

### Faculty of Medicine University of Dhaka

# COVID-19 SURVIVORSHIP: A QUALITATIVE STUDY OF PERSISTENT SYMPTOMS OR LONG-COVID EXPERIENCED BY SPINAL CORD INJURY SURVIVORS IN BANGLADESH.

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#### **Bangladesh Health Professions Institute (BHPI)**

Department of Physiotherapy CRP, Savar, Dhaka-1343 Bangladesh August, 2020 We the undersigned certify that we have carefully read and recommended to the Faculty of Medicine, University of Dhaka, for the acceptance of this dissertation entitled

## COVID-19 SURVIVORSHIP: A QUALITATIVE STUDY OF PERSISTENT SYMPTOMS OR LONG-COVID EXPERIENCED BY SPINAL CORD INJURY SURVIVORS IN BANGLADESH.

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#### **DECLARATION**

I declare that the work presented here is my own. All sources used have been cited appropriately. Any mistakes or inaccuracies are my own. I also decline that same any publication, presentation, or dissemination of information of the study. I would bind to take consent from the Department of Physiotherapy of Bangladesh Health Professions Institute (BHPI).

Signature:	<b>Date:</b>
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#### **Acronyms**

**ARDS** Acute Respiratory Distress Syndrome

**BHPI** Bangladesh Health Professions Institute

**BMRC** Bangladesh Medical Research Council

**CDC** Centers for Disease Control and Prevention

**CRP** Centre for the Rehabilitation of the Paralysed

**IPA** Interpretative Phenomenological Analysis

ICFInternational Classification of functioning, Disability and Health

IRB Institutional Review Board

LTC Long Term Care

PTSD Posttraumatic Stress Disorder

PWD Persons with Disability

**SCI** Spinal Cord Injury

**UNO** Upazila Nirbahi Officer

WHO World Health Organization

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#### **ABSTRACT**

Background: In terms of individual lived experiences, it is yet unknown how the COVID-19 outbreak has affected vulnerable populations of people, such as those living with spinal cord injury. Individuals living with spinal cord injury in Bangladesh who had survived a confirmed COVID-19 infection were invited to participate in this study to gain insight and understanding of their own lived experiences of long-COVID and the nature of symptoms experienced by these people. And also we want to understand how the Long-COVID has affected their lifestyles, as well as the lives of their families. Methodology: In this qualitative studywith Phenomenological design, we purposively sampled eight people living with spinal cord injury who had been admitted into the Centre for Rehabilitation of the Paralyzed during the pandemic in Bangladesh. We conducted semi-structured telephone interviews in Bengali, which were audio-recorded, transcribed, and translated into English. An interview topic guide was used with questions focused on participants' experiences of COVID-19 and their perceptions of how it had impacted their lives. Data were gathered by interviews and analyzed manually. We conducted a thematic analysis by actively developing themes from the data. Results: Analysis revealed 5 themes and those themes are (1) Adaptation to Post-COVID condition and experiencing existing disability and comorbidities. (2) Preexisting limitations in ambulation and activities of daily living. (3) Gaining experience of social isolation and lack of information and resources. (4) Experiencing negative effects and mental issues. (5) Experiencing social barriers strongly affects the new-normal life. Conclusion: During this study, I discovered Spinal Cord Injury and Long-COVID related to many bio-psycho-social problems. The biological Long-COVID and SCIrelated problems were fatigue fever, wheelchair-bound, difficulties in ambulation, and physical week. The Psychological problem was fear, anxiety, and mental stress. The Psychosocial problem was isolation. And the Social problem was the stigma. However, the key issue was that the participants denied their persistent symptoms, making it difficult to determine the participants' Long-COVID symptoms.

**Key words:** SCI, COVID-19, Post COVID-19 Symptoms, Long-COVID, Qualitative study.

#### 1.1 Background

A pandemic, as a public health emergency, increases people's susceptibility to various health problems, which may be exacerbated further by the social distancing approach, which disrupts daily routines, restricts interpersonal communication, and limits the availability of social support. While the modern world has faced other epidemics and pandemics, none have had such global and drastic effects on the majority of people and their daily lives as the current COVID-19 pandemic (Kavcic et al., 2020).

