

Chronic Disease Self-Management of Post-Acute Sequelae of COVID-19 Among Older Adults: A Mixed-Methods Analysis

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Introduction: Approximately 20–30% of individuals who contract acute coronavirus disease (COVID-19) infection develop longer term complications of their initial infection, referred to as Post-Acute Sequelae of SARS-CoV-2 infection (PASC). PASC is characterized by chronic, varying symptomatology.

Methods: Using a mixed methods study design, we aimed to gain insight into individuals' experience with PASC, including cognitive issues, fatigue, and sleep disturbances. We explored whether our previously developed application (app), aimed at improving self-management skills among individuals with chronic diseases, is relevant for individuals with PASC and gained information to adapt the app for individuals with PASC. The study included 19 individuals, aged 40 years and older, recruited from our research participant database, Nova Southeastern University clinics, and community locations. We included this age range because older adults are more likely to have comorbid conditions, allowing us to better understand the impact of COVID-19 infection in these individuals. Participants completed seven standardized self-report questionnaires online, and an individual semi-structured interview via video-conferencing. Quantitative data were assessed using descriptive statistics and calculating individuals' scores in relation to norms. Qualitative data were analyzed using a thematic analysis approach. Triangulation of the data was accomplished by calculating correlations between participants' responses on self-report scales and themes found in semi-structured interviews.

Results: Themes included disruption of everyday life, diverse physical symptoms, and cognitive problems including brain fog, fatigue, coping, and emotional upset. Quantitative analysis demonstrated that participants experienced high levels of fatigue, negative mood, cognitive problems, and overall reduction in health-related quality of life (HRQOL). Correlation analyses revealed that individual interview responses were related to participants' self-report of symptoms on standard questionnaires.

Discussion: Findings indicate that self-report questionnaires may reflect the experience of individuals with PASC and its impact. Additionally, further efforts to expand our prior mobile app are warranted among individuals with PASC.

Keywords: post-acute sequelae of SARS-CoV-2 infection, COVID-19, long COVID, SARS-CoV-2 cognitive issues, health-related quality of life, self-report questionnaires, qualitative analysis

Introduction

Research on the effects of acute COVID-19 infection remain ongoing, which has increasingly demonstrated that approximately 20–30% of individuals will develop longer term complications of their initial infection, referred to as Post-Acute Sequelae of SARS-CoV-2 infection (PASC). Symptoms of PASC, including fatigue, post-exertional malaise (PEM), muscle and joint pain, sleep disturbances, respiratory and cardiovascular complications, and cognitive issues, can range in severity and continue months after the initial infection.^{1–3}

As research on PASC continues to evolve it is clear that many affected individuals will require healthcare services to address these symptoms.⁴ In addition, further research is needed to provide insight into PASC presenting and ongoing symptomatology and to understand the most effective methods to successfully support affected individuals. The problems encountered by individuals with PASC are in many respects like those of persons with other chronic health conditions, including Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and autoimmune diseases.^{5,6}

The impetus for this research endeavor was based on a previous mobile application (app) our research team developed to improve the health literacy of individuals with chronic diseases through improved chronic disease self-management (CDSM).⁷ Using computer-tailoring to match CDSM information to participants' level of health literacy and reported problems,⁸ the app provided basic information on CDSM for problems that often arise in individuals with chronic health conditions, such as fatigue, sleep disturbance, and cognitive problems.

Based on participants' positive reaction to our app as well as to other interventions focused on developing chronic disease management skills^{9–11} in improving self-management in established chronic diseases, our research team aimed to gain insight into whether this previously-developed CDSM app might be helpful to individuals with PASC. As such, it was determined that additional information on PASC, especially with respect to the problems addressed by the mobile app, would be necessary to further develop the app to make it useful to individuals with PASC. Our research team was most interested in how standardized self-report questionnaires could be used to accurately measure PASC symptoms. Therefore, the purpose of this study was to use a triangulation mixed methods design to provide information on individuals' experience of PASC symptoms such as fatigue, sleep disturbance, and cognitive problems and relate them to their responses on standard self-report questionnaires.

