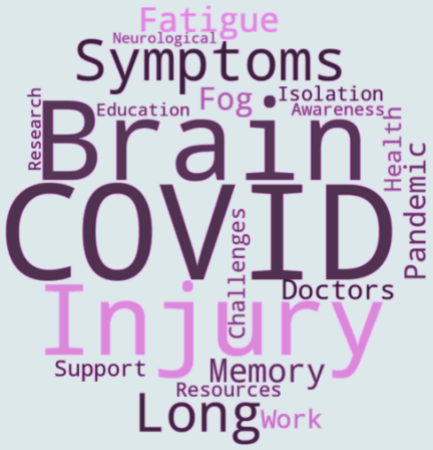
Nebraska VR (Vocational Rehabilitation)

Nebraska Traumatic Brain Injury (TBI) Grant
Supplemental Project



The Impact of COVID-19 on Individuals with Brain Injuries: Experiences, Challenges, and Insights

Key Findings from Interviews

Report prepared by Partners for Insightful Evaluation

September 2024

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Introduction

The COVID-19 pandemic has greatly impacted public health, healthcare systems, and individuals' daily lives. For people with pre-existing brain injuries (BI), the pandemic has presented unique challenges. This report summarizes findings from interviews conducted with **13** individuals who have experienced brain injury and COVID-19 and/or long COVID symptoms. The study aimed to explore how the pandemic and COVID-19 infection affected brain injury symptoms, access to healthcare and support services, and overall quality of life for this population.

Participants included individuals with diagnosed brain injuries prior to the pandemic and those who developed neurological symptoms after COVID-19 infection (often referred to as "long COVID"). Through semi-structured interviews, participants shared their experiences with COVID-19, changes in brain injury symptoms, challenges accessing care, helpful coping strategies, and ongoing concerns.

This report synthesizes participants' experiences to provide insights into the intersection of brain injury and COVID-19. The findings highlight areas where additional support, resources, and research are needed to serve this population better. By amplifying the voices of those directly impacted, this study aims to inform healthcare practices, policy decisions, and public understanding of the complex relationship between brain injury and COVID-19.

Acknowledgments

We would like to express our sincere gratitude to the **Nebraska VR** (Vocational Rehabilitation) program for their support and collaboration in this research project. We also thank the **Brain Injury Alliance of Nebraska** (BIA), the **Nebraska Brain Injury Advisory Council**, and **Madonna Rehabilitation Hospitals** for their crucial assistance in participant recruitment. We are deeply grateful to all the interviewees who generously shared their time, experiences, and insights. Their candid and thoughtful responses have provided invaluable perspectives on individuals' brain injuries and COVID-19 challenges.

This publication was supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $86,400.00 with 100 percent funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.

Summary

This summary synthesizes critical insights from interviews with **13** individuals with brain injury (BI) conditions and COVID-19 and/or long COVID. The interviews explored participants' experiences with brain injury symptoms, COVID-19 infection, long COVID, access to healthcare and support services, and ongoing challenges. While participants had diverse backgrounds and experiences, several common themes emerged regarding the impacts of COVID-19 on cognitive functioning, daily life, and access to care. These impacts are as follows:

1. **Long-term COVID impacts:**
    a. Significant cognitive effects include memory problems, difficulty concentrating, and "brain fog"
    b. Physical symptoms such as fatigue, breathing difficulties, and changes in smell/taste
    c. Worsening of pre-existing conditions, including mental health issues and prior brain injuries
    d. New neurological symptoms

2. **Healthcare system challenges:**
    a. Lack of knowledge about long COVID among healthcare providers, especially in the early stages
    b. Long wait times for specialists and difficulty accessing appropriate care
    c. Need for a multidisciplinary approach to diagnosis and treatment
    d. Gaps in pediatric and elderly care for long COVID

3. **Patient experiences:**
    a. Feelings of isolation and misunderstanding, both socially and medically
    b. Difficulty maintaining employment or daily activities due to symptoms
    c. Financial strain from medical expenses and reduced work capacity
    d. Importance of support groups and online communities for information sharing

