## **Marquette University**

# e-Publications@Marquette

College of Nursing Faculty Research and Publications

Nursing, College of

2023

# Lived Experiences of American Adults who Survive COVID-19: Implications for Physical Activity and Interpersonal Stress

Linda B. Piacentine Marquette University

Hannah C. Barbosa Marquette University

Kristin Haglund Marquette University

Lauren Opielinski Marquette University

Sandra K. Hunter *Marquette University* 

See next page for additional authors

Follow this and additional works at: https://epublications.marquette.edu/nursing\_fac

C Part of the Nursing Commons, Physical Therapy Commons, and the Physiotherapy Commons

#### **Recommended Citation**

Piacentine, Linda B.; Barbosa, Hannah C.; Haglund, Kristin; Opielinski, Lauren; Hunter, Sandra K.; Papanek, Paula E.; Bement, Marie K. Hoeger; and Johnson, Norah L., "Lived Experiences of American Adults who Survive COVID-19: Implications for Physical Activity and Interpersonal Stress" (2023). *College of Nursing Faculty Research and Publications*. 963.

https://epublications.marquette.edu/nursing\_fac/963

# Authors

Linda B. Piacentine, Hannah C. Barbosa, Kristin Haglund, Lauren Opielinski, Sandra K. Hunter, Paula E. Papanek, Marie K. Hoeger Bement, and Norah L. Johnson

This article is available at e-Publications@Marquette: https://epublications.marquette.edu/nursing\_fac/963

Draft version 01-09-2023. This paper has not (yet) been published and is not therefore the authoritative document of record.

© 2023, American Psychological Association. This paper is not the copy of record and may not exactly replicate the final, authoritative version of the article. Please do not copy or cite without authors' permission. The final article will be available, upon publication, via its DOI: 10.1037/fsh0000792

# Lived Experiences of American Adults who Survive COVID-19: Implications for Physical Activity and Interpersonal Stress

Piacentine, Linda. B., Barbosa, Hannah C., Haglund, Kristin A., Opielinski, Lauren E., Hunter,

Sandra K., Papanek, Paula E., Hoeger Bement, Marie, & Johnson, Norah L.

Affiliations: All authors are at Marquette University, Milwaukee, WI

Linda B. Piacentine, Nursing

Hannah C. Barbosa, Nursing

Kristin A. Haglund, Nursing

Lauren E. Opielinski, Exercise Science, Physical Therapy

Sandra K. Hunter, Athletic & Human Performance Center (AHPRC), Exercise Science,

Physical Therapy

Paula E. Papanek, Exercise Science, Physical Therapy

Marie Hoeger Bement, Physical Therapy

Norah L. Johnson, Nursing

Corresponding Author:

- Linda Piacentine, PO Box 1881, Milwaukee, WI 53201-1881, <u>linda.piacentine@marquette.edu</u>, Phone: 414-288-5696, Fax: 414-288-1939
- Grant Support: This work was supported by the Athletic and Human Performance Research

Center and the Institute for Women's Leadership at Marquette University.

Acknowledgements: We would like to thank the participants in the study.

Conflicts of Interest: The authors report no conflicts of interest.

#### Abstract

**Introduction:** The cumulative number of COVID-19 cases has surpassed 579 million globally. Symptoms during and after COVID-19 infection vary from mild cold symptoms to severe multisystem illness. Given the wide range of symptom presentations and complications post COVID-19, the purpose of this study was to describe the lived experience of American adults surviving COVID-19.

**Method:** This study employed an exploratory qualitative description design. Semi-structured interviews were conducted with a sample of 35 individuals, [white (94%), female (71%), mean age = 43.7 years], with proximity to a university in an urban Midwest American city. Interviews occurred between May and August 2021, three or more months after participants tested positive for COVID-19.

**Results:** Forty percent of the 35 participants experienced prolonged COVID-19 symptoms impacting their lifestyle. Four themes characterized the impacts of the post COVID-19 condition on the lives of the participants within the context of a global pandemic: (a) disruptions in health & well-being, (b) persistent uncertainty, (c) disruptions in interpersonal relationships, (d) beneficent outcomes and adaptation.

**Discussion:** This study of COVID-19 has identified important implications for physical activity and interpersonal stress. Prolonged COVID-19 symptoms led to disruptions in the health, wellbeing, and interpersonal relationships of participants. Healthcare professionals need to attend to symptoms post COVID-19, assess interpersonal functioning, and provide guidance on physical activity. Future studies are recommended to track consequences of COVID-19's impact on longterm health and well-being.

Keywords:

Adult: 19-44 years; COVID-19 Psychosocial factors; COVID-19 Symptoms; Fatigue; Middle Aged: 45-64 years;

Public Significance Statement:

Adults who have had COVID-19 may have long-lasting impacts from the infection affecting their health and well-being. The uncertainty of having COVID-19 may lead to deferring needed care for symptoms unrelated to COVID-19, altered interpersonal functioning, or decreased ability to exercise.

# Lived Experiences of American Adults who Survive COVID-19: Implications for Physical Activity and Interpersonal Stress

The cumulative number of people diagnosed with COVID-19 has surpassed 579 million globally as of August 2022 (World Health Organization, 2022). The severity of COVID-19 symptoms varies widely. While many individuals experience mild to moderate cold symptoms, others are hospitalized with complications. Long term survivor health outcomes also vary according to age (Mueller et al., 2020), underlying medical conditions (Garg et al., 2020; Petrilli et al., 2020) and/or physical activity levels (Sallis et al., 2021). Given the range of symptom presentations and complications post COVID-19, it is difficult for healthcare professionals to predict an individual's response to infection and appropriately support the patient and/or their family members.

