Fostering Fatigue-Management in People with Post-Acute COVID-19 Syndrome - Experiences with the „Untire" App

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Abstract. Background: Many patients suffering from post-acute COVID-19 syndrome must deal with fatigue. They need physical and psychological support, strengthening, and adaption of their individual lifestyle. The use of apps can foster fatigue management. Objectives: The aim of this study was to analyse experiences of patients with fatigue caused by post-acute COVID-19 syndrome after using Untire for more than two weeks. Methods: A qualitative research design was chosen to identify user-experience after using the app. Seven semi-structured interviews were conducted and qualitative content analysis according to Mayring was applied. Results: The Untire App was generally perceived as being easy to use. Patients judged the Untire App as supportive in most of the features, especially in energy measurement and relaxation exercises. Conclusion: Thus, though developed for cancer patients, this mobile health (mHealth) application is with some restrictions also suitable for patients with post-acute COVID-19 syndrome.

Keywords. post-acute COVID-19 syndrome, fatigue, self-management, mobile application, mHealth

1. Introduction

While most people with COVID-19 recover and return to normal health, some people show symptoms that last for weeks or even months after recovery from acute illness [1, 2].

1.1. Post-acute COVID-19 syndrome and fatigue

Fatigue is the symptom that occurs most often, affecting 58% of all patients [2, 3]. Other post-acute COVID-19 syndrome health issues include respiratory and/or cardiovascular problems, pain (head, chest, abdomen, joints, muscles, "pin and needles" sensation), forgetfulness, depression, anxiety, diarrhea, and rash [1, 4, 5, 6, 7].

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1.2. Fatigue management

Fatigue is defined as extreme tiredness that lasts for a long time, is profound, and cannot be relieved by rest. It reduces the energy level of a person and may impact daily living with devastating effects on an individual's physical, social, psychological, and cognitive functioning. Those affected feel physically and mentally exhausted [4]. Many patients worldwide experience disabling fatigue as the main side effect of their illness [8].

Experts recommend that fatigue management during a post-acute COVID-19 syndrome may be beneficial in cases where a) physical and psychological support is delivered so that patients can plan their functional response to fatigue; b) strengthening rather than endurance is used to prevent deconditioning; and c) home-based activities are applied and fatigue is regarded in the context of individual lifestyle [4, 9]. Face-to-face therapy is effective but resource intensive. Additional adequate support can be provided by self-management programs via mobile phone app [10].

1.3. Mobile health (mHealth) and the Untire mobile application

The use of mobile devices to support treatment and self-management of a chronic condition is very helpful to raise awareness and support decisions in everyday life [11, 12].

There are hundreds of apps for people with chronic conditions to handle their symptoms, but up to now just a few that may help to manage fatigue caused by post-acute COVID-19 syndrome. Therefore, there is a need to identify an existing, reliable app suitable for usage in the new context of post-acute COVID-19 syndrome.

A systematic search of apps in the iOS and Android app stores was carried out. In total, 41 fatigue management apps fulfilled the inclusion and exclusion criteria. All these apps were evaluated with the "App Behaviour Change Scale" (ABACUS) [13] and the "Fatigue Impact Scale" (FIS) [14] to review how the applications address the cognitive, physical and psychosocial dimensions of fatigue. Six apps were identified as recommendable and the Untire mobile application was ranked in the first position (20 out of 24 possible points). Thus, a decision in favor of this highest scoring app was taken.

The Untire App was developed by psychologists, patients, and researchers and has been proven to be an effective measure against fatigue in cancer patients [15]. The program consists of energy measurement, education, stress-reducing activities, and physical exercises. Untire helps to identify thoughts, behaviours, and symptoms that affect energy levels with videos, tutorials, online support, and a step-by-step program [15]. But is this app also suitable for post-acute COVID-19 syndrome? Is it helpful and does it support self-managing problems caused by fatigue? The aim of this study was to analyse experiences of patients with fatigue caused by post-acute COVID-19 syndrome after using the Untire App for more than two weeks.

2. Methods

We conducted a qualitative research to identify user-experience after more than two weeks of using the app.

2.1. Recruitment

After receiving ethical approval (Ethics board decision A-2021-076 by MR Dr. Herbert Stekel, LL.M.), we started recruitment via social media, flyers in rehabilitation-centres, and word-of-mouth advertisement. Thirteen persons responded, but just seven fulfilled the inclusion criteria. Participants had to be adults with a diagnosed post-acute syndrome after COVID-19 infection and a self-reported fatigue level of three or more (on a scale from one to ten).