4. **Adaptive strategies:**
    a. Use of organizational tools like calendars, lists, and reminders
    b. Lifestyle changes, including rest, vitamins, and increased self-care
    c. Engaging in cognitive exercises like puzzles to maintain mental acuity
    d. Importance of a positive attitude and supportive environment

5. **Recommendation regarding research and education needs:**
    a. More studies on long COVID mechanisms and effective treatments
    b. Better education for healthcare providers, especially primary care, pediatrics, and geriatrics
    c. Increased public awareness about the potential long-term impacts of COVID-19
    d. Development of guidelines for schools and workplaces to accommodate those with long COVID

6. **Systemic improvements required:**
    a. Development of clear diagnostic criteria and treatment pathways for long COVID
    b. Improved communication between specialists and primary care providers
    c. Creation of resources and support systems for patients and their families
    d. Integration of long COVID care into existing healthcare structures

Methodology

Study Design

This study employed a qualitative research design using semi-structured interviews to explore the experiences of individuals with brain injuries (BI) and COVID-19 symptoms.

Participants

The study included **13** participants (11 females[1] and 2 males) from Nebraska who had a history of brain injury and had experienced COVID-19 and/or long COVID. See **Appendix A** for detailed details on each interviewee. Participants were recruited through emails and fliers shared by the Nebraska Vocational Rehabilitation, Nebraska Brain Injury Alliance and Madonna Rehabilitation Hospitals (see **Appendix B** for details) and on social media. Potential participants were offered a $20 gift card as an incentive for their participation in the interview. Individuals who did not meet the health condition criteria or were not residents of Nebraska were excluded from the study.

Methods

Interviews were conducted face-to-face (*n* = 2) and online (*n* = 11) between September 9th and September 17th, 2024. Interviews lasted on average about 30 minutes. All online interviews were conducted via the **Zoom video conferencing platform**, utilizing its built-in cloud recording feature. Subsequently, automated transcripts were generated in VTT (Video Text Tracks) format and converted to plain text for qualitative thematic analysis. Face-to-face interviews were audio-recorded and transcribed using **Rev.com's** professional transcription services. A **Partners for Insightful Evaluation** Project Associate conducted all interviews.

Data Collection

Semi-structured interviews were conducted with each participant via video call or face-to-face. See **Appendix C** for further details of the interview protocol. The interview protocol consisted of 10 main questions covering topics such as:

1. Background on brain injury and COVID-19 experience
2. Overall pandemic experience
3. Challenges faced during the pandemic
4. Access to services and supports
5. Impact of COVID-19 on brain injury symptoms
6. Experiences with long COVID symptoms
7. Helpful strategies for managing symptoms

[1] One female interviewee responded on behave of her husband.

8. Ongoing concerns about COVID-19
9. Additional resources or support needed
10. Final thoughts on brain injury and COVID-19

Data Analysis

Participants were grouped into two groups: 1) those who had brain injury and experienced COVID-19 (n = 8), and 2) those who experienced long-term COVID (n = 5). A thematic analysis approach was used to analyze the interview transcripts using the following steps:

1. Familiarization with the data through multiple readings of the transcripts
2. Initial coding of relevant information
3. Grouping codes into potential themes
4. Reviewing and refining themes
5. Defining and naming final themes

A research analyst conducted the content thematic analysis of the interviews.

Limitations

The study's limitations include the small sample size and potential selection bias in participant recruitment. Additionally, the self-reported nature of the data may be subject to recall bias. Thus, our grouping of participants was based on participants' interpretations of their symptoms and recollections, which may have affected the classification of participants between these two categories.

Results

Specific Impacts of COVID-19 on Participant's Brain Injuries

How did the interviewees describe the changes in their brain injury symptoms due to COVID-19? Several interviewees described changes in their brain injury symptoms or experienced new neurological issues after having COVID-19. Overall, the interviewees described COVID-19 as either worsening their existing brain injury symptoms or introducing new neurological problems that affected their cognitive function, sensory perception, energy levels, and ability to perform daily tasks. Many described these changes as significant and long-lasting, often meeting the criteria for long COVID. The following quotes from interviewees have been edited for brevity and clarity.