Post COVID-19 condition usually occurs at least three months post-acute infection with symptoms lasting at least 2 months (Soriano et al., 2022). This condition has also been referred to as post-acute COVID-19 syndrome or long COVID-19 (Jimeno-Almazán et al., 2021). In a meta-analysis including 24,255 people, 72% had at least one COVID-19 symptom at 8 weeks post-infection and 46% had one or more symptoms at 12 or more weeks post-infection (Fernandez-de-las-Penas et al., 2021). This syndrome is a multi-system disorder with respiratory, cardiovascular, hematologic, and neuropsychiatric symptoms either alone or in combination (Chippa et al., 2022; Kingstone et al., 2020; Petersen et al., 2022). Post-acute COVID-19 syndrome has a multifactorial etiology with inflammation playing a prominent role in the development of this syndrome (Chippa et al., 2022).

COVID-19 causes uncertainty for many people (Sodi et al., 2021). Individuals missed or had late diagnoses with potentially serious health consequences as a result of forgoing health care during the pandemic for financial reasons or fear of acquiring COVID-19 (Anderson et al., 2021; Gonzalez et al., 2021; Kakietek et al., 2022). Along with avoiding primary care visits, individuals avoided potentially life-saving emergency department care to avoid exposure to COVID-19 (Gale et al., 2021).

Another concern caused by the pandemic was the relational cost of the public health policies implemented during the pandemic (Long et al., 2021). Families were directed to stay in their own homes. Individuals who lived alone were isolated from family and friends for extended periods of time. Adults and children who tested positive were mandated to stay home and rely on others to bring them food and supplies while they were in isolation. Individuals with prolonged symptoms felt particularly alone.

The high rates of COVID-19 related morbidity and mortality indicated significant disruption of society and individual lives (Centers for Disease Control and Prevention, 2022). The systemic nature of our health care system and society has led to inequities in testing, follow up, information, vaccination, and forgone care that is predicted to exacerbate existing disparities in access to care and health outcomes (Dickinson et al., 2021; Grimm, 2021; Ramprasad et al., 2022). The results of this study fill a gap in understanding the variety of ways prolonged COVID-19 symptoms affect the daily lives of individuals. The purpose of this study was to describe the lived experience of American adults surviving COVID-19.

#### Methods

# Design

We used a qualitative description methodology (Bradshaw et al., 2017), as it offers findings that are closer to the data with lower level of interpretation compared to other qualitative methods (Sandelowski, 2010). Institutional Review Board (IRB) approval was obtained from a university. Inclusion criteria included English speaking adults aged 18 years or older, and who self-reported that they had COVID-19 more than 3-months prior to participation in the study. No incentives were offered to participants.

## Recruitment

Thirty-five adult participants with proximity to a university in an urban Midwest American city were interviewed between May and August 2021. Participants were recruited via messaging on television news, social media, and posted flyers in community locations. Additional recruiting occurred through word of mouth on a university campus.

#### **Data Collection**

Demographic data collected through written questionnaires included gender, age, race, ethnicity, education, occupation, income, COVID-19 symptom history, and timing of COVID-19 illness and vaccination. Qualitative data were gathered through individual, semi-structured, and audio-recorded interviews, or written responses. One or more of the research team then conducted 30-minute interviews in a private room. An interview guide (see Figure 1) elicited stories of acute infections and recoveries, assets/strengths, challenges/deficits, and unmet needs. Participants were offered rest and snack breaks during study visits to prevent fatigue from limiting responses. A written survey was offered to adults who preferred this modality to capture the perspective of individuals who had limited time available to participate in a synchronous interview.

#### **Data Analysis**

Audio recordings were uploaded to Otter.ai, a voice to audio transcription online application (otter.ai). An accuracy check of transcription was completed. Written online responses were downloaded and identifiers were removed. Data analysis followed with an iterative process of coding and thematic analysis (Braun & Clarke, 2006) using NVIVO software

7

(QSR International, 2022). An initial code list reflected the research and interview questions. Two researchers from a larger group of coders independently coded all transcripts with the initial list. Changes to the initial code list reflecting new codes or combining previous codes were discussed within the larger team to reach full consensus. Any disagreements on codes were resolved through the discussion of the larger group. The revised code list was applied to previously coded transcripts. After coding was complete, researchers created a table of preliminary themes and supporting codes. Data within the supporting codes were reviewed and summarized. Themes were identified and supported with analyzed data.

#### Rigor

Several methods were employed to ensure rigor and limit bias. Validity in qualitative studies refers to how well the themes and findings represent the actual phenomenon (Morse, 2015). Participants' quotes are included to support the descriptions of themes to establish validity and to allow readers to assess whether these results apply, or are transferable, to other populations. Details of the methods and limitations were included to increase study reliability (Morse, 2015). A coding system was developed and agreed upon by the researchers and inter-coder agreement was used to establish reliability (Morse, 2015). A detailed account of the methods and limitations was provided for transparency regarding reproducibility and to increase reliability of this study and results (Morse, 2015). Member-checking was conducted to further ensure trustworthiness of the findings. The results were sent to three participants who agreed to be contacted after the study to ascertain if the results captured the experiences of people like them who have survived COVID-19. They verified the accuracy of our interpretation of the aggregate experience, not their individual story. Research team members had different expertise and professional backgrounds which helped with reflexivity, the practice of overtly examining

one's own biases and preconceptions (Morse, 2015). The multidisciplinary research team met regularly during data collection, analysis, and manuscript preparation. Biases and preconceptions were checked with frequent discussions and manuscript reviews based on the disciplinary knowledge and experiences of the team. Under the guidance of an experienced qualitative researcher, initial coding of themes was agreed upon by the team and reviewed several times during data analysis.