The findings of this research effort will facilitate understanding PASC from the perspective of the patient, including understanding the challenges of symptom self-management and help to determine which symptoms are amenable for intervention via a modification of our previously developed mobile app. In addition, understanding the meaning of self-report questionnaires in persons with PASC may improve the health assessment phase of the patient encounter, providing a starting point for treatment.

Materials and Methods

Study Design

A mixed methods triangulation study design was employed using semi-structured individual in-depth interviews to describe the acute and PASC experience from the perspective of patients. In addition, seven standardized questionnaires were administered in effort to determine whether standardized self-report questionnaires can be used to accurately measure reported PASC symptoms. All study procedures were carried out under a protocol approved by the Nova Southeastern University (NSU) Institutional Review Board (IRB;# 2021–315-NSU) which complies with the Declaration of Helsinki.

Recruitment

Study recruitment methods consisted of contacting potential individuals from our research study participant database (this included names of past participants who consented to be contacted for future research studies) and advertising via flyers within NSU's university clinics and community locations. A purposeful sampling method was used. Purposeful sampling is widely used in qualitative research for the identification and selection of information-rich cases related to a phenomenon of interest. Eligible participants included those who were 1) 40 years of age and older, 2) met Centers for Disease Control and Prevention (CDC) criteria for probable COVID-19 infection,¹² and 3) continued to have characteristic PASC symptoms after the resolution of the acute illness. Individuals who met the inclusion criteria were invited to schedule a time for an online video informed consent interview. We included persons in this age range because older adults are more likely to have comorbid conditions, allowing us to better understand the impact of COVID infection in these individuals.¹³

We completed informed consent procedures online in a video interview during which a written information form was reviewed with the potential participants and his or her questions were answered. Participants had been mailed a link to an

online form in the REDCap electronic data capture tools hosted at Nova Southeastern University.^{14,15} The form included a statement about the potential participant's willingness to participate in the study and required an affirmative response (checking a box for "yes") before proceeding. After indicating their willingness in this form, an electronic popup box was presented to electronically record their signature. The person conducting the interview recorded the interview and the person's responses on a form during the interview. After obtaining participants' consent for their participation, they completed the battery of self-report measures and then were scheduled to sit for an online interview later.

Study Instruments

Quantitative

Participants completed self-report questionnaires online using Research Electronic Data Capture (REDCap) software.¹⁶ Self-report questionnaires were chosen to include widely used measures of health-related quality of life (HRQOL), cognitive function, fatigue, and sleep. These included the 36-Item Short Form Survey ([SF-36],¹⁷ the Cognitive Failures Questionnaire (CFQ),¹⁸ the Center for Epidemiological Studies-Depression scale (CESD),¹⁹ the Chalder Fatigue Scale (Chalder),²⁰ and the Perceived Stress Scale, 10-item version.²¹ The battery also included measures from the Patient Reported Outcomes Measurement System (PROMIS),²² including Sleep Disturbance, Sleep Impairment, Cognitive Function, and Fatigue. Finally, we included the Pittsburgh Sleep Quality Index (PSQI).²³

Qualitative

A semi-structured in-depth interview guide was developed based on a review of the most current PASC literature available at the time of the study. The questions elicited information on symptoms and experiences tied to the acute COVID-19 infection and PASC. All interviews were conducted via video conferencing (Zoom Video Communications, Inc: San Jose, CA) by a trained interviewer to ensure consistency and monitored by a lead investigator to support in the event of technical issues. With the consent of the participants, interview responses were audio recorded and additional handwritten notes were taken.

Sample Size

The target sample size balanced the need to be able to detect relations between qualitative findings and quantitative measures. We aimed for a sample size of 20 because that would provide a power of 0.80 to detect large effect size (eg, correlations > 0.60) relations between the two types of data. Power analyses were completed using Power Analysis and Sample Size (PASS)15 (NCSS, Kaysville UT). Given others' findings on sample size needed for thematic analysis,^{24,25} we believed that this sample size was likely to allow us to achieve saturation in coding interviews.