In January 2020, the World Health Organization declared the outbreak a Public Health Emergency of International Concern, and in March 2020, it was declared a Pandemic (WHO, 2020). Wuhan was the outbreak's epicenter of COVID-19, Massive public health interventions have been launched across China to halt the spread of coronavirus disease by 2020 (Leunget et al., 2020). Since the outbreak, it has rapidly infected people all over the world and turned into a pandemic (Islam et al., 2021).

Although it is still unknown where the outbreak began, many early cases of COVID-19 have been linked to visitors to the Huanan Seafood Wholesale Market in Wuhan, Hubei, China. The World Health Organization (WHO) named this disease "COVID-19" on February 11, 2020, short for coronavirus disease 2019 (Sohrabi et al., 2020). And early April 2020, more than a third of the world's population was subject to movement restrictions or COVID-19 lockdown. On January 23, China became the first country to implement a COVID-19 lockdown, in Wuhan (Koh, 2020). Many social, economic, environmental, and healthcare determinants of health have been altered as a result of the Coronavirus Disease 2019 (COVID-19) pandemic (Kontis et al., 2020).

COVID-19 had spread to approximately 200 countries and territories as of the publication date of this article, with over 4.3 million infections and over 290,000 deaths as it has erupted into a global pandemic. Concerns about public health are growing as the situation evolves, with an increasing number of infection hotspots around the world (Stawicki et al., 2020). The first case of a COVID-19 patient was discovered in Bangladesh on March 8, 2020. Since then, a total of 263,503 people have been officially reported as COVID-19 infected with 3,471 deaths until August 11, 2020 (Islam et al., 2020).

On March 7, Bangladesh confirmed the first COVID-19 case on its territory, though many experts speculated that nCoV-2 may have entered the country earlier but was not detected due to insufficient monitoring. However, concerns have been raised that a severe lack of testing assays may be causing many cases in the country to go undetected. Initially, Bangladesh did not impose any strict protocol, and millions of people were on the streets, particularly in Dhaka, a megacity with 46 thousand people living per square kilometer. It appears that social distance is difficult to maintain while taking public transportation and living in slums (Anawar et al., 2020).

Surprisingly, while many developed countries, including the United States, the United Kingdom, Italy, and Spain, suffered greatly during the COVID-19 pandemic despite having highly efficient healthcare systems, many less developed countries with inadequate healthcare systems fared better. Where has the magic gone? Unfortunately, there is no magic. Rather, the reality behind this mysterious facade tells a different story (Al-Zaman, 2020).

As the coronavirus outbreak spreads, many countries are implementing non-therapeutic preventive measures such as travel bans, remote office activities, country lockdown, and, most importantly, social distancing. These measures, however, face difficulties in Bangladesh, a lower-middle-income country with one of the world's densest populations. Social distancing is difficult in many areas of the country, and implementing mitigation measures would be extremely difficult given the country's limited resources (Anawar et al., 2020). On the other hand, there is a statistically positive association between fear of the COVID-19 outbreak and the healthcare system in Bangladesh, due to the lack of testing facilities and a fragile healthcare system contributing to the fear that has been experienced due to the COVID-19 pandemic in Bangladesh (Bodrud-Doza et al., 2020). COVID-19 prompted the implementation of public health protocols to control the virus's spread, many of which involved social distancing, hand washing, and lockdown procedures, but it also resulted in public anguish and widespread fear, particularly among the unaffected population. Bangladesh has never experienced epidemics like SARS or MERS, and it is clear that the public healthcare systems are unprepared for COVID-19 (Ferdous et al., 2020). In late December 2019, an unknown pneumonia disease was

reported in Wuhan, China, with clinical symptoms similar to viral pneumonia, and the World Health Organization (WHO) named the virus COVID-19 (Wang et al., 2020).

The coronavirus disease 2019 (COVID-19) pandemic caused by severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) has devastated patients, communities, and healthcare systems (Lutchmansingh et al., 2020). The first experience of people with this disease is related to the onset of the first symptoms of the disease. Due to this pandemic, there are many news and stories as well as considerable fear and anxiety in society in connection with this disease (O'Neill & Natea, 2020).