#### Results

There were 35 participants (n=33 audio recorded interviews, n=2 written responses). Two participants deferred completing the interview due to time constraints and the desire for a written format later. The majority of participants were white (94%) and female (71%), with a mean age of 43.7 years (min 19 years- max 75 years) and diagnosed with COVID-19 on average 7.7 months prior to participation (min three months - max 13 months). Participants also generally reported education beyond high school (88.5%) and were employed or students (91.4%). Five (14%) participants had been hospitalized with COVID-19. Thirty-two participants were infected with COVID-19 in 2020 and early 2021, before vaccines were widely available and, thus, were not vaccinated at the time of their illnesses (see Table 1). Twenty-one (60%) of participants reported experiencing COVID-19 symptoms for at least two months and continuing at time of study participation. We identified four themes in the experiences related by the participants: (a) disruptions in health & well-being, (b) persistent uncertainty, (c) disruptions in interpersonal relationships and (d) beneficent outcomes and adaptation.

#### **Disruptions in Health and Well-being**

Disruptions in health and well-being were experienced in physical and mental health. The COVID-19 survivors were most bothered by symptoms of activity intolerance, the insufficient

physiological or psychological energy to support or supplement the required or desired daily activities (North American Nursing Diagnosis Association, 2008). They also experienced cognitive impairments, sadness, and frustration. According to participant responses to the question "Are you still experiencing COVID-19 related symptoms now?", almost 40% of participants (n = 13) reported activity intolerance at 3 or more months post infection. One participant noted, "My physical fitness I'd say is poor, that's deteriorated over the last couple years. And with COVID, I feel like it's worse. It's a little harder to breathe, I'm just more likely to avoid physical activity than normal" (43 years old, female). Another participant noted limited exercise due to her continued difficulty breathing and she did not seek medical care because of insurance copay costs and "they [physicians] didn't want you there anyway" (56 years old, female).

Some participants reported post-exertional fatigue (after exercise or on the next day) that required bedrest. One participant said, "You feel good on a given day, then you just overdo it, because you finally feel good. And then the next day you pay for it" (52 years old, male).

Feelings of sadness and loss also impaired activity. Participants reported feeling sad about losing family members to COVID-19. For example, one participant lost her mother to COVID-19 and has had persistent fatigue. She spoke about how feeling sad decreased her interest in physical activity:

I have weakness too and poor endurance because I didn't go a lot of places and I didn't feel like I wanted to go to a lot of places, so I think that the sadness probably had played into it (54 years old, female).

The survivors also reported feelings of permanent loss regarding their identity as active, vigorous people. They attributed their activity intolerance and loss of strength to both COVID-19

and their advancing age. Feeling sad was also noted to be associated with decreased interest in physical activity. Activity intolerance limited the frequency, duration, and intensity of physical activity. Participants reported decreased physical activity as they did not feel good in general, and they anticipated exercise would make them feel even worse.

Participants also expressed frustration with lingering cognitive symptoms that they called "brain fog." Brain fog was the experience lack of cognitive clarity, slowness of mental processing; difficulty sustaining concentration; memory deficits such as forgetting appointments and repetitive questioning; and difficulty finding a word when speaking and writing. About 50% (n = 17) reported brain fog with acute infection that resolved by 8 weeks. For 12 participants (34%), brain fog persisted after 3 months. In addition to the physical effects of the COVID-19 infection, being isolated during shut down and the continued stress of the pandemic exacerbated the brain fog and sadness.

#### **Persistent Uncertainty**

Participants reported uncertainty about the future impact of having COVID-19. They wondered if their symptoms were related to COVID-19 or something else. One stated that "I do feel tired. I don't know if I can say it's because of COVID. I really can't pinpoint that. You know, is it more than before? I'm not quite sure" (61 years old, female). A second stated a similar uncertainty "You know, the stamina thing, it's hard to tell with getting older, you know, if it's COVID related, or if it's just age related. I know I tire more easily than I used to" (69 years old, female). A third participant noted she has brain fog and trouble with memory yet is uncertain about the origin of the symptoms. She said,

I lose words more than I did before I had COVID where it's really difficult to get words multiple times in a conversation. I have I stop and start doing things more than I did before I had COVID ... Sometimes I forget what I read almost as soon as I read it. I don't know if that's unusual or not (43 years old, female).

The participants also noted uncertainty regarding how COVID-19 might continue to affect their future health. One participant stated that "we're still not getting there, and there's still a part of me that just goes, God, when is this going to be over?" (62 years old, male). A second stated that "It's impacted me because now I'm worried, futuristically what kind of health conditions are going to happen or come my way. How did it affect my heart and my lungs? Really? I wasn't hospitalized. Who knows? my joints?" (56 years old, female). A third participant stated,

I just want to get better. I don't need to run a marathon. But I just want to be able to run. I want to be able to bike. My kids are getting older I want to be able to chase him for a couple more years. This heart and the lungs, that worries me. Is that going to shorten my life? . . . I don't want it to be any shorter than it's already going to be (42 years old, male).

Participants described their unmet needs for full recovery from COVID-19. One stated that they wished there was a solution to feeling better: "Yeah, some doctor to create some miracle pill or shot that all of us can take and make us feel better . . . we all want to be back to what we used to be and feel good." (52 years old, male). One participant said, "I would like to find something that would help with concentration and that foggy feeling" (50 years old, female). The participant also noted, "It would be nice to find something like more resources for treating that fogginess and stuff like that" (50 years old, female).

# **Disruptions in Interpersonal Relationships**

Participants noted disruptions in interpersonal relationships and social well-being. Regarding having COVID-19, a participant said, "It's really changed things when we get together with them [family]. I still keep my distance from them" (42 years old, male). Other participants experienced isolating times, e.g. "I live alone so when I did get COVID, it was a very isolating time for me. I just really had myself and had to take care of myself" (40 years old, female). Another participant talked about her experience and hesitancy to share her feelings with her family and friends, stating, "It's just that they don't need or want to hear about this [experience of COVID-19 illness]" (61 years old, female).

Disruptions included relationship conflicts largely due to disagreements about COVID-19. One participant noted conflicts from differing opinions about safety measures taken to prevent infection during the pandemic, stating "It's all very isolating, and you didn't really know what was too much risk or what was not that big of a risk" (31 years old, male). Another stated "with my immediate family, most of them don't really take COVID seriously, and they haven't been vaccinated. And I just worry a lot about it, and I don't really know how to talk to them about it" (29 years old, female). Some mentioned the strain placed on relationships with extended family members. Another talked about the stress they felt from the differing opinions, stating "with all of this social division that's come out of it, including with family and just society as a whole, that's been pretty stressful" (29 years old, female).