1. **Worsening of existing symptoms:**

   Many participants reported that COVID-19 worsened their pre-existing brain injury symptoms, particularly cognitive issues like memory problems and brain fog.

   > *"The brain fog lasted about a week and a half each time, but the confusion lasted about a month." […] "I also have body aches and pains regardless, but they were intensified with COVID"* [Participant with BI and COVID-19]

   > *"After I had COVID... it amplified my post-concussion symptoms with memory and neural fatigue—kicked up a couple of notches."* [Participant with BI and COVID-19]

2. **New neurological symptoms:**

   Several interviewees developed new neurological issues after contracting COVID-19.

   > *"[…] we went to a neurologist and learned that his short-term memory and executive brain function were damaged. That part of the brain helps with planning, retaining information, and doing things the right way. That part of the brain was very damaged, especially the frontal part on both sides."* [Participant with BI whose husband had COVID-19]

After getting COVID, I had severe brain fog, no memory, muscle weakness, muscle deterioration, exhaustion, and migraines." [Participant with BI and COVID-19]

3. **Cognitive impacts:**

Many reported increased difficulty with memory, focus, and executive function after COVID.

" Memory issues and brain fog were new symptoms after COVID, along with inconsistency in completing tasks." [Participant with BI and COVID-19]

"My brain fog was so bad I barely could function with COVID... it felt like living in a dream state where nothing really made sense." […] "Cognition becomes a greater challenge for me. I call it TBI mode, and it's a state I sometimes get into where I revert back to the time I was in the hospital. My thinking slows down." [Participant with BI and COVID-19]

4. **Fatigue and sleep disturbances:**

Sleep pattern changes and increased fatigue were commonly reported.

"The second time I had COVID, I was out of commission. I had headaches, a sore throat, and had to sleep a lot." [Participant with BI and COVID-19]

"I had extreme fatigue and needed to take breaks... using adaptive tools helped, but it was hard to stay on task after COVID." [Participant with BI and COVID-19]

5. **Sensory changes:**

Loss or alteration of smell and taste was frequently mentioned.

"I completely lost my sense of smell and taste, which was odd. I just couldn't eat—I lost quite a few pounds during that because I couldn't eat." [Participant with BI and COVID-19]

6. **Difficulty with daily functioning:**

Many interviewees described how COVID impacted their ability to work or perform daily tasks.

"He became less willing to engage in activities or stay on task after COVID, and I had to change my approach to get him to participate." [Participant with BI whose husband had COVID-19]

> *"After COVID, I couldn't keep up with my job. I had to be retrained, but I couldn't retain the information. It was overwhelming."* [Participant with BI and COVID-19]

7. **Long-lasting effects:**

   Several participants reported that these symptoms persisted long after the acute COVID-19 infection.

   > *"About a year and a half after getting COVID, I finally got out of the brain fog, memory improved, and I was performing where I wanted."* [Participant with BI and COVID-19]

   > *"COVID symptoms lingered for over a month each time, with brain fog and confusion persisting for weeks."* [Participant with BI and COVID-19]

8. **Variability in experiences:**

   The impacts varied among participants, with some experiencing more severe effects than others. Some participants reported that COVID-19 exacerbated pre-existing physical symptoms. For example, one participant mentioned:

   > "*I think I did notice when I did have covid, it was weird because every bone that I had broken, the pain was intensified in those areas where it was weird because I've broken both arms, rib, everything that was broken hurt more than it typically does.*" [Participant with BI and COVID-19]

A Comparative Thematic Analysis of Brain Injury and COVID-19 Experiences

This section presents a thematic analysis of the interview responses, organized by question. The analysis compares and contrasts the experiences of two groups: those who reported long COVID symptoms and those who did not.