The most common COVID-19 symptoms are fever, fatigue, dry cough, myalgia, dyspnoea, etc. that may develop within 2–14 days of infection through respiratory droplets and close contact (Naser et al., 2020; Wang et al., 2020). Although coronavirus disease 2019 (COVID-19) most commonly manifests with acute respiratory symptoms, one very common symptom of COVID-19 is pain (Attal et al., 2021). The coronavirus disease 2019 (COVID-19) may take weeks to overcome; however, in some patients, symptoms persist even after the original infection (Mardani, 2020). Approximately 10% of patients with Covid-19 experience symptoms beyond 3–4 weeks. Patients call this "long Covid" (Ladds et al., 2020). Isolation and loneliness are linked to a variety of health issues. Physical performance is an important aspect of health. Its association with isolation and loneliness, however, is not fully recognized (Philip et al., 2020).

A significant number of people continue to describe ongoing symptoms long after the acute phase of Covid-19, often referred to as Long-COVID. Long-COVID is a heterogeneous condition with an uncertain prevalence, for which there is currently no precise case definition (Michelen et al., 2020). People with long-COVID experience a confusing array of persistent and fluctuating symptoms including cough, breathlessness, fever, sore throat, chest pain, palpitations, cognitive deficits, myalgia, neurological symptoms, skin rashes, and diarrhea (Ladds et al., 2020). The persistent post-COVID syndrome also referred to as long COVID, is a pathologic entity, which involves persistent physical, medical, and cognitive sequelae following COVID-19, including persistent immunosuppression as well as pulmonary, cardiac, and vascular fibrosis(Oronsky et al., 2021).

People with spinal cord injury (SCI) represent a unique diagnostic challenge as it relates to coronavirus disease COVID-19 pandemic. Individuals with SCI develop a myriad of physiological changes that not only increase their risk of morbidity from COVID-19 but may also mask the presence of an acute respiratory illness which can potentially delay the diagnosis of COVID-19 (Korupolu et al., 2020). Spinal cord injury (SCI) is a life-changing event, often resulting in chronic physical impairment and substantial challenges to maintaining a good quality of life and well-being. Difficulties associated with SCI include increased risk of secondary health conditions and mortality, less vocational and community integration, disturbance of romantic relationships, and lower quality of life. Individuals with SCI are at greater risk of mental health difficulties as well (Bowles et al., 2020).

The time taken to recover from COVID-19 varies for individuals affected and some people can experience persistent symptoms up to 60 days after a positive diagnosis (Mardani, 2020). Amongst symptoms reported, fatigue appears to be the most common followed by breathlessness and neuropsychological issues (Halpin et al., 2020). It is estimated that approximately 10% of people suffer from longer-term symptoms (Greenhalgh et al., 2020) and the term long-COVID has been adopted by some patients to describe their ongoing experience of illness (Perego et al., 2020). There is little research knowledge on post-COVID-19 syndrome and a new guideline focused on the management of the long-term effects of COVID-19 has recommended further research on this (Ladds et al., 2020).

There is a need to understand how vulnerable individuals within Bangladeshi society, for example, people living with Spinal Cord Injury (SCI), have survived symptomatic SARS-CoV-2 infection.

In this research study, we aim to explore the experiences of people living with SCI, who have survived beyond a positive diagnosis of COVID-19.

#### 1.2 Rationale

The medium and long term problems experienced by survivors of COVID 19 after discharge from hospitals are currently unknown. Some studies found that the survivors of SARS and MERS had reduced lung function and exercise capacity at 6 months post-discharge. At 1 year, posttraumatic stress disorder (PTSD), depression and anxiety, and reduced quality of life were observed.

COVID 19 is a truly multisystem disease, with common extra-respiratory complications affecting the cardiac, renal, gastrointestinal, nervous, endocrine, and musculoskeletal systems. Specific data concerning urgent rehabilitation must be required of this group.

In this study, I try to justify the impact of Long-COVID and to acquire their Bio-psychosocial problem, and the vulnerable Spinal Cord Injury COVID positive are the most common people who had these long term problems.

#### 1.4 Research Question

- 1. How do vulnerable people living with spinal cord injury experience diagnosis of COVID-19 in Bangladesh?
- 2. How do people living with spinal cord injury, who survive beyond a positive diagnosis of COVID-19, experience recovery?
- 3. Do these survivors experience any long-term symptoms that they perceive are related to COVID-19? If so, what are these symptoms?
- 4. Do these survivors have any ideas on what they think might help improve the management of their condition?

#### 1.4 Objectives of the study

#### **General objectives**

• Try to gain in-depth insights and understand their own experiences and perspectives of long-COVID according to the ICF domain.

#### **Specific objectives**

- To gather Biological factors for example Long-COVID related symptoms and Spinal Cord Injury-related symptoms.
- To perceive information on Psychological factors for example mental health and its related issues.
- To gain insights on Social factors related to community barriers.