Another common experience was disturbed work-life and school-life balance related to poorly defined boundaries between work and home. One participant mentioned their change in routine, stating "I worked remotely. I would go from my room to my office and then that was it. I wouldn't go anywhere else in the house" (43 years old, female). Another participant talked about the difficulties finding balance when they said, "it was weird, having the same sleeping and relaxing environment as my school environment" (19 years old, female). Furthermore, the participant related to an increase in stress surrounding school when stating, "definitely a challenge was keeping up the motivation to be a good student" (19 years old, female).

#### **Beneficent Outcomes and Adaptation**

In addition to disruptions, participants reported how they have made positive changes in response to surviving COVID-19 infection. Time at home led to family assisting with healing, e.g., "My husband's trying to get me out every day to walk whether I want to or not" to rebuild stamina and "he's got like this whole list of things that he wants me to do to keep healthy" (59 years old, female). Participants reprioritized their time to plan healthy diets, exercise, and connect with family instead of doing chores. Others increased time spent on hobbies or educational activities. One participant related, "I feel like I never had hobbies before. Like, I love reading now" (20 years old, female). Another stated that, "I went back to school for a second degree with online classes . . . Just for some kind of intellectual stimulation. And that's been the best thing I've ever decided in my life" (31 years old, female). Several participants related increased time spent on mindfulness or spiritual activities such as yoga, meditation, journaling, or prayer. One participant noted, "I've kept a journal of thankful moments of the day and inspirational moments" (52 years old, male). Another participant stated, "I've also tried to pray more often just because you have more time to and there so many things to pray about in today's world" (19 years old, female). Others noted how the new flexibility of attending online church added to their spiritual activities.

Other participants commented on how they felt supported by the people with whom they were living. For some, time at home was a chance for their family to become closer and spend more time together. One said, "It's kind of nice that we had that time in a way, like we did a lot of family games and TV, because that's all we could do together really, stayed at home and

cooked together" (22 years old, female). Another stated that "we [family] kind of leaned on each other a lot because we had COVID and no one else did" (50 years old, female).

Finally, participants related that approaching COVID-19 infection with a positive attitude was beneficial. One person stated, "I just was like, okay, eventually I'm going to get better, things will be back to normal . . . just got to take everything in strides and just try and be positive" (29 years old, female). Another noted, "I became more positive, just because that's the only way I felt I could deal with it. Otherwise, it would just be a tailspin" (46 years old, male). Several participants noted things could have been worse, they could have been hospitalized or had bigger health issues. One participant noted how she had learned from the experience of her mom having COVID-19 and was determined to be more positive. She said, "I kind of used her experience to push myself in a different headspace, you know, because I didn't want to be down in the dumps like she was because that was just super hard for me to see" (29 years old, female). Another participant stated, "I look at this COVID-19 thing as just a, a minor inconvenience that has happened. And you just move on, and you get better" (31 years old, female).

#### Discussion

This study probed how COVID-19 and prolonged symptoms impacted physical, emotional, relational, and social aspects of daily life. Findings provide unique and important implications for healthcare professionals to address physical activity and interpersonal stress concerns in COVID-19 survivors. Disruptions in life caused by the illness and the uncertainty of COVID-19 were accompanied by beneficent outcomes and adaptation.

The first theme, disruptions in health and well-being, participants had many post COVID-19 concerns and often mentioned how physical activity was negatively impacted. Fatigue and shortness of breath, both of which impair physical activity, are the most common prolonged COVID-19 symptoms (Fernandez-de-Las-Penas et al., 2021). Additionally, the combined effects of fatigue, cognitive impairment, and feeling sad, anxious, or depressed, can cause people to avoid physical activity, placing them at increased risk for severe COVID-19 complications and prolongation of symptoms (Sallis et al., 2021). Regular physical activity can enhance immune function and reduce the risk of systemic inflammation; increase cardiovascular health, lung capacity and muscle strength; and improve mental health (Jimeno-Almazán et al., 2021; Pedersen & Saltin, 2015; Ruegsegger & Booth, 2018). However, activity after COVID-19 may be limited by symptoms and may lead to a symptom exacerbation, post-exertional fatigue, and psychological distress, particularly frustration and decreased self-esteem at not being able to perform usual daily activities (Humphreys et al., 2021; Shelley et al., 2021).

Tailored and supervised exercise is being promoted as an effective multisystemic therapy for recovery from prolonged symptoms and post COVID-19 syndrome (Jimeno-Almazán et al., 2021). Tailored activity plans may emphasize returning to normal physical activity in daily life, rather than focusing on planned exercise, as survivors with more symptoms cope with daily living (Shelley et al., 2021). For those with less severe symptoms, a gradual increase in structured exercise may be appropriate (Shelley et al., 2021). Elements of a tailored plan should include psychological support, managing post-exertional fatigue, and a gradual return to activities based on individual symptoms (Humphreys et al., 2021; Shelley et al., 2021). COVID-19 survivors could benefit from a multidisciplinary approach to guide physical activity and healthcare professionals should foster continued efforts at exercise to promote recovery.