2.2. Procedure

We conducted the study in November and December 2021 in the Austrian province of Upper Austria. Participants had to use the app at least three times a week for 20 minutes. After two to three weeks of testing, two interviewers performed semi-structured online interviews with patients, which lasted about 30 minutes and were recorded. Questions referred to functions of the app, helpful self-management strategies, and suggestions for improvement.

2.3. Data analysis

Recordings were transcribed, and the opportunity of member-checking was offered to participants [16]. Qualitative content was analysed according to Mayring [17]. Two researchers worked separately from each other to determine coding categories and code the content. This was done in order to achieve researcher triangulation, which is recommended to improve the quality of data analysis [16].

They compared their results and discussed divergent opinions. After this, researchers assessed validity and reliability, and analysed results. Additionally, an external review was conducted. This process meets quality criteria of qualitative scientific research.

3. Results

3.1. Participants

All participants were women with a mean age of 38.4 years; the average level of fatigue was six (out of 10); most of them worked part-time when the study was conducted. All participants had already developed strategies to manage their everyday life.

3.2. User-experience

The Untire App was generally perceived as being easy to use. Patients judged the app features as follows:
- The "vase of energy" is the measurement of personal energy level (currently possible once per week); 83.3% saw this as supportive, as it helped to reveal causal relations. Patients proposed that the App should allow for measuring their energy level more often than just weekly.

- <u>Tips and reminders</u> to improve lifestyle: for 50% this was motivating and supportive.
- <u>Physical exercises ("body")</u>: 42.9% found this content useful and carried out the strengthening exercises on a regular basis; 57.1% already knew exercises and thus did not use the app.
- <u>Relaxation exercises ("mind")</u>: 71.4% loved these exercises and applied the newly learned strategies to their everyday life.
- <u>Themes</u> such as "anxiety" and "sleep" helped to better understand fatigue; patients suggested that some of the themes should be adapted to special problems induced by the post-acute COVID-19 syndrome.
- <u>Community and Buddy</u>: None of the participants invited a buddy to share their experience. Patients did not use the community function as no COVID-19 specific community was available.

All participants reported that they would recommend the Untire App to other post-acute COVID-19 patients.

4. Discussion

This paper presents the perspectives and preferences of seven individuals. The Untire App was considered as useful, especially for energy measurement and relaxation. The weekly measurement of the personal energy level helps to measure progress. Yet, particularly at the beginning of fatigue symptoms, it would be helpful to measure the level more often. Tracking the ad-hoc energy level might give important insights into what helps and what hurts energy levels [18]. This enables patients to plan their day and work on their own pace, thereby identifying effective energy conserving strategies [9].

Exercises for body and mind help some patients to increase or sustain their energy levels. In face-to-face therapy sessions, exercises are often individually chosen and adapted during therapy sessions. The app can remind and support patients to perform these exercises regularly.

Information given to themes like anxiety or sleep is helpful to better understand fatigue [15]; some of the other existing themes of the app should be adapted to special needs for COVID-specific fatigue management.

Even though dealing with fatigue is challenging, the community function was not used to exchange ideas how this could be achieved. Inviting a buddy or meeting peers can help to stick with the program [15]. It would be important to establish an online community with other post-acute COVID-19 syndrome peers to exchange experiences, additional tips, and support each other.

The use of the app must be considered well, as it must suit the individual patient. Patients need basic skills to operate a mobile application. One participant was overwhelmed by using the app because the symptom "brainfog" was still prominent. In therapy, affected people are coached to develop strategies for fatigue management [12]. Thereby, the focus is placed on energy conserving strategies [9], and apps can foster this process in a positive way.

There are some limitations to this study. Just seven persons participated; saturation of data may not have been reached yet. The sample comprises women only, as men did not volunteer to attend. This raises the question whether results obtained can be generalised.

This study was the first step in a scientific process to identify if the Untire App is experienced as helpful when used in a new context (it had originally been developed against fatigue in cancer patients [15]). The qualitative data obtained in this study are the basis for performing a quantitative study design in a second step. The latter will serve to quantify the reduction in fatigue severity by using the Untire App and prove its effectiveness.

Even though this mobile health (mHealth) application was developed for cancer patients, the authors conclude that it is - with some restrictions - also suitable for patients with post-acute COVID-19 syndrome. In combination with face-to-face therapy, the Untire App can foster self-management by mentally and physically engaging users, thus breaking the vicious circle of fatigue.

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