and Antje WULFF[a]
[a] *Big Data in Medicine, Department of Health Services Research, Carl von Ossietzky Universität Oldenburg, Oldenburg, Germany*
[b] *Psychological Methods and Statistics, Department of Psychology, Carl von Ossietzky Universität Oldenburg, Oldenburg, Germany*
[c] *Ambulatory Assessment in Psychology, Department of Psychology, Carl von Ossietzky Universität Oldenburg, Oldenburg, Germany*
ORCiD ID: Ann-Kathrin Knak https://orcid.org/0009-0007-8059-5719, Mandy Roheger https://orcid.org/0000-0002-6015-3194, Antje Wulff https://orcid.org/0000-0002-2550-2627

Abstract. While it would be quite helpful to learn more about the daily fluctuations of fatigue and cognitive impairments of post-COVID patients, their condition can make investigating these especially challenging. By discussing these issues with post-COVID patients and clinical practitioners, we identified six challenges that specifically apply to daily computerized assessment of cognitive functions of post-COVID patients. We proposed solutions for each of the challenges which can be summarized as offering a carefully planned and flexible study design to participants and monitoring their well-being throughout the assessments. We argue that when the proposed precautions are taken, it is feasible to conduct a study that will generate valuable insights into the trajectories of (cognitive) post-COVID symptoms.

Keywords. Post-COVID, long-COVID, smartphone-based assessment, ecological momentary assessment, ambulatory assessment

1. Introduction

Many patients suffering from long term sequalae after a COVID-19 infection are burdened in their daily lives by fatigue and cognitive deficits [1]. If symptoms last longer than 12 weeks and remain unexplained, this is referred to as post-COVID [2]. Our research group is particularly interested in the daily fluctuations of post-COVID cognitive functions and how these changes depend on context factors, such as medication, sleep quality or activities. Therefore, ecological momentary assessment (EMA) represents a well-known methodological approach. In EMA, participants are assessed during everyday life, often multiple times a day. Thus, external validity is increased and changes within short time periods are captured [3]. To measure cognitive functions in daily settings, participants often conduct cognitive tests via mobile devices [3]. However,

---

[1] Corresponding Author: Ann-Kathrin Knak; E-Mail: ann-kathrin.knak@uol.de.

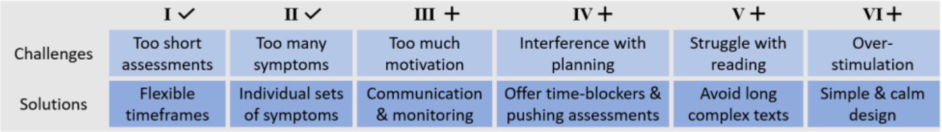
in post-COVID, we hypothesize two specific challenges regarding the use of EMA: 1) Many post-COVID patients suffer from fatigue (58% [1]) and are likely to experience regular cognitive tests as more exhausting than healthy participants would. Results could be biased due to higher levels of fatigue causing non-participation, drop-outs and missing values [4]. Further, the strain of the assessments might worsen the symptoms of patients, as it has been found in fibromyalgia [5]. Considering these points, the assessments would have to be relatively short. 2) Contrary, there is a high number of post-COVID symptoms which could possibly be measured [2]. Asking each participant to rate all of them daily would not be practically feasible. Consequently, before implementing our own EMA of cognitive functions in post-COVID patients, we need to consult people with advanced practical experience with post-COVID to confirm these two challenges, identify additional ones and discuss how and whether all of these challenges can be overcome.

2. Methods

To identify specific challenges with EMA in post-COVID patients, we conducted interviews with post-COVID patients and clinical practitioners. Ethics approval for the interviews was given by the Medical Ethics Committee of the Carl von Ossietzky Universität Oldenburg (approval number: 2023-243). We recruited a total of ten patients (six female, four male) via a neurological study ambulance for post-COVID patients (Hannover Medical School) and via a post-COVID rehabilitation program (Reha-Zentrum Oldenburg). We interviewed six clinical practitioners (neurologists, psychologists, physiotherapists and occupational therapists) working in the above-mentioned rehabilitation program. The 30-60 minutes interviews were semi-structured and focused on a) the measurements to be included in the EMA, b) the anticipated challenges and c) the possible mitigation strategies. The interview guidelines (https://github.com/AnkaUol/COVISION/) were defined in collaboration with experts from medicine, psychology and sociology. The conversations were conducted face-to-face, except for three patients who preferred to be interviewed online due to their health condition. All interviews were audio-recorded, transcribed and reviewed.

3. Results

We identified six challenges for EMA of cognitive functions of post-COVID patients (see Figure 1, described from left to right (I-VI) in the following sections).