Questions 1-5 examine both groups' experiences with brain injury and COVID-19. **Questions 6-7** focus specifically on the challenges and coping strategies of those with long COVID symptoms. Finally, **questions 8-10** explore general concerns, needed resources, and final thoughts from all participants regarding brain injury and COVID-19.

Question 1: Background on brain injury and COVID-19 experience

Long COVID group:

- Most experienced COVID-19 multiple times, with the first infection typically occurring in 2020.
- Some had pre-existing conditions or injuries that may have contributed to long COVID symptoms.
- Symptoms often worsened with each subsequent COVID-19 infection.

> *"I got COVID the first time on Halloween of 2020, [...] I've had COVID four times now, and it changed my life forever. Before, I worked out five days a week, high-intensity workouts. Now, I get lactic acid build-up just from walking. I struggle with word-finding, can't focus, and have ADHD-like symptoms. I could only remember one thing at a time when trying to look up terms."* [Participant with long COVID]

Non-long COVID group:

- COVID experiences varied, with some having mild symptoms and others more severe.

> *"COVID amplified my post-concussion symptoms, especially memory and neural fatigue. Each time I got COVID, it felt like my symptoms got worse.* [Quote has been rewritten for clarity and brevity. [Participant with BI and COVID-19]

- For some, distinguishing between brain injury symptoms and COVID symptoms was hard.

> *"Honestly, it's tough to gauge what is from Covid because they talk about brain fog. Well, I brain fog every day in my life, to be honest with you. And so I don't know if I can decipher between what is the brain injury, what is covid."* [Participant with BI and COVID-19]

Insight: The long COVID group generally reported more severe, persistent, and life-altering symptoms compared to the non-long COVID group.

Question 2: One-word description of pandemic experience

Long COVID group:

- "Took my life away"
- "Not normal"
- "Conflicted"

Non-long COVID group:

- "Unchanged"
- "Learning curve"
- "Unvalidated"

Insight: Those with long COVID tend to view the pandemic more negatively, emphasizing its life-altering impact. The non-long COVID group had more varied experiences.

Question 3: Most challenging aspect of the pandemic

Long COVID group:

- Health effects and symptoms
- Difficulty working or maintaining daily activities
- Social isolation

> *"My neurologist referred me to speech therapy at* [name of a healthcare institution] *for cognitive issues. I started that in 2021. It helped because I was still teaching, and I needed to work. At the beginning of the school year, I had trouble with my schedule—it was different each day. I couldn't remember what day it was or which schedule to follow, even after looking at the calendar. I'd check my phone 15 times a day just to see what day it was. Speech therapy helped [...]."* [Participant with long COVID]
>
> *"The most challenging part was just getting, you know, groceries. It became a whole new world for a lot of us, especially at work."* [Participant with long COVID]

Non-long COVID group:

- Adapting to new technologies and ways of working
- Social isolation
- Concerns for vulnerable populations (e.g., elderly)

> *"I had a real difficult time with just kind of being isolated and working from home. And again, then staying on task with things."* [Participant with BI and COVID-19]
>
> *"It's the isolation that came with the injury that I saw have a hugely detrimental effect on everyone, but in particular the people who were isolated already."* [Participant with BI and COVID-19]

Insight: While both groups experienced challenges, the long COVID group faced more severe health-related obstacles that impacted their daily functioning.

Question 4: Access to services and supports during the pandemic

Long COVID group:

- Difficulty accessing healthcare due to lack of knowledge about long COVID
- Long wait times for specialists
- Financial strain due to medical expenses

Key quote: *"The main problem was that no one knew about long COVID. I was educating my providers."* [Participant with long COVID]

Non-long COVID group:

- Generally able to access needed services, though often in different formats (e.g., telehealth)
- Some experienced delays in non-essential medical care

Recommendation: Develop and disseminate educational materials about long COVID for healthcare providers to improve diagnosis and treatment.