#### 1.5 Operational Definition

#### **Spinal Cord Injury**

Spinal Cord Injury (SCI) is defined as damage to the neural elements in the spinal canal (Spinal Cord and Cauda-equina) which can be traumatic or non-traumatic and results in temporary or permanent loss of motor and/or sensory function.

#### COVID-19

"Long-COVID" is a term when people who have recovered from COVID-19 but are still reporting lasting effects of the COVID-19 or have had the usual symptoms (Mahase, 2020).

If these symptoms last >12 weeksthen it is known as Long-COVID and if these symptoms last >24 weeksthen it is known as Persistent Long-COVID (Fernandez-de-Las-Penas, 2021).

#### **Paralysis**

Injury or disease to the nervous system can affect the ability to move a particular part of the body. This reduced motor ability is called paralysis.

#### Neurological level

Up to the level where both sensory and motor function remains intact.

#### **Paraplegia**

Impairment or loss of motor or sensory function / partial or complete paralysis of the lower half of the body with involvement of both legs that is usually due to damage to the spinal cord in the thoracic or lumber or sacral regions.

#### **Tetraplegia**

Tetraplegia is also known as Quadriplegia. It means paralysis of all four limbs, motor and/or sensory function in the cervical spinal segment is impaired or lost due to damage to that part of the spinal cord resulting in impaired or loss of function in the upper limbs, lower limbs, trunk, and pelvic organs.

The COVID-19 pandemic, also known as the coronavirus pandemic, is an ongoing pandemic of coronavirus disease 2019 (COVID-19) caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). It was first identified in December 2019 in Wuhan, China (Lai et al., 2020). The World Health Organization declared the outbreak a Public Health Emergency of International Concern in January 2020 and a Pandemic in March 2020. Although it is still unknown exactly where the outbreak first started, many early cases of COVID-19 have been attributed to people who have visited the Huanan Seafood Wholesale Market, located in Wuhan, Hubei, China. On 11 February 2020, the World Health Organization (WHO) named this disease "COVID-19", which is short for coronavirus disease 2019 (Sohrabi et al., 2020). COVID-19 has emerged as one of the most lethal and destructive occurrences in modern human history (Yam et al., 2020). COVID-19 exhibits some unique pathogenic, epidemiological, and clinical characteristics that have yet to be fully understood, such as its widespread and widespread transmission in the community versus the nosocomial spread of SARS and MERS, as well as its milder infection and lower mortality compared to the severe phenotype and higher mortality caused by the two other viruses (Bchetnia et al., 2020). Authors discovered the "Long Covid" patterns throughout the medium and long-term follow-up. We looked at dyspnea, exercise capacity, exhaustion, cough, fever, chest discomfort, elevated heart rate with exertion, persistent smell and taste problems, headache, arthralgia, and myalgia, as well as psychosocial and neurocognitive impairment (Ausin-Garcia et al., 2021). While there is no clear definition of protracted COVID, the most prevalent symptoms documented in several studies are tiredness and dyspnea that linger for months after acute COVID-19. Cognitive and mental impairments, chest and joint problems, palpitations, myalgia, smell and taste dysfunctions, cough, headache, and gastrointestinal and cardiac disorders are all possible long-term effects (Yong, 2021).

Numerous studies of COVID-19 patients in China during the disease's spread revealed that some of these psychological disorders, such as anxiety, fear, depression, mood changes, insomnia, and post-traumatic stress disorder, had a high prevalence rate among these patients (Zhanget al., 2020). A large proportion of patients with coronavirus disease 2019 (COVID-19) in Italy presented with symptoms (71.4 percent of 31 845 confirmed cases as of June 3, 2020). Cough, fever, dyspnea, musculoskeletal symptoms myalgia, joint pain, fatigue, gastrointestinal symptoms, and anosmia are all common symptoms. However, there is a scarcity of data on symptoms that persist after recovery. We looked at patients who had been discharged from the hospital after recovering from COVID-19 (Carfi et al., 2020). Covid-19 spread quickly throughout China during the first two months of the current outbreak, causing varying degrees of illness. Patients frequently did not have fevers, and many did not have abnormal radiologic findings (Guan et al., 2019). Various studies on other diseases show that when a patient is hospitalized and is exposed to an unknown environment, being away from one's family, losing one's professional function, and being exposed to unknown processes and tools, negative emotions such as stress and anxiety can emerge in the patient (Bo et al., 2021). Long-haulers are patients who have not entirely recovered from their sickness after weeks or months. Although the acute symptoms of COVID-19 have been well recorded, the long-term repercussions are less well understood due to the pandemic's relatively brief history. Symptoms can be caused by persistent chronic inflammation (e.g., exhaustion), organ damage sequel (e.g., lung fibrosis, chronic kidney disease), hospitalization, and social isolation (eg, muscle wasting, malnutrition). Health care professionals play an important role in devising a comprehensive strategy for recognizing and addressing post-COVID-19 problems (Scordo et al., 2021).