Data Analysis

Qualitative Evaluation

Thematic analysis^{26,27} was used to better understand qualitative findings. Interviews were transcribed and entered into NVivo 11 (QSR International, Burlington MA). The first 10 interviews were coded by the first and senior author (KTP and RLO), who then discussed codes and content and agreed on a coding approach for the remainder of the interviews. Any disagreements were resolved through iterative discussion between researchers. We used the procedure recommended by Guest et al²⁴ to assess the likelihood that we had achieved saturation, which indicated a high probability (> 0.95) that saturation was obtained after 12 interviews, a number similar to that found in other studies.²⁵ Since we intended to evaluate the relation of codes to the self-report questionnaire responses, all interviews were coded.

Quantitative Evaluation

Descriptive statistics were calculated using Statistical Package for the Social Sciences (SPSS, Armonk, NY: IBM). Self-report questionnaires were scored according to each one's standard procedure, and for the questionnaires with normative data (PROMIS measures), the T score for each was obtained and reported. Correlations were calculated between the occurrence of each code in interviews (scored as 1, present, or 0, absent) and raw scores on questionnaires using the

nonparametric Spearman rank order correlation coefficient because of the small sample size and likelihood that distributions analyzed would not be normal.²⁸

Results

Qualitative

Seven themes were identified that encompassed much of our participants' experience of both the acute COVID-19 infection and resulting PASC.

Physical Symptoms

When asked about their experience with the acute COVID-19 infection, participants often listed a number of physical symptoms that characterized their experience with the infection. Symptoms such as chronic cough, shortness of breath, fever, headache, fatigue, and loss of sense of taste or smell were common. For many, symptoms persisted long after the acute infection, resulting in PASC.

Participant 110: And I have a chronic cough...The cough that I have. At night, when – and when I am – during the day, and I have to take a mentho-lyptus because I am choking. It's really bothersome. And I do not know what to – to do to get – and that's very, very, really hard. And then, people think you are sick with COVID. Because you are always coughing.

Participant 105: I have had reoccurring headaches. I have had fever that have come and gone. When I first got ill, I had a fever for probably three months. And most recently, I have had it for four months. And I take a picture every day because it's just so abnormal and no one can explain it.

Fatigue was not only a physical symptom but was in some cases so severe that the person could no longer work and might even find self-care difficult.

Participant 110: I-I am up on the third floor. I could not even walk downstairs to the mailbox.

Participant 111: But in one of those fatigue days, I end up staying in bed for the majority. I would just get out of bed to do things that are extremely necessary, like I have to take out my dog otherwise, he's gonna pee, things like that. But if I can, I just stay laying down.

Disruption of activities of daily living. One of the most common comments focused on how having acute COVID infection and the resulting PASC had upended participants' daily activities.

Participant 105: I could not drive this whole time. I have not driven since August 2020.

Participant 112: I am just taking more time off. And I work more part-time, not as much as I used to... I was working full-time. I was going in every day. I am part-time now.

Cognition. Similarly, cognitive difficulties, sometimes referred to as "brain fog", made work difficult for some participants and interfered with other daily activities. Participants described lapses in memory, feeling as though their thinking was slow, and problems in concentrating.

Participant 108: ... right after COVID, oh my God. ...I can recall going into the bank, I could not think of my account number... One of the bank officials came over and asked, and I said I am so sorry, I am just recovering from COVID, I cannot think of my account number. And I have had this account for over 40 years, and it was routine.

Participant 119: I was a wiz at mathematics. I mean, I could do scientific numeration, logarithm readings, I could read blood work, everything like that. I have got to grab a calculator now. Because I will look at zeros and commas, and I will just draw a blank.

Notably, some older participants attributed cognitive difficulties after COVID to the aging process.