Question 5: Impact of COVID-19 on brain injury symptoms

Long COVID group:

- Exacerbation of existing cognitive issues
- New neurological symptoms (e.g., brain fog, memory problems)
- Physical symptoms (e.g., fatigue, breathing difficulties)

> *"The brain fog was tough. I had sticky notes everywhere. It took me longer to catch on to things. I had to learn coping strategies, like writing*

everything down. Over time, I figured out ways to deal with it, like brain puzzles and regular puzzles." [Participant with long COVID]

Non-long COVID group:

- Minimal impact on pre-existing brain injury symptoms
- Some experienced temporary cognitive effects during acute COVID infection

Insight: Long COVID appears to have a more significant and lasting impact on cognitive function, even in those without prior brain injuries.

Question 6: Challenges experienced with long COVID

Challenges:

- Fatigue and sleep disturbances
- Cognitive issues (memory, focus, executive function)
- Sensory changes (smell, taste)
- Physical symptoms (breathing difficulties, heart palpitations)

"I struggle with word-finding, can't focus, and have ADHD-like symptoms. I could only remember one thing at a time when trying to look up terms." [Participant with long COVID]

"I still occasionally get heart palpitations. I had to have knee surgery, and when they tested my heart and stuff — before COVID, my heart was beating like it should, because they were getting me ready for surgery before COVID. Then I had to wait. But my heart was fine then, and now they say, well, it's really slow, and you're barely passing to have surgery." [Participant with long COVID]

"[…] right now I see my doctor, my regular doctor, my psychiatrist, my counselor. So those people review the charts, and they can't really tell what is aggravating what. You know, is it the COVID aggravating my mental health? Is it my mental health aggravating the COVID symptoms? […] I did find a support group out of Vermont, and they helped me compile a list of providers. That was helpful." [Participant with long COVID]

Recommendation: Develop multidisciplinary treatment approaches that address the diverse symptoms related to COVID-19.

Question 7: Helpful strategies for navigating long COVID symptoms

Common strategies:

- Online support groups
- Adaptive strategies (e.g., lists, reminders, puzzles)
- Lifestyle changes (e.g., rest, vitamins, sunshine)
- Working with understanding healthcare providers and supportive employers

> *"Facebook groups have been the most helpful. I can see patterns across the country and the world, like what people are trying, what works, and what doesn't."* [Participant with long COVID]

Those who felt their symptoms were acknowledged by healthcare providers and had understanding and supportive employers reported more positive outcomes. In contrast, individuals who lacked this validation and support shared more negative experiences, emphasizing the impact of both medical and workplace environments on long-term recovery:

> *"Working with my physician has been great — they believe me, and they're interested in what I'm experiencing."* [Participant with long COVID]

> *“About a year and a half after getting COVID, I finally got out of the brain fog, memory improved, and I was performing where I wanted. My new boss gave great feedback, which built my confidence.” […]. There was compassion [in my new job] and understanding about long-term COVID. I’ve been able to help others going through the same thing and validate their experiences.”* [Participant with BI and COVID]

> *"Eventually, I got written up* [due to underperformance], *had to be retrained, but I couldn't retain it. I have ADHD and autism, which I learned about this year, and I usually hyper-fixate on tasks and learn quickly. This was extremely difficult. I went months without a pay raise because I didn't meet satisfactory needs."* [Participant with BI and COVID]

> *“I posted things about my experiences with Covid on Facebook, and that was helpful for me. But then my school told me I couldn’t post anything because it made me look like I was incapable of teaching. […]. I think they just didn’t want me there talking about Covid.* [Participant with long COVID-19]

Recommendations: Create a centralized resource hub for long COVID patients to share experiences and coping strategies. This hub should include peer support networks, access to healthcare resources, and adaptive tools to manage symptoms. Additionally, provide guidelines and education for employers on accommodating and supporting employees with long COVID, including flexible work arrangements, mental health support, and understanding cognitive challenges.