Patients have limited psychological tolerance, and given the disease's existing global state, these individuals are predisposed to mental diseases such as anxiety, fear, sadness, and negative emotions (Bo et al., 2021). Death anxiety is a multifaceted notion that cannot be readily articulated, and it often comprises themes such as the fear of one's death and the death of others. The following themes were identified as subthemes of the experience of death anxiety in a study of COVID patients (Menzies & Menzies, 2020).

In the social sciences of health, disability, and mental disorders, stigma has long been one of the societal issues (Room, 2005).

The uncontrolled spread of COVID-19, the unsatisfactory condition of patients isolated in intensive care units with acute respiratory diseases, the lack of an effective drug, and the mortality caused by this disease are among the most serious factors that can have an impact on one's mental health (Bo et al., 2021).

Long- COVID or post-COVID-19 syndrome was first recognized in social support groups, and then in scientific and medical communities. This illness is poorly understood because it affects COVID-19 survivors at all disease severity levels, including younger adults, children, and those who are not hospitalized (Yong, 2021). Initial therapy (self-administered, hospitalized), chronic COVID-19 symptoms "long-COVID", and if COVID-19 causes changes in people's mental states, such as depressive symptoms, are unknown in Bangladesh (Islam et al., 2021). As COVID-19 spreads, with the number of cases in the United States approaching 29 million, health care providers are starting to see individuals who have been infected with SARS-CoV-2 seek treatment for the virus's long-term physical and mental impacts (Scordo et al., 2021).

Previous research on Chinese nurses has similarly revealed changes in psychological features over time. A survey of Chinese healthcare professionals discovered that hard labor physically and psychologically exhausts healthcare workers, but that these providers demonstrate resilience and a sense of professional devotion in overcoming problems (Ardebili et al., 2021).

Long-term consequences of coronavirus disease 2019 (COVID-19) in patients who recovered from acute infection with severe acute respiratory syndrome coronavirus 2 were documented in an increasing number of case reports, case series, and small observational studies in 2020 (Parums, 2021). According to Islam et al. (2021), a minority (20%) of those who recovered from COVID-19 maintained lasting COVID-like symptoms. Diarrhea (12.7 percent) and weariness were the most commonly reported lasting effects (11.5 percent). Forty-eight percent of those polled were classified as having moderate to severe depression. Depression during COVID-19 was linked with lower family income, poor health status, sleep disruption, lack of physical activity,

hypertension, asthma/respiratory issues, fear of COVID-19 re-infection, and persistent COVID-19 symptoms, according to multivariate regression analysis.

Our world has changed dramatically in just a few weeks. Things we took for granted have been seriously disrupted and we are now suddenly concerned about our mortality and the health of our loved ones (Stoessl et al., 2020).Regardless of the specific symptoms of each of these outbreaks (SARS, MERS, and COVID-19), the COVID-19 progressive outbreak is causing challenges similar to those of the SARS and MERS outbreaks, and the lessons learned from those outbreaks could be used in the COVID-19 outbreak (Arabi et al., 2020). Long COVID is seen in 10–30% of individuals with a recent history of SARS-CoV-2 infection. The involvement of pulmonary, hematologic, cardiovascular, neuropsychiatric, renal, endocrine, gastrointestinal and hepato-biliary, and dermatologic systems, as well as a chronic multisystem inflammatory syndrome in children (MIS-C), emphasizes the need for a multidisciplinary approach to the management of patients with long COVID (Parums, 2021).