The second theme, persistent uncertainty, the participants' narratives were similar to current literature showing that the unpredictability of COVID-19 and the fear of long-term health consequences, impacted mental health (Gardiner et al., 2022). Uncertainty also impacted delayed or missed care. The presence of uncertainty regarding etiology of symptoms, may lead

people to misattribute their symptoms and not seek care thereby potentially missing important diagnoses and treatments. For example, participants in this study attributed their decreased stamina, brain fog, and memory issues to normal aging. When people attribute symptoms to normal or expected causes, they may delay seeking care (Machluf et al., 2021). Other researchers have reported patients, or primary care clinicians, attributing symptoms to their COVID-19 infections which has resulted in significant and detrimental delays in care. For example, a study conducted in Israel identified delayed diagnoses of cancer in children because attribution of symptoms to COVID-19 infection precluded work-up for other etiologies (Dvori et al., 2021). In a second report from Israel (Machluf et al., 2021), clinicians identified "misattributed dyspnea (shortness of breath)" (p. 2), which they defined as dyspnea in pregnant women that is considered as normal, when in actuality this dyspnea is an abnormal symptom of a COVID-19 infection and warrants immediate care. Healthcare professionals should be aware that misattribution of symptoms is a problem that has been highlighted in the COVID-19 pandemic and has led to delayed care. Primary care clinicians can avoid misattribution of symptoms by not reaching premature conclusions regarding etiology of symptoms. Instead, clinicians should generate a thorough differential diagnosis, tell patients signs and symptoms that warrant return care, and not delay warranted work-up for possible serious diagnoses.

Concern regarding the uncertainty surrounding COVID-19 exposure contributed to changed health care behaviors among Americans. To prevent exposure to the virus, individuals sought telehealth for primary care issues, which may have limited the thorough assessment of their symptoms (Maffoni et al., 2021). Professionals also noted difficulties with video communication, including managing emotions online. Telehealth was most acceptable for patients with an established clinician for less serious health issues that did not need a physical examination to make a diagnosis (Imlach et al., 2020). Likewise, emergency department care was impacted by individuals fearing COVID-19 exposure (Gale et al., 2021). Telehealth is a way to increase access to health care and answer non-urgent questions that may prevent need for urgent care later.

The third theme, disruptions in interpersonal relationships, captured the way people socialized, managed school and work, and the alterations in how they made connections with others. This finding matches existing literature on the shift among social support systems during the pandemic, where people with family and social networks have better outcomes than individuals who are isolated from others physically or due to strong differences in family beliefs (Long et al., 2022). Survivors have also felt stigmatized because of the disease and continued to isolate themselves after recovery (Toulabi et al., 2021). The consequences of COVID-19 infection are pertinent to those working with families such as in integrated behavioral health settings (IBH). People present to primary health care for treatment of physical symptoms such as breathing difficulty. The evidence from this study and others revealed how people experience detrimental effects on psychosocial health from having COVID-19 infections (Gardnier et al., 2022; Long et al., 2022; Toulabi et al., 2021). Participants in our study were concerned that their family and friends did not want to listen to them speak about their COVID-19 illnesses. Yet, our participants found talking about their experiences to be therapeutic. This is similar to another study in which sharing illness experiences in an online support group helped people with prolonged symptoms of COVID-19 cope (Ladds et al, 2021).

It is important for health care providers to let patients know psychosocial health effects are common among persons who have had COVID-19 infections. By routinely asking about psychosocial health, patients will feel more comfortable relating their experiences and more confident that their provider is interested and will listen. Making this content part of routine teaching, normalizes patients' concerns and fears about their psychosocial health and conveys that not only are the patients not alone, but there are ways to get help. For providers in IBH settings, a warm hand-off to a behavioral health clinician may increase patients' comfort with the referral and likelihood that they will engage with the clinician (Fountaine et al., 2022; Sheldrick et al., 2022). Consulting with IBH professionals, can aid in assessment, consideration of differential diagnoses, and recommendations for appropriate treatments. In our study, participants stated they wished there was a "miracle pill" or more "resources" to help them. The multidisciplinary team is an important resource for patients. A multidisciplinary perspective facilitates a holistic assessment of patients' health to understand and address the relationships between the physiological effects of infection, such as the effects of inflammation on the respiratory and neurological systems, and the psychosocial effects of the illness experience, such as feeling isolated, afraid, and sad.

The final theme, beneficent outcomes and adaptation, captured how participants adopted positive attitudes and behaviors to promote health and well-being in response to experiences with COVID-19. The theme included increased connections with families and friends, reassessment of personal priorities, and the benefits of a positive attitude. Similar to prior research on prolonged COVID-19 (Humphreys et al., 2021) participants in this study could be considered to have altered expectations of their future lives (i.e., biographical disruption) beyond COVID-19. However, some of our participants identified positive outcomes from the COVID-19 pandemic including renewal and strengthening of interpersonal relationships and increasing health promotion behaviors. Healthcare professionals may be able to help people focus on these positive experiences to overcome the lasting and negative effects of COVID-19.

This study had limitations. The results are self-report of adults who have had a COVID-19 infection and may be influenced by variations in the severity of this illness and any lasting symptoms. Additionally, these data are not from family, friends, or healthcare professionals, which limits the data to an individual's point of view. When telling their stories, participants frequently discussed family dynamics and interactions caused by COVID-19 infection. Another limitation was two participants desiring to complete the interview in a written format. While this is a different format, it was their desire to have their stories heard, and, thus, their data were included in analysis. Due to the semi-structured nature of the interviews, these data were more limited in depth, although this was somewhat addressed through including all the follow-up prompts on the written questionnaire. Participants were largely white, educated, young, and from one geographic region. The participants are not, therefore, particularly representative of the populations that were disproportionately impacted by COVID-19 or most likely to be seriously and adversely impacted by the pandemic. Even with adequate social determinants of health the participants still experienced significant challenges due to COVID-19 infections. Given the systemic racism that affects access and forgone care, marginalized communities may or may not have the same themes or the same degree of effects from infection (Dickinson et al., 2021; Grimm, 2021; Ramprasad et al., 2022; Stepanikova & Oates, 2017). The lack of diversity in the participants, in part due to location of study and method of recruitment, needs to be explored in future research.