Question 8: Ongoing concerns about COVID-19

Concerns:

- Fear of reinfection and worsening symptoms
- Uncertainty about long-term health impacts
- Lack of public awareness and precautions

> *“I worry about whether the shots and boosters are really helping, especially with new strains constantly coming out. I'm doing everything I can, but it feels like it's never going to end. Is it all worth it? I don't know if it's really making a difference."* [Participant with BI and COVID-19]
>
> *"The problem is that people aren’t taking COVID seriously anymore, and doctors still aren’t up-to-date."* [Participant with long COVID]
>
> *"I still don't think people take it as seriously as they should. I'm estranged from my family, in part because of COVID-they didn't take it seriously. I think people still aren't going to be safe. If they feel sick, they'll brush it off like it's the flu."* [Participant with BI and COVID-19]

Recommendation: Continue public education efforts about the potential long-term impacts of COVID-19 and the importance of prevention measures.

Question 9: Additional resources, support, or information needed

- Better education for healthcare providers, especially primary care and pediatrics
- Improved access to specialists and coordinated care
- More research on long COVID treatments and interventions

- Support for schools and workplaces in accommodating those with long COVID

> *"My children have PANS/PANDAS[2], an autoimmune disease that inflames the brain, which I think has relevance for brain injury people. COVID made it worse. [...]. "They also developed mast cell activation and struggled with physical symptoms like shin pains. COVID induced or exacerbated these issues."* [Participant with long COVID]

> *"Educating pediatricians on screening for PANS/PANDAS is critical. If caught early, it can be treated easily with ibuprofen, avoiding the need for long-term treatments."* [Participant with long COVID]

> *"We need doctor education, especially for primary care and pediatric doctors. Specialists like cardiology, rheumatology, and immunology should know what long COVID looks like and have a plan for treating it. There needs to be a local network or communication about long COVID—what to do, where to send patients, and how to help while they wait for specialists."* [Participant with long COVID]

> *"Any kind of research to help long haulers would be helpful. I know it will take time, but it's important to keep learning about how it affects people like me. Publishing information as it's discovered would be helpful."* [Participant with long COVID]

Recommendation: Develop comprehensive guidelines for diagnosing and treating long COVID, including referral pathways and potential interventions.

[2] PANS stands for Pediatric Acute-onset Neuropsychiatric Syndrome. It is characterized by the sudden onset of obsessive-compulsive symptoms and/or severe eating restrictions, along with other neuropsychiatric symptoms. PANDAS stands for Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections. It is a subset of PANS where the symptoms are triggered specifically by a streptococcal infection. O'Dor, S. L., Zagaroli, J. S., Belisle, R. M., Hamel, M. A., Downer, O. M., Homayoun, S., & Williams, K. A. (2024). The COVID-19 pandemic and children with PANS/PANDAS: An evaluation of symptom severity, telehealth, and vaccination hesitancy. Child Psychiatry & Human Development, 55(2), 327-335.

Question 10: Final thoughts on brain injury and COVID-19

- Appreciation for ongoing research efforts
- Need for increased awareness about brain injuries and long COVID
- Importance of support systems and understanding from others
- Emotional and psychological challenges faced by spouses

> *"I appreciate that you're doing these studies. I think brain injury is poorly understood, and more awareness would help. People don't realize how serious concussions and brain injuries are, and it's important to raise awareness."* [Participant with long COVID]

> *"Brain injury in general is a devastating injury that again, affects the person that sustains the injury as well as the family."* [Participant with BI and COVID-19]

> *The elderly population is a huge problem and they get zero attention. Would be a big step forward if people were more aware of it.* [Quote rewritten for clarity. Participant with BI and COVID-19]

Participants explained that support groups were forced to move online during the pandemic, which initially had a negative effect on participation. However, virtual support groups became more beneficial for people, particularly those in remote or rural areas over time. This shift allowed more individuals to attend without needing to travel long distances, and many appreciated the convenience of joining from home. As a result, these groups have continued in a hybrid format post-pandemic:

> *"It was during the pandemic that we started doing the virtual support groups that we still do today, four times a month. We have people that attend from all over Nebraska, and it's worked out well for people. People like having that option, not only because they don't have to drive somewhere, but also for those in more rural communities without in-person groups nearby. People like that they can be sitting in their living rooms and connect with others."* [Participant with BI and COVID].