	I ✓	II ✓	III +	IV +	V +	VI +
Challenges	Too short assessments	Too many symptoms	Too much motivation	Interference with planning	Struggle with reading	Over-stimulation
Solutions	Flexible timeframes	Individual sets of symptoms	Communication & monitoring	Offer time-blockers & pushing assessments	Avoid long complex texts	Simple & calm design

Figure 1. Challenges and solutions confirmed (check) and found (plus) during interviews.

3.1. I: "Sometimes Five Minutes of Testing are Already Too Much"

In line with our expectations, fourteen out of sixteen interviewees were concerned that the assessments might last too long. We decided that our EMA would feature one or two measurement time points a day for two to four weeks. Based on this assumption, patients and clinical practitioners mostly estimated that the duration of one assessment could last between five to ten minutes without causing physical and mental strain. However, some individuals stated that on bad days five minutes could already be too much. Similar statements from patients (multiple sclerosis) with fatigue have been reported before [6]. Unfortunately, less than five minutes is insufficient for participants to evaluate their current symptoms (including cognitive tests) and ask them about influencing factors such as their medication, sleep quality or activities. One solution considered effective by all interviewees, is allowing the participants to select the time frame before each assessment (e.g., three, five or seven minutes). Evidently, this would require prioritizing assessment items. Some interviewees also thought that this function might have some positive effects, such as being an additional indicator of fatigue and teaching participants energy management. Since participants might overestimate their energy, all interviewees agreed that it is important to be able to end the assessment quickly and easily at any time.

3.2. II: "There Are Too Many Post-COVID Symptoms to Measure Them All"

As expected, we identified over thirty symptoms worth being assessed on a daily basis. It is practically infeasible to include ratings of all potential symptoms. A different EMA study long-term sequalae of COVID-19 solved this by selecting only five symptoms to be measured [7]. However, by this, we may overlook important mechanisms that only apply to certain subgroups of patients. Therefore, we suggest allowing participants to select their most frequent symptoms at the beginning. Later assessments will only ask them to rate these symptoms and add new symptoms.

3.3. III: "I'd Rather Do Too Much than Too Little, When It Comes to Research"

All ten patients expressed their eagerness to support post-COVID research and signed up to be contacted for future studies. In related research works, this type of increased study motivation also has been observed in other patient groups (multiple sclerosis) [6]. While this is convenient for recruitment, it bears the risk that patients might be willing to participate in a study even if it puts them under an unreasonable amount of strain. The interviews revealed that the most important solution for this problem is communication. It is very important to clarify with each participant that their health has a higher priority than the research results. Further, it should be stressed that if the participants have a few missing or incomplete assessments, this does not mean the rest of their data is useless. In addition, we recommend to keep in personal contact with patients.

3.4. IV: "On Bad Days It Is Even More Important to Plan Every Little Thing You Do."

Discussion within our research team and literature search [3] revealed that it would decrease ecological validity, if participants knew the exact timing of assessments and could prepare (e.g., by strategic resting). However, several patients reported that they planned their days very carefully to deal with their fatigue. One of them insisted that the interference of unexpected assessments would be too much of a burden, a concern that is shared by other patient groups (multiple sclerosis) suffering from fatigue [6]. To minimize the burden for participants, they could be given the option to block specific time periods to ensure uninterrupted rest or push assessments to a later time point (e.g., 30 minutes later).

3.5. V: "Patients with Strong Impairments Need Support to Answer Questionnaires"

Five out of ten patients reported to struggle with reading, especially when fatigued and three out of six practitioners stressed that long questions might be too difficult to read for some patients. Difficulties in understanding written questionnaire items would likely lead to frustration and invalid answers. Fortunately, many possible design solutions were proposed by the interviewees, such as using short and simple sentences, reusing the same questions every day and replacing written text by images or audios.

3.6. VI: "Loud Noises and Too Many Lights Make Me Very Uncomfortable"

All ten patients stated that they found visually and or auditory stimulating environments very exhausting. Thus, the design should be as calm and simple as possible, with only the necessary stimuli being presented. The same has been recommended for other patient groups (multiple sclerosis) suffering from fatigue and cognitive deficits [6, 8].