#### Conclusion

The impacts of COVID-19 may be deeper and more disruptive than the signs or symptoms suggest. Clinical implications include healthcare professionals proactively screening patients for COVID-19 impacts, rather than waiting for the patient to identify specific concerns. Thus, healthcare professionals can help people navigate the uncertainty regarding COVID-19 by managing long-term effects and preventing the generation of new problems. People who think their symptoms were due to COVID-19 or due to aging, for example, could have a more serious illness. Fear of COVID-19 infection and uncertainty about symptoms and sequelae contribute to forgone care. Delayed care during a pandemic poses a health risk for discovery of progressive diseases (Gonzalez et al., 2021). Healthcare professionals should not dismiss patient concerns. Physical activity may improve outcomes of COVID-19; however, tailored plans may be needed as infection sequalae may include physical activity limitations. While the illness experience can contribute to schisms in personal relationships, people also have set new priorities and committed to improved self-care. Future studies are recommended to track consequences of the impact of COVID-19 infection on long-term health and well-being and to develop tailored interventions.

#### References

- Anderson, K. E., McGinty, E. E., Presskreischer, R., & Barry, C. L. (2021). Reports of forgone medical care among US adults during the initial phase of the COVID-19 pandemic.
   *Journal of the American Medical Association (JAMA) Network Open, 4*(1), Article e2034882. <u>https://doi.org/10.1001/jamanetworkopen.2020.34882</u>
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in healthcare research. *Global Qualitative Nursing Research*, 4, Article 2333393617742282. <u>https://doi.org/10.177/2333393617742282</u>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Centers for Disease Control and Prevention. (2022). COVID-19. https://www.cdc.gov/coronavirus/2019-ncov/cdcresponse/laws-regulations.html
- Chippa, V., Aleem, A., & Anjum, F. (2022). Post acute coronavirus (COVID-19) syndrome. *StatPearls*. StatPearls Publishing. Retrieved May 26, 2022 from <u>https://www.ncbi.nlm.nih.gov/books/NBK570608/</u>
- Dickinson, K. L., Roberts, J. D., Banacos, N., Neuberger, L., Koebele, E., Blanch-Hartigan, D.,
  & Shanahan, E. A. (2021). Structural racism and the COVID-19 experience in the United States. *Health Security*, 19(S1), S14-S26. <u>https://doi.org/10.1089/hs.2021.0031</u>
- Dvori, M., Elitzur, S., Barg, A., Barzilai-Birenboim, S., Gilad, G., Amar, S., Toledano, H.,
  Toren, A., Weinreb, S., Goldstein, G., Shapira, A., Ash, S., Izraeli, S., & Gilad, O.
  (2021). Delayed diagnosis and treatment of children with cancer during the COVID-19
  pandemic. *International Journal of Clinical Oncology, 26*,1569–
  1574. https://doi.org/10.1007/s10147-021-01971-3

- Fernandez-de-Las-Penas, C., Palacios-Cena, D., Gomez-Mayordomo, V., Florencio, L. L., Cuadrado, M. L., Plaza-Manzano, G., & Navarro-Santana, M. (2021). Prevalence of post-COVID-19 symptoms in hospitalized and non-hospitalized COVID-19 survivors: A systematic review and meta-analysis. *European Journal of Internal Medicine*, 92, 55-70. https://doi.org/10.1016/j.ejim.2021.06.009
- Fountaine, A., Iyar, M., & Lutes, L. (2022). Facilitating mental health treatment engagement in integrated primary care: Examining Canadian perspectives on the utility of virtual warm handoffs amidst COVID-19 and beyond. *International Journal of Integrated Care* (*IJIC*), 22 (S3), Article 81. http://doi.org/10.5334/ijic.ICIC22291
- Gale, R., Eberlein, S., Fuller, G., Khalil, C., Almario, C. V., & Spiegel, B. M. R. (2021). Public perspectives on decisions about emergency care seeking for care unrelated to COVID-19 during the COVID-19 pandemic. *Journal of the American Medical Association (JAMA) Network Open, 4*(8), Article e2120940.

https://doi.org/10.1001/jamanetworkopen.2021.20940

- Gardiner, E., Baumgart, A., Tong, A., Elliott, J. H., Azevedo, L. C., Bersten, A., Cervantes, L.,
  Chew, D. P., Cho, Y., Crowe, S., Douglas, I. S., Evangelidis, N., Flemyng, E., Horby, P.,
  Howell, M., Lee, J., Lorca, E., Lynch, D., Marshall, J. C., ... Craig, J. C. (2022).
  Perspectives of patients, family members, health professionals and the public on the
  impact of COVID-19 on mental health. *Journal of Mental Health*, *31*(4),1-10.
  https://doi.org/10.1080/09638237.2021.2022637
- Garg, S., Kim, L., Whitaker, M., O'Halloran, A., Cummings, C., Holstein, R., Prill, M., Chai, S.J., Kirley, P. D., Alden, N. B., Kawasaki, B., Yousey-Hindes, K., Niccolai, L., Anderson,E. J., Openo, K. P., Weigel, A., Monroe, M. L., Ryan, P., Henderson, J., ... Fry, A.

(2020). Hospitalization rates and characteristics of patients hospitalized with laboratoryconfirmed coronavirus disease 2019 — COVID-NET, 14 states, March 1–30, 2020. *MMWR. Morbidity and Mortality Weekly Report*, 69(15), 458-464.