> *"For some people, these support group meetings were vital; it was very beneficial to find that type of support during the isolation period."* [Participant with BI and COVID].

One participant, who had experienced brain injury, reported issues with domestic abuse. The participant described her husband as undergoing significant personality changes after he contracted COVID-19, becoming more controlling and easily angered over minor issues.

> *"After he had COVID, that's when he became so controlling… After COVID, his whole outlook changed, and he's controlling everything—who I see, what I eat. He goes to the store, buys food for himself, and gets angry if I eat any of it."* [Participant who had BI whose husband had COVID]

Overarching Themes

Worsening of Symptoms: Both groups experienced heightened cognitive and physical symptoms due to COVID-19. Long COVID participants had more prolonged issues, while those without long COVID faced acute exacerbations tied to the stress and isolation of the pandemic.

Access to Services: Both groups faced significant barriers to healthcare, which worsened their conditions. Long waiting times and canceled appointments left many feeling unsupported in their recovery.

Mental Health and Isolation: Social isolation during the pandemic was a key theme for both groups, with many reporting worsened mental health. The isolation of brain injury was magnified by the pandemic, leaving participants feeling more disconnected from their communities.

Employment and Financial Strain: Both groups reported difficulties maintaining jobs, though those with long COVID felt the strain more acutely. Participants experienced challenges ranging from discrimination at work to struggles with performance due to cognitive fatigue.

Recommendations Provided By Interviewees

Throughout the interviews, participants shared valuable insights and suggestions based on their experiences with brain injury, COVID-19, and long-term COVID-19. These recommendations span various aspects of care, support, and awareness. The following list compiles key recommendations offered by the interviewees, providing a patient-centered perspective on potential enhancements to healthcare, support systems, and public awareness.

1. Improved education and awareness:

- Better education for healthcare providers, especially primary care and pediatric doctors, on long COVID and brain injuries
- Increased public awareness about the potential long-term impacts of COVID-19
- More information and resources for schools on accommodating students with long COVID

2. Enhanced healthcare services:

- Develop clear diagnostic criteria and treatment pathways for long COVID
- Improve access to specialists and reduce wait times
- Create a network or communication system for specialists dealing with long COVID patients
- Offer interim treatments that primary care doctors can suggest while patients wait for specialist appointments

3. Research and information dissemination:

- Conduct more studies on long COVID mechanisms and effective treatments
- Provide regular updates on the latest research findings to patients
- Create opportunities for local participation in research studies

4. Support systems:

- Establish support groups for people with brain injuries and their families
- Create mental health retreats or respite care for caregivers and those dealing with long COVID

5. **Resources and tools:**
    - Develop comprehensive websites with resources, articles, and personal experiences related to brain injury and long COVID
    - Create apps or step-by-step guides for people with memory issues to help with daily planning and reminders
    - Provide sample 504 plans for schools to accommodate students with long COVID

6. **Policy and funding:**
    - Implement standard rules for notifying families about COVID cases in care facilities
    - Allocate funding specifically for long COVID research and support services

7. **Workplace accommodations:**
    - Provide training and resources for employers on accommodating employees with long COVID or brain injuries

8. **Community outreach:**
    - Increase awareness and support services in smaller communities and rural areas

9. **Vulnerable population focus:**
    - Develop interventions and treatments specifically for children and elderly populations with long COVID
    - Educate pediatricians on screening for PANS/PANDAS, which COVID can exacerbate

10. **Multidisciplinary approach:**
    - Foster better communication between specialists and primary care providers
    - Create a more holistic treatment approach that addresses both physical and cognitive symptoms