A review of previous research in this area revealed that the majority of COVID-19 research has thus far focused on the epidemiological, pathological, and physical aspects of the disease (Wei et al., 2020). As a large number of treated patients are discharged from the hospital, the burden on healthcare systems, patients' families, and society, in general, to care for these medically devastated COVID-19 survivors will grow. While the majority of COVID-19 cases are mild or asymptomatic, 5–8% of infected patients develop adult respiratory distress syndrome (ARDS), which is characterized by hypoxemia, bilateral pulmonary infiltrates secondary to non-cardiogenic pulmonary edema, and decreased lung compliance, often necessitating mechanical ventilation (Oronsky et al., 2021).

The risk of Acute Respiratory Distress Syndrome (ARDS) from COVID19 may be greater than in the general population due to physiologic disturbances. As a result, individuals suffering from SCIs may benefit from intensive early therapy (Palipana, 2020). The impairment of arm and hand function is one of the most severe elements of a cervical SCI, and it has a significant influence on the amount of independence. Only two pieces of research on the impact of SCI-related impairments and SCI patients' requirements have so far addressed upper extremity dysfunction (Snoek et al., 2004).

During a pandemic like COVID-19, societal stigma toward various stakeholders may play a crucial role in eroding social cohesion and imposing social division. The International Red Cross, World Health Organization, and UNICEF produced recommendations to avoid and manage the social stigma associated with COVID-19. The paper examines the influence that social stigma may have on both illness treatment and prevention. (Bhattacharya et al., 2020).

SCI is a life-changing event that frequently results in persistentphysical disability and significant hurdles to maintaining a decent quality of life and well-being. SCI is connected with difficulties such as a higher risk of secondary health disorders and death, less career and community integration, disruption of romantic relationships, and a worse quality of life (McDonald et al., 2018). Furthermore, persons with SCI may experience nonspecific symptoms during infection, such as new or worsening spasticity, neuropathic pain, Alzheimer's disease (AD), and/or exhaustion, which is inconsistent with current Centers for Disease Control and Prevention (CDC) recommendations for COVID-19. Because normal respiratory physiology is disrupted in SCI patients with COVID-19, the cough may not be evident. Due to loss of innervation to the abdominal and/or intercostal muscles, individuals with cervical or upper thoracic SCI have a substantially compromised capacity to cough (Korupolu et al., 2020). Besides, Bowles et al. (2020) showed that Depression affects 19-26 percent of people with SCI, which is around three times the rate in the general population. Anxiety, post-traumatic stress disorder (PTSD), drug misuse, and other mental health disorders are also more prevalent in SCI than in the general population.

It is a public health emergency in itself that increases the proneness of people to various mental health problems, which may be further aggravated by the social distancing approach disrupting daily routines, restraining interpersonal communication, and limiting the availability of social support. While the modern world has faced other epidemics and pandemics before, none of them had such worldwide and drastic effects on most individuals and their everyday life as the current COVID-19 pandemic (Song et al., 2020).

According to the Persons with Disabilities Rights and Protection Act of 2013, a PWD is "any individual who is physically, psychologically, and/or mentally not functioning

efficiently owing to social/environmental barriers." "Anyone unable to effectively engage in society is referred to be handicapped."PWD face social discrimination as well as cultural and mobility barriers that prevent them from fully and equitably participating in society. Furthermore, many medical professionals and healthcare workers are either unaware of or untrained in disability concerns. According to accounts from other destitute countries, there is a prevalent belief in Bangladesh that disability is a curse and a punishment for wrongdoing. People with disabilities have worse economic positions and less access to education and employment as compared to individuals without impairments. PWD has a higher unemployment rate (65%) than non-disabled persons (46 percent) (Mckercher & Darcy, 2018).

COVID-19 impacts people in a variety of ways. As a result, it was necessary to do a study on how a person with tetraplegia adjusts to the COVID-19 state. Because COVID-19 is a current issue, we conducted a case study to learn about a person with tetraplegia's real-life experiences(Ong et al., 2021). Furthermore, the possibility of being impacted by the COVID-19 may cause fear, anxiety, and other psychological problems in patients with SCI. As a result, the current study solely focuses on patients with traumatic tetraplegia, because the physiological barriers of SCI make this group more prone to delay the diagnosis of the COVID-19, which may cause further mental stress. As a result, the goal of this study was to look at the experience of a tetraplegic living in Bangladesh and adjusting to spinal cord injury (SCI) during COVID-19. The most current study on COVID-19 individuals co-morbid with SCI demonstrates that the multiple physiological changes in people with SCI, such as respiratory issues, loss of sensation, and fever from secondary complications, might cause a person's diagnosis to be delayed(Korupolu et al., 2020).