Participant 117: ... And being the forgetful I think is just part of aging, you are going to forget anyway.

Emotional upset. Participants understandably described strong emotional reactions to the experience of having acute COVID infection, including fear before and after the acute infection. Many described frustrations with the slow pace of recovery and their ongoing difficulties, especially those related to PASC.

Participant 101: In every way because I look at people differently. I do not wanna go in. I mean, I am just afraid, I am just afraid. I was sitting at a table August the 1st with a lady—and it was like scattered tables...and August the 18th I found out she died from COVID. I am afraid, okay? I am totally afraid—

Participant 112: It's still bad. It affects my body. It seems like things are ongoing. It seems like it's staying the same.

Coping. In the face of the stress of having persistent and ongoing symptoms, especially related to PASC, we were interested in individuals' coping strategies. Participants reported learning to reduce activities, for example, in coping with fatigue. A number had developed compensatory strategies in coping with memory lapses, such as writing themselves reminder notes or enlisting the assistance of others to remember important appointments.

Participant 105: ... I just use natural remedies like cava root, which is a tea, and – It's just a drink. It's a tea that I make. But that – I have to watch that because it can bother my organs.

Participant 101: But some days I do not want to get up, I am like—'cause I started a routine as far as I said, "Okay, you got to do this, you got through this." And I listen to a seminar, so I'm like, "You got to get up, you gotta do a stretch", just positive things. So, I started walking, and some days I do not even wanna walk. After I walk, I feel better, but some days I do not even wanna get up.

Participant 118: Well, I got a little better with the anxiety. The depression is just a little now...I would just pray and sit still and just talk myself down. I used self-talk to help me calm down.

"Don't be too anxious. This will pass."

Experience of self. A small number reported a change in how they saw themselves as a result of the illness.

Participant 116: No, I have not experienced the brain fog, in fact, I was going to say it's almost the opposite, it's also almost a brain clarity. It could also be a function of aging too of just simply having a better grasp of what's important and what's not important.

Participant 103: I lost something in the progress – in the process of my sickness. I lost something with myself. Yeah. I lost myself somewhere.

Summary. These findings emphasize the substantial impact becoming ill with acute COVID infection and resulting PASC had on our participants. Fatigue was mentioned by all participants as an aspect of the illness that had an impact on their lives. Perhaps in response to questions that included prompts about sleep and cognition, participants provided information on these topics as well. Possibly most significant, was the level of disruption of everyday life experienced by the participants, many of whom were at least partially disabled by PASC.

Quantitative

Nineteen persons completed study procedures, including 11 women and eight men. Of the 19 participants, five were African American and 14 were white. Their ages ranged from 40 to 85 years of age, with a mean of 60.3 years ($SD = 9.1$). Descriptive statistics for the self-report measures are presented in [Table 1](#).

The most common symptoms during acute illness were fever (84%), followed by fatigue (79%), taste disorder (79%), olfactory disturbance (74%), headache (68%), shortness of breath (63%), and sore throat (63%). Based on CDC criteria for probable or confirmed COVID-19 infection, 10 participants had probable cases of acute COVID-19 infection and nine confirmed cases. We assessed the time between the acute infection and the telephone recruitment screening and found that the average number of months that participants had experienced persistent symptoms was 10.9 months (standard deviation (SD) 7.6 months).