https://doi.org/10.15585/mmwr.mm6915e3

- Gonzalez, D., Karpman, M., Kenney, G. M., & Zuckerman, S. (2021, February). Delayed and forgone health care for nonelderly adults during the COVID-19 pandemic. *Urban Institute*. Retrieved May 15 from <u>https://www.urban.org/</u>
- Grimm, C. A. (2021). Hospitals Reported That the COVID-19 Pandemic Has Significantly Strained Health Care Delivery. U.S. Department of Health and Human Services Office of Inspector General. Retrieved May 15 from <u>https://oig.hhs.gov/oei/reports/OEI-09-21-00140.pdf</u>
- Humphreys, H., Kilby, L., Kudiersky, N., & Copeland, R. (2021). Long COVID and the role of physical activity: A qualitative study. *British Medical Journal Open*, 11(3), Article e047632. <u>https://doi.org/10.1136/bmjopen-2020-047632</u>
- Imlach, F., McKinlay, E., Middleton, L., Kennedy, J., Pledger, M., Russell, L., Churchward, M., Cumming, J., & McBride-Henry, K. (2020). Telehealth consultations in general practice during a pandemic lockdown: survey and interviews on patient experiences and preferences. *BMC Family Practice*, 21(1), Article 269. <u>https://doi.org/10.1186/s12875-020-01336-1</u>
- Jimeno-Almazán, A., Pallarés, J. G., Buendía-Romero, Á., Martínez-Cava, A., Franco-López, F., Sánchez-Alcaraz Martínez, B. J., Bernal-Morel, E., & Courel-Ibáñez, J. (2021). Post-COVID-19 syndrome and the potential benefits of exercise. *International Journal of*

*Environmental Research Public Health, 18*(10), Article 5329. https://doi.org/10.3390/ijerph18105329

- Kakietek, J. J., Eberwein, J. D., Stacey, N., Newhouse, D., & Yoshida, N. (2022, Jun 13).
  Foregone healthcare during the COVID-19 pandemic: Early survey estimates from 39 low- and middle-income countries. *Health Policy and Planning*, *37*(6), 771-778.
  <a href="https://doi.org/10.1093/heapol/czac024">https://doi.org/10.1093/heapol/czac024</a>
- Kingstone, T., Taylor, A. K., O'Donnell, C. A., Atherton, H., Blane, D. N., & Chew-Graham, C.
  A. (2020). Finding the 'right' GP: A qualitative study of the experiences of people with long-COVID. *British Journal of General Practice (BJGP) Open, 4*(5).
  https://doi.org/10.3399/bjgpopen20X101143

<u>https://doi.org/10.3377/0jgp0pen20X101143</u>

- Ladds, E., Rushforth, A., Wieringa, S. Taylor, S., Rayner, C., Husain, L., & Greenhalgh, T. (2020). Persistent symptoms after Covid-19: Qualitative study of 114 "long Covid" patients and draft quality principles for services. *BMC Health Services Research, 20,* Article 1144. https://doi.org/10.1186/s12913-020-06001-y
- Long, E., Patterson, S., Maxwell, K., Blake, C., Boso Perez, R., Lewis, R., McCann, M., Riddell, J., Skivington, K., Wilson-Lowe, R., & Mitchell, K. R. (2022). COVID-19 pandemic and its impact on social relationships and health. *Journal of Epidemiology & Community Health*, 76(2), 128-132. <u>https://doi.org/10.1136/jech-2021-216690</u>
- Machluf, Y., Rosenfeld, S., Ben Shlomo, I., Chaiter, Y. & Dekel, Y. (2021) The Misattributed and silent causes of poor COVID-19 outcomes among pregnant women. *Frontiers in Medicine*, 8, Article 745797. https://doi.org/10.3389/fmed.2021.745797
- Maffoni, M., Torlaschi, V., Pierobon, A., Zanatta, F., Grasso, R., Bagliani, S., Govoni, L., Biglieri, M., Cerri, L., Geraci, L., Salvaneschi, G., & Piaggi, G. (2021). Video calls

during the COVID-19 pandemic: A bridge for patients, families, and respiratory therapists. *Families, Systems, & Health, 39*(4), 650-658. https://doi.org/10.1037/fsh0000661

- Morse, J. M. (2015, Sep). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, 25(9), 1212-1222. https://doi.org/10.1177/1049732315588501
- Mueller, A. L., McNamara, M. S., & Sinclair, D. A. (2020). Why does COVID-19 disproportionately affect older people? *Aging*, 12(10), 9959-9981. https://doi.org/https://doi.org/10.18632/aging.103344
- North American Nursing Diagnosis Association. (2008). Nursing diagnoses: Definitions and classification 2009–2011. Oxford: Wiley-Blackwell.
- Pedersen, B. K., & Saltin, B. (2015). Exercise as medicine evidence for prescribing exercise as therapy in 26 different chronic diseases. *Scandinavian Journal of Medicine & Science in Sports, 25*(S3), 1-72. <u>https://doi.org/10.1111/sms.12581</u>
- Petersen, E. L., Gossling, A., Adam, G., Aepfelbacher, M., Behrendt, C. A., Cavus, E., Cheng, B., Fischer, N., Gallinat, J., Kuhn, S., Gerloff, C., Koch-Gromus, U., Harter, M., Hanning, U., Huber, T. B., Kluge, S., Knobloch, J. K., Kuta, P., Schmidt-Lauber, C., ... Blankenberg, S. (2022). Multi-organ assessment in mainly non-hospitalized individuals after SARS-CoV-2 infection: The Hamburg city health study COVID programme. *European Heart Journal 43*(11), 1124-1137. <u>https://doi.org/10.1093/eurheartj/ehab914</u>
- Petrilli, C. M., Jones, S. A., Yang, J., Rajagopalan, H., O'Donnell, L., Chernyak, Y., Tobin, K.
  A., Cerfolio, R. J., Francois, F., & Horwitz, L. I. (2020). Factors associated with hospital admission and critical illness among 5279 people with coronavirus disease 2019 in New

York City: Prospective cohort study. *British Medical Journal (Clinical research ed.)*, 369, Article m1966. <u>https://doi.org/10.1136/bmj.m1966</u>

QSR International. (2022). NVIVO. In (Version 12) www.qsrinternational.com

Ramprasad, A., Qureshi, F., Lee, B. R., & Jones, B. L. (2022). The relationship between structural racism and COVID-19 related health disparities across 10 metropolitan cities in the United States. *Journal of the National Medical Association*, *114*(3), 265-273. https://doi.org/10.1016/j.jnma.2022.01.008