There is a significant relationship between social isolation and cognitive function, which can result in depression, anxiety, sleep issues, and cognitive impairment. Amid this worldwide calamity, however, there is a lack of information on people with disabilities, particularly those with spinal cord injury (SCI) in Bangladesh and other parts of the world. While people with disabilities have additional challenges during times of crisis in general, the pandemic may worsen the situation for individuals with SCI owing to their specific illnesses(Araujo et al., 2021).

Since its resurgence, COVID-19 has posed a hazard to both physical and mental health. Interventions such as quarantine and social isolation may have had an influence on mental health during COVID-19, which was studied in some research throughout the world, including Bangladesh(Tang et al., 2020).

Another statewide research in Bangladesh, which is now in pre-print, revealed that stress, anxiety, and depression were present in 59.7 percent, 33.7 percent, and 57.9 percent of individuals, respectively(Banna et al., 2020). COVID-19 has presented a threat to both physical and mental health since its return. Quarantine and social isolation may have had an impact on mental health during COVID-19, which was researched in a variety of studies throughout the world, including Bangladesh. An online cross-sectional poll was conducted during Bangladesh's countrywide lockdown to evaluate the mental health of the healthy population. The researchers observed that social isolation and confinement had a considerable negative impact on adult mental health(Ali, 2020).

Spinal cord injury (SCI) is a medically complex and life-altering illness that results in a wide range of functional restrictions and health-related difficulties. It is well acknowledged that people with SCI face difficulties performing activities of daily living (ADL) and participating in social activities as compared to individuals who do not have an SCI.Furthermore, once discharged from the hospital, they are vulnerable to life-threatening complications like pressure ulcers urinary tract infections and breathing problem; as a result, many of them die within a few years after the SCI.

#### 2.1 Theoretical framework

The theoretical framework was based on adopting the constructivist paradigm, where it was understood that there are multiple realities, experienced by individuals, which were all equally valid and carry meaning for the individual. This paradigm also asserts the theory that knowledge and meaning were generated through the interaction of humans with each other, individual experiences, and ideas. We had also taken into account the emerging clinical knowledge base on the post-COVID-19 syndrome to inform the design of our research questions.

#### 2.2 Study design

A qualitative study design with semi-structured interviews was conducted on the telephone.

#### 2.3 Study area and Site

Data were collected from patients with spinal cord injury who were discharged from the Centre for the Rehabilitation of the Paralysed Savar, Dhaka and they lived in the community.

#### 2.4 Study period

I started data collection on 16<sup>th</sup> June 2021 and ended on 16<sup>th</sup> August 2021 after that I started data analysis.

#### 2.5 Study Population

Eight potential Spinal Cord injury COVID-positive patients were taken as a sample for this study.

#### 2.6 Inclusion criteria

- Age 18 years and above
- Spinal Cord Injury people who had been diagnosed COVID-19 positive.
- Both male and female.

#### 2.7 Exclusion criteria

- Not agree to provide the interview
- A similar experience is considered saturated data.

#### 2.8 Data collection tools

A semi-structured qualitative questionnaire has been used for data collection by phone call interview.

#### 2.9 Data management and analysis plan

- All audio data were saved and stored in a research folder.
- Audio data has been anonymously translated and Transcribed from Bengali to English.
- Transcribed data were organized and managed carefully.
- I started data analysis through coding and categorization
- I have used a combination of Interpretative Phenomenological Analysis (IPA) and thematic analysis to analyze the data.

#### 2.10 Quality control and assurance

The investigator has enough knowledge in the designated study, hence the study area and underneath issues were keenly explored. The format of the questionnaire was purely semi-structured, thus it has to enable a definitive answer. The questionnaire was developed according to the literature search and peer review for a reliable questionnaire. The investigator was tried to avoid selection bias due to strictly maintained inclusion and exclusion criteria.

#### 2.11 Field test

After getting approval for conducting the research and before starting the final data collection, the researcher accomplished the field test with two participants. A field test was necessary as it helped the investigator to develop a final question and to collect data from participants easily. This test was performed to find out the difficulties that exist in the question. By this test, the researcher re-arranged and modified the question as required for the participants, so they can understand the question clearly.