4. Discussion

We gathered challenges and formulated solutions that apply specifically to daily computerized assessment of cognitive post-COVID symptoms from interviews with post-COVID patients and experienced clinical practitioners. Six challenges were identified, of which only two were expected before. This highlights the importance of exchange between research and clinical practice. Three of the identified challenges align with findings from interviews with patients with multiple sclerosis, who also tend to suffer from fatigue and cognitive deficits [6]. They are also concerned with the duration of assessments, their interference with daily energy management and overstimulating designs [6, 8]. While they are also highly motivated to participate in research, this was not regarded as a concern by other authors [6]. Handling the found challenges requires a carefully drafted design which is adaptive to individual differences and circumstances. It should be noted that our recommendation to avoid long texts is in conflict with some other literature. For patients with fibromyalgia it has been recommended to reduce cognitive burden by using written instead of verbal instructions [5]. Further, to avoid overstrain of post-COVID patients, it is important to properly communicate the relevance of their own health to participants and monitor their well-being throughout the study. Such monitoring is recommended for EMA in general [3] and EMA of long-term sequalae of COVID-19 [7]. Finally, researchers have to be aware that even with the most minimal testing, patients with high levels of fatigue will be more likely to be underrepresented because they likely have missing values, drop out of the study or decide against participating in the first place. Since the participants were recruited via two institutions, they may share similar beliefs about post-COVID and not be sufficiently representative. However, we did not observe systematic differences between the answers given by the clinical practitioners and the patients from either of the two institutions. Representativity is also limited due to the comparatively small sample size. In addition, we are aware that the results are still premature. We intend to conduct an in-depth analysis in the near future and implement as many of the solutions as possible. In our upcoming study, we will evaluate the solutions' effectiveness with an appropriately large sample size. Nevertheless, based on the expectations of people who are experienced with post-COVID, the results presented here give a first insight into the challenges and possible solutions for such a study. We are confident that these findings will help improve the quality and reduce the patients' burden in our and other future EMA studies of cognitive functions of post-COVID patients.

5. Conclusions

Computerized EMA of cognitive functions in post-COVID patients poses specific challenges. However, these can be dealt with by taking the necessary precautions when designing the study, monitoring patients throughout the assessments and bearing in mind biases when interpreting results. By this, EMA has the potential to provide new insights into the mechanisms that underly post-COVID symptoms, which will help improve treatment for patients in the long-term.

Acknowledgments and Funding

As part of the COVISION project, this work is supported by the COVID-19-Research Network Lower Saxony (COFONI) through funding from the Ministry of Science and Culture of Lower Saxony in Germany (14-76403-184). We thank our fellow researchers from the COVISION consortium (M. Dirks, A.-K. Hennemann, A. Hildebrandt, L. Jespersen, J. Voelter, K. Weissenborn, G. Zoch) and M. von Kutzleben (Mixed-Methods Labor, Carl von Ossietzky Universität Oldenburg) for their expertise and advice. Moreover, the time and energy of all participants and the cooperation of the Reha-Zentrum Oldenburg and the Hannover Medical School was greatly appreciated.

References

[1] Lopez-Leon S, Wegman-Ostrosky T, Perelman C, Sepulveda R, Rebolledo PA, Cuapio A, et al. More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. Sci Rep. 2021 Aug 9;11(1):16144. doi: 10.1038/s41598-021-95565-8

[2] Koczulla AR, Ankermann T, Behrends U, Berlit P, Brinkmann F, Frank U, et al. S1-Leitlinie Long/ Post-COVID - Living Guideline [Internet]. 2023 [cited 2024 Mar 14]. Available from: https://register.awmf.org/assets/guidelines/020-027l_S1_Long-Post-Covid_2023-11.pdf

[3] Mehl MR, Conner TS. Handbook of research methods for studying daily life. New York (NY): The Guilford Press; 2012. 676 p.

[4] Nielsen AS, Kidholm K, Kayser L. Patients' reasons for non-use of digital patient-reported outcome concepts: a scoping review. Health Informatics J. 2020 Dec;26(4):2811-2833. doi: 10.1177/1460458220942649

[5] Dailey DL, Keffala VJ, Sluka KA. Do cognitive and physical fatigue tasks enhance pain, cognitive fatigue, and physical fatigue in people with fibromyalgia? Arthritis Care Res (Hoboken). 2015 Feb;67(2):288-96. doi: 10.1002/acr.22417

[6] Karnoe A, Kayser L, Skovgaard L. Identification of factors that motivate people with multiple sclerosis to participate in digital data collection in research: sequential mixed methods study. JMIR Hum Factors. 2019 Oct 9;6(4):e13295. doi: 10.2196/13295

[7] Mansoubi M, Dawes J, Bhatia A, Vashisht H, Collett J, Greenwood DC, et al. Digital home monitoring for capturing daily fluctuation of symptoms; a longitudinal repeated measures study: Long Covid Multi-disciplinary Consortium to Optimise Treatments and Services across the NHS (a LOCOMOTION study). BMJ Open. 2023 Aug 8;13(8):e071428. doi: 10.1136/bmjopen-2022-071428

[8] Atreja A, Mehta N, Miller D, Moore S, Nichols K, Miller H, et al. One size does not fit all: using qualitative methods to inform the development of an internet portal for multiple sclerosis patients. AMIA Annu Symp Proc. 2005;2005:16–20.