Ruegsegger, G. N., & Booth, F. W. (2018). Health benefits of exercise. *Cold Spring Harbor Perspectives in Medicine*, 8(7), Article a029694.

https://doi.org/10.1101/cshperspect.a029694

- Sallis, R., Young, D. R., Tartof, S. Y., Sallis, J. F., Sall, J., Li, Q., Smith, G. N., & Cohen, D. A. (2021). Physical inactivity is associated with a higher risk for severe COVID-19 outcomes: A study in 48,440 adult patients. *British Journal of Sports Medicine*, 55(19), 1099-1105. <u>https://doi.org/10.1136/bjsports-2021-104080</u>
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33(1), 77-84. https://doi.org/10.1002/nur.20362
- Sheldrick, R., Bair-Merritt, M., Durham, M., Rosenberg, J., Tamene, M., Bonacci, C., Daftary, G., Tang, M., Sengupta, N., Morris, A., & Feinberg, E. (2022). Integrating pediatric universal behavioral health care at federally qualified health centers. *Pediatrics*, *149*(4), 27–38. https://doi.org/10.1542/peds.2021-051822
- Shelley, J., Hudson, J., Mackintosh, K. A., Saynor, Z. L., Duckers, J., Lewis, K. E., Davies, G.A., Berg, R. M. G., & MNarry, M. A. (2021). 'I live a kind of shadow life': Individual experiences of COVID-19 recovery and the impact on physical activity levels. International

Journal of Environmental Research and Public Health, 18, Article 11417. https://doi.org/10.3390/ijerph182111417

- Sodi, T., Han, B., & Singh, P. (2021). Special issue on psychology of uncertainty and vulnerabilities: COVID-19 pandemic related crisis. *Psychological Studies (Mysore)*, 66(3), 235-238. https://doi.org/10.1007/s12646-021-00623-w
- Soriano, J. B., Murthy, S., Marshall, J. C., Relan, P., Diaz, J. V. & WHO Clinical Case Definition Working Group on Post-COVID-19 Condition. (2022). A clinical case definition of post COVID-19 condition by a Delphi consensus. *The Lancet Infectious Diseases*, 22(3), 316-317. https://doi.org/10.1016/S1473-3099(21)00703-9
- Stepanikova, I., & Oates, G. R. (2017). Perceived discrimination and privilege in health care: The role of socioeconomic status and race. *American Journal of Preventive Medicine*, 52(1S1), S86-S94. https://doi.org/10.1016/j.amepre.2016.09.024
- Toulabi, T., Pour, F. J., Veiskramian, A., & Heydari, H. (2021). Exploring COVID-19 patients' experiences of psychological distress during the disease course: a qualitative study. *BMC Psychiatry*, 21(1): 625. https://doi.org/10.1186/s12888-021-03626-z
- World Health Organization. (2022). *WHO coronavirus (COVID-19) dashboard*. Retrieved May 15<sup>th</sup> from https://covid19.who.int/

| Table 1                          |           |
|----------------------------------|-----------|
| Demographics N=35                |           |
| Item                             | N (%)     |
| Gender                           |           |
| Female                           | 25 (71.4) |
| Male                             | 10 (28.6) |
| Age (Years)                      |           |
| 19-28                            | 9 (25.7)  |
| 29-38                            | 5 (14.3)  |
| 39-48                            | 5 (14.3)  |
| 49-58                            | 5 (14.3)  |
| 59-68                            | 8 (22.8)  |
| 69-75                            | 3 (8.6)   |
| Race                             |           |
| White                            | 34 (97.1) |
| Asian                            | 1 (2.9)   |
| Ethnicity                        |           |
| Non-Hispanic                     | 33 (94.3) |
| Hispanic                         | 2 (5.7)   |
| Occupation                       |           |
| Management / Finance             | 9 (25.7)  |
| Students                         | 8 (22.9)  |
| Educators / Researchers          | 6 (17.1)  |
| Health care workers              | 6 (17.1)  |
| Retired                          | 3 (8.6)   |
| Human Resources                  | 1 (2.9)   |
| Customer Service                 | 1 (2.9)   |
| Engineer                         | 1 (2.9)   |
| Education                        |           |
| High School Diploma              | 4 (11.4)  |
| College 1-3 years                | 9 (25.7)  |
| College Graduate                 | 11 (31.4) |
| Master's Degree                  | 10 (28.6) |
| PhD or equivalent                | 1 (2.9)   |
| Annual Income                    |           |
| 20,001-30,000                    | 1 (2.9)   |
| 30,001-40,000                    | 3 (8.6)   |
| 40,000 and up                    | 21 (60.0) |
| Unreported (students, retired)   | 10 (28.6) |
| Hospitalized with acute COVID-19 | 5 (14.0)  |
| COVID-19 > 3 months              | 21 (60.0) |
| COVID-19 vaccine timing          |           |
| Illness before vaccination       | 27 (77.1) |
| Illness after vaccination        | 2 (5.7)   |
| Unvaccinated                     | 5 (14.3)  |
| Unknown                          | 1 (3)     |

Figure 1

Semi-Structured Interview Guide

Tell me about you and your health?

How has your life has been impacted by COVID-19?

Prompts:

What have been the impacts on your physical health? What have been the impacts on your sleep? What have been the impacts on your stamina (prolonged physical/mental effort)? What have been the impacts on your personal and family life? What have been the impacts on your work life? What have been the impacts on your finances? What have been the impacts on your thinking? What have been the impacts on your mood and level of irritability/patience? What has been the impact on your ability to think positively and be optimistic?

Tell me about your experience with COVID-19?

How have you been coping with the effects of COVID-19 infection?

Prompts:

What things have helped you since getting COVID-19?

What things have made your recovery difficult?

What are you doing to look after yourself (prompts: physical, emotional, social, and spiritual well-being)?

What exercise have you been able to do since getting COVID-19?

What work have you been able to do since getting COVID-19?

What unmet needs do you still have? Or what do you need to improve your recovery? What barriers do you have to full recovery?