Table 1 Descriptive Statistics for Self-Report Measures

| | Mean | Std. Deviation |
|---------------------------|-------|----------------|
| SF Physical Functioning | 59.21 | 25.94 |
| SF Limitations, Physical | 23.68 | 33.82 |
| SF Limitations, Emotional | 29.82 | 36.67 |
| SF Energy/Fatigue | 41.58 | 17.24 |
| SF Emotional Well-being | 61.47 | 13.01 |
| SF Social Function | 48.68 | 27.92 |
| SF Pain | 53.55 | 22.27 |
| SF General Health | 56.18 | 17.28 |
| CFQ Forgetful | 16.58 | 4.80 |
| CFQ Distractibility | 13.95 | 5.25 |
| CFQ False Triggering | 11.42 | 5.24 |
| CFQ Total | 43.89 | 14.94 |
| CDSM | 5.94 | 2.33 |
| CESD | 23.47 | 7.26 |
| Chalder Total | 16.53 | 4.90 |
| Chalder, Physical | 11.58 | 4.06 |
| Chalder, Mental | 4.95 | 1.93 |
| PSS | 17.00 | 5.74 |
| PROMIS Sleep Disturbance | 20.58 | 3.76 |
| PROMIS Sleep Impairment | 19.21 | 7.35 |
| PROMIS Cognition | 27.53 | 7.14 |
| PROMIS Fatigue | 22.89 | 8.12 |
| PSQI | 9.05 | 3.94 |

Notes: All rows that begin with SF are subscales of the SF-36; CFQ = Cognitive Failures Questionnaire.

Abbreviations: CDSM, Chronic Disease Self-Management; CESD, Center for Epidemiological Studies—Depression scale; Chalder, Chalder Fatigue Scale Total score and Physical, and Mental subscales; PSS, 10-item Perceived Stress Scale; PSQI, Pittsburgh Sleep Quality Index.

Many participants reported low levels of HRQOL (SF-36, general health sub-scale) and high levels of depression symptoms (CESD); 16 is often used as a cutoff for depression), fatigue (Chalder scale; SF-36 energy/fatigue sub-scale), and sleep disturbance (PSQI; Scores greater than 5 suggest sleep problems).

Descriptions of codes and tallies of their frequencies are presented in Table 2. It is noteworthy that all participants reported that acute COVID-19 infection and the resulting PASC had disrupted their daily lives, and that nearly all reported fatigue.

Table 2 Codes and Their Frequencies

| Code | Description | n | % |
|----------------------------|--|----|-----|
| Cognition | Problems in memory, attention, or slowed thinking | 13 | 68 |
| Coping | Physical (eg, medication), behavioral, or spiritual techniques used to cope with persisting symptoms | 17 | 89 |
| COVID Is Real | When asked what they thought others should know | 10 | 53 |
| Death | Mention of fearing death or experiencing it | 10 | 53 |
| Disruption in Medical Care | Problems in obtaining needed medical care | 9 | 47 |
| Disruption of Daily Life | Inability to maintain daily routines, work, or have normal relations with others | 19 | 100 |
| Emotional Upset | Anxiety, depression, irritability, or other alteration of mood | 11 | 58 |
| Experience of Self | Change in how the participant saw themselves | 4 | 21 |

(Continued)

Table 2 (Continued).

| Code | Description | n | % |
|---------------------------|--|----|----|
| Experience with Providers | Interactions with health care providers related to COVID | 13 | 68 |
| Fatigue | The experience of low physical and mental energy | 18 | 95 |
| Long COVID | Mention of long COVID as an entity | 14 | 74 |
| Physical Symptoms | Diverse symptoms of the disease, such as cough, shortness of breath, and headache. | 13 | 68 |
| Political Effects | Concern that the illness became a political issue | 4 | 21 |
| Sleep Disturbance | Changes in sleep pattern after COVID | 15 | 79 |

Integration

Correlations Between Scores and Themes

Spearman correlations of codes with self-report measures are presented in [Table 3](#). We present tests of the statistical significance of the relationship between codes and the questionnaire responses (bolded in the table). However because of our small sample size, we also present correlations of 0.20 and greater (in italics) as they may be meaningful.²⁹ A subset of all possible correlations is presented in the table, with the complete correlation matrix included in [Table 3](#).

We found that several qualitative interview codes were related to several measures. Specifically, report of cognitive difficulties was inversely related to HRQOL (SF-36 general health sub-scale). On the other hand, the report of cognitive difficulties was positively related to questionnaire report of cognitive difficulties (CFQ). In addition, participants' report of emotional upset was related to questionnaire report of cognitive problems (CFQ), fatigue (PROMIS fatigue scale), and sleep disturbance (PSQI).