APPENDIX A

Participants' characteristics

Participant #	Gender	Category	Had BI?
Participant 001	Female	Long COVID	Yes
Participant 002	Female	BI + COVID	Yes
Participant 003	Female	BI + COVID	Yes
Participant 004	Female	BI + COVID	Yes
Participant 005	Male	BI + COVID	Yes
Participant 006	Female	BI (husband with COVID)	Yes
Participant 007	Female	Long COVID	No, but have had two concussions in her lifetime
Participant 008	Female	BI + COVID	Yes
Participant 009	Female	BI + COVID	Yes
Participant 010	Female	Long COVID	Experienced BI symptoms from COVID
Participant 011	Female	Long COVID	No
Participant 012	Female	Long COVID	No
Participant 013	Male	BI + COVID	Yes

APPENDIX B

Fliers for Recruitment

APPENDIX C

Nebraska Traumatic Brain Injury (TBI) Grant – Supplemental Project
Interview Protocol

Introductions

I'm Mindy Anderson-Knott with Partners for Insightful Evaluation, or PIE for short. We've been working with Nebraska VR (Vocational Rehabilitation) on a variety of projects related to brain injury. One is looking at the impact that COVID-19 had or still has on those with brain injury.

Purpose

The purpose of this interview is to learn more about your experiences as either 1) someone with a brain injury who has experienced COVID-19, or 2) someone dealing with the effects of long COVID, as many of those symptoms can mirror brain injury symptoms. We are especially interested in hearing about your challenges as well as what has been helpful. Your feedback will be used by PIE to create a summary report for Nebraska VR and the Brain Injury Advisory Council. This will be used to better understand the impact and see where additional support or resources may be needed.

Things to Know

As we go through this discussion please know:

- What you share is confidential. This means we won't share your name when we report what we've learned through this discussion. The information you provide may be shared with others who may want to learn more about the impacts of COVID-19 on those with brain injury, but any information shared will not be linked to your name.
- This should take less than an hour.
- If you are okay with it, I'd like to record today's discussion. We do that so we can make sure we've accurately captured what is shared. Again, your feedback will remain confidential as you will not be identified by name.

Ground Rules

To help with the discussion, I want to outline some guidelines for the conversation:

- There are no right or wrong answers. Your experiences and opinions are important, and we're interested in hearing all points of view.
    - While it's important to hear from you, your participation is voluntary. It's okay if you'd like to skip questions you aren't comfortable with, and you can also let us know if you don't know or don't have an opinion on something. That's helpful for us to know as well.

Are there any questions before we begin?

Introductions

1. To get started, I'd love to know a little background about you. If you're comfortable, can you share some brief details about your brain injury, and the timing of the injury in relation to when you experienced COVID-19, if you've had COVID. (PROBE: Did you have BI first and then experience COVID or did you experience BI after the pandemic?)

First Name	Had COVID?	Had BI?	Brain Injury Details (if shared)

2. The COVID-19 pandemic started in March 2020. What's <u>one word</u> you would use to describe your experience during the pandemic?

3. What was the most challenging thing about the pandemic? (PROBE: rehab during the pandemic, covid health effects)

4. What types of services and supports, if any, were you NOT able to get access to during the pandemic?
    a. If you couldn't get access to certain services, how did that impact your brain injury recovery or management?

5. What impact did or has COVID-19 had on your brain injury symptoms? If there hasn't been an impact, you can share that too.

Long COVID

Long COVID is typically having symptoms that last 3 months or longer after having COVID-19. The symptoms may include tiredness or fatigue, difficulty thinking, forgetfulness or memory problems (sometimes referred to as 'brain fog'), difficulty breathing or shortness of breath, joint or muscle pain, fast-beating or pounding heart, chest pain, dizziness, changes to taste/smell.

6. What challenges, if any, have you experienced with long COVID?

7. What has been helpful for you when navigating long COVID symptoms?

Next Steps

8. What concerns or worries, if any, do you still have about COVID-19?

9. What additional resources, support, or information would be helpful?

Closing

10. What other final comments, thoughts, or feedback would you like to share about brain injury and/or COVID-19?