Several relations, while not statistically significant, appear likely to be meaningful. Interviewee report of sleep disturbance was only significantly related to scores on the Chandler, but were related at the level of a moderate effect size to cognitive difficulties (CFQ), and questionnaire reports of sleep problems (PROMIS sleep disturbance scale; PSQI). Overall, participants' experience of PASC as revealed in their qualitative interviews is similarly reflected in the results of their completed standardized questionnaires. These results provide evidence for the usefulness of the questionnaires for reporting symptoms of PASC.

Discussion

PASC comprises several symptoms, including fatigue, sleep disturbances, cognitive issues, muscle and joint pain, cardiovascular and respiratory dysfunction, which result from the impact of COVID-19 on multiple organ systems. This study aimed to understand the challenges of symptom self-management and determine which are amendable for intervention via our previously developed mobile app. Similar to our findings, researchers have argued that several symptoms can persist long after the acute COVID-19 infection has resolved.³² Fatigue as episodic disability is characterized by periods of wellness and fatigue that fluctuate over time. Brown and O'Brien³³ argued that PASC can be presented with clusters of overlapping and episodic symptoms such as fatigue or exhaustion. Indeed, Ceban et al (2022)¹ found fatigue and cognitive impairment to be amongst the most common and debilitating symptoms of post-COVID-19 syndrome. Groff et al (2021),³ and Nalbandian et al (2021)² noted that even months after acute COVID-19 infection, PASC had a profound impact on individuals' lives, in some cases severely impairing their ability to carry out activities of daily living including dressing, self-care, work, etc. Groff et al (2021) also noted that ongoing and persistent symptoms for persons suffering PASC include continuing respiratory problems and other physical symptoms that impacted individual daily lives.³ Eaton et al (2022) in their qualitative study also uncovered a deep sense of emotional upset as a result coping with confinement and social isolation recovery after being discharged.³⁴

Some of our participants attributed their post-acute COVID-19 infection cognitive difficulties to natural aging rather than the infection itself. This finding may be significant for clinicians, as previous studies have shown that older persons may attribute treatable functional and cognitive problems to "old age" rather than seek help.^{35,36} Given the evidence that

Table 3 Correlations of Self-Report Measures with Codes

| | SF-36 General Health | CFQ | CDSE | CESD | Chalder | PSS | Sleep Disturbance | Sleep Impairment | Cognition | Fatigue | PSQI |
|----------------------------|----------------------|--------------|-------|--------------|--------------|-------------|-------------------|------------------|--------------|--------------|---------------|
| Cognition | -0.53* | 0.52* | -0.42 | 0.03 | <i>0.38</i> | <i>0.20</i> | <i>0.43</i> | <i>0.37</i> | -0.39 | <i>0.36</i> | 0.62** |
| COVID Is Real | 0.15 | -0.03 | -0.02 | 0.05 | 0.05 | -0.34 | -0.29 | -0.17 | -0.28 | 0.08 | 0.07 |
| Death | -0.23 | <i>0.22</i> | -0.32 | 0.07 | <i>0.21</i> | -0.03 | <i>0.28</i> | <i>0.28</i> | 0.01 | <i>0.26</i> | 0.01 |
| Disruption in Medical Care | 0.06 | <i>0.20</i> | -0.20 | -0.10 | <i>0.26</i> | -0.13 | -0.07 | 0.06 | -0.15 | <i>0.14</i> | -0.12 |
| Emotional Upset | -0.43 | 0.56* | -0.07 | <i>0.41</i> | <i>0.35</i> | -0.15 | <i>0.41</i> | <i>0.17</i> | -0.40 | 0.48* | 0.62** |
| Experience of Self | -0.13 | <i>0.20</i> | -0.07 | 0.46* | 0.47* | -0.38 | <i>0.31</i> | <i>0.34</i> | -0.06 | 0.48* | <i>0.27</i> |
| Experience with Providers | -0.15 | <i>0.19</i> | -0.08 | -0.16 | <i>0.28</i> | <i>0.21</i> | 0.06 | <i>0.14</i> | 0.02 | <i>0.32</i> | <i>0.17</i> |
| Fatigue | 0.00 | <i>0.26</i> | -0.09 | -0.39 | <i>0.35</i> | -0.32 | 0.02 | <i>0.30</i> | -0.13 | <i>0.33</i> | <i>0.35</i> |
| Long COVID | -0.20 | <i>0.34</i> | -0.11 | -0.14 | <i>0.40</i> | 0.01 | <i>0.36</i> | <i>0.09</i> | -0.11 | <i>0.26</i> | <i>0.25</i> |
| Physical Symptoms | -0.11 | -0.34 | 0.07 | -0.13 | 0.01 | 0.02 | 0.53* | -0.08 | 0.46* | -0.22 | 0.07 |
| Political Effects | 0.11 | -0.06 | 0.04 | 0.13 | -0.17 | 0.02 | -0.24 | -0.23 | -0.15 | -0.20 | <i>0.24</i> |
| Sleep Disturbance | -0.20 | <i>0.34</i> | -0.19 | -0.01 | 0.51* | -0.19 | <i>0.31</i> | <i>0.18</i> | -0.25 | <i>0.34</i> | <i>0.36</i> |

Notes: Significant correlations are in bold font and marked as with * ($p < 0.05$) or ** ($p < 0.01$); correlations equal to or greater than 0.20 are italicized as they may represent relations that are important^{30,31}

cognition can be affected in PASC^{37–39} it may be helpful to educate older persons on the symptoms of PASC and help them to find ways to cope with them.

Our findings were also consistent with that of Case et al (2022), Jacobs et al (2020), and Suyanto et al (2022)^{40–42} who observed their study participants as having a low HRQOL score after a COVID-19 infection. These findings indicate the need for broader interventions to support self-care in individuals with PASC. Indeed, self-management of symptoms in the long term is often costly, with some individuals using a substantial proportion of their income, which threatens to widen existing health inequalities.⁴³ Even with excellent support from healthcare providers, much of the burden of coping with PASC will fall on patients,⁴⁴ many of whom may not be well prepared to develop routines for self-management and advocate on their own for the support and services they need.⁴³

The implementation and deployment of digital tutorials have proven to be a quick and effective health education tool to alleviate the burden that healthcare professionals and patients face due to the COVID-19 pandemic.⁴⁵ The use mobile health (mHealth) apps have facilitated symptom monitoring of COVID-19 infection and have been used to share data with health care professionals and support disease prediction, prevention, management, diagnostics, and improvements in treatments and patient education.⁴⁶ Using the results of this study, we plan to modify our previously developed digital health app to address the needs of those coping with PASC. Research has supported the use of mobile apps to assist patient chronic disease self-management via digital education, self-monitoring, and feedback.⁴⁷

Conclusion

In this study, we explored the experience of individuals with persistent symptoms after acute COVID-19 infection, especially with respect to fatigue, sleep, and cognition. We found that while they are affected by diverse symptoms based in multiple organ systems, some problems cut across types of physical symptoms and are like those encountered by others with chronic diseases. By relating participants' response in interviews to their responses to widely used self-report questionnaires, we were able to better understand the meaning of these scales in the context of PASC, supporting their further use. These data may be helpful in further developing digital health apps to assist persons with PASC better manage their symptoms, and our research team aims to expand these research efforts to explore our previously developed mobile app for this application.

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Disclosure

Dr Raymond L Ownby is a stockholder of and officer in entity focused on the development of digital therapeutics for Enalan Communications, Inc. In addition, Dr Raymond L Ownby has a patent Assessment of Human Comprehension by an Automate Agent pending to Nova Southeastern University. The authors report no other conflicts of interest in this work.

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