#### 2.12 Ethical considerations

- I conducted this research by the guidelines of the Bangladesh Heath Professions institute (**BHPI**) of the Institutional Review Board (**IRB**).
- Informed consentwas taken from all participants.
- All the participants were informed about the aim and objectives of the study, And they has the liberty to exclude their participation after one month of data collection.
- The confidentiality was maintained Strictly

#### 2.13Rigor of the study

The rigorous manner was maintained to demeanor the study. This study was conducted systemically by next the steps of research under the supervision of an experienced supervisor. During the interview session and analyzing data, never tried to influence the process my value, perception, and biases. Be accepted the answer to the questions whether they were of positive or negative impression. The participants' information was coded accurately and checked by the supervisor to eliminate any possible errors. Try to keep all the participants' related information and documents confidential.

CHAPTER – IV RESULTS

Qualitative study results were analyzed by content analysis. By using this analysis process, the researcher organized collected data according to categories, coding, and themes. The study aims to gain insight and understand the participants' own lived experiences of long-COVID and the nature of symptoms experienced by these people. And also we want to understand how the Long-COVID infection had affected their lifestyles, as well as the lives of their families. Participants respond according to their experiences. In this section, coding is used to understand the participants' statements and to generate the themes.

A total of 14 potential participants were approached to take part in the study and six refused and they did not want to undertake an interview. A final total of 8 participants took part, seven male and one female, and the average age was 29.88 years. Further demographic details can be found in Table-1.

**Table-1: Socio-Demographic information** 

Code Number	Age	Gander	Results of RT-PCR Test	The month of COVID-19 Positive
P1	21 Years	Male	Positive	15 month
P2	50 Years	Male	Positive	11 month
Р3	25 Years	Female	Positive	15 month
P4	53 Years	Male	Positive	14 month
P5	25 Years	Male	Positive	11 month
P6	28 Years	Male	Positive	14 month
P7	18 Years	Male	Positive	13 month
P8	19 Years	Male	Positive	13 month

#### Participant-1

P1 was 21 years old male patient. He was a traumatic tetraplegic ASIA-A patient. He had an SCI problem. He came to the CRP in July 2020 for better treatment. Everyone was tested for COVID before being admitted into CRP. As he was positive on that test, CRP authorities did not allow him to admit to their center and told him to stay at home. He hid the COVID positive result from everyone for the poor attitudes of society during the COVID period. He became mentally depressed after returning home/ because he was also suffering from SCI conditions at that time. Those conditions were fear, lack of physical and emotional challenge, weakness in the lower limb, difficulties in ambulation, bounded with the wheelchair, and loss of bowel bladder control. Afterward, he recovered mentally. Despite being COVID positive, he did not face any physical problems and had no COVID symptoms such as fever, cold, cough, body aches, Shortness of breath.

After 18 days, he has tested the COVID again and the result was negative. He did COVID test one more time after 7 days and the result remained negative.

#### Participant-2

P2 was 50 years old male. He was a Traumatic Tetraplegic ASIA-A patient. He had an SCI problem too. He had an accident on October 26, 2019. His spinal cord was injured in that accident. He came directly to the CRP but the CRP authorities did not allow him to admit for not having ICU support. His condition was very bad. He felt a lot of pressure on his chest and difficulty breathing. Then he was taken to Dhaka Medical College Hospital. There was a lack of accommodation facilitates so that he was shifted to a private hospital named popular hospital. He stayed there for 5 days. He was later admitted to Neuro-science Hospital. He had SCI issues such as low oxygen saturation, respiratory complication, chest tightness, weakness, loss of consciousness, speaking very slowly, loss of bladder sensation. He used to lie on the bed most of the time. And bedsores could be seen on his body. He was still unconscious, had to feed by nasal tube. He did the COVID test there and it was negative. Then he moved to the CRP again. But there he became COVID positive. He had symptoms of COVID which include breathlessness, fatigue, headache, sore throat, vocal problem, mental stress, thirsty feeling, nightmares, sleep disturbance, anxieties, loss of smell, weakness, self-isolation, fever, weakness. He was admitted later to Magda Medical College. There he had an SCI problem. Therefore, he was again shifted to Dhaka Medical for ICU support. At that time, he became very depressed mentally. After 15 days of admission to Dhaka Medical, his oxygen level improved. He could eat on his own at that time. After 5 more days, he did the COVID test twice and returned to CRP as his COVID test was negative. But his wife did not test COVID. He had shortness of breath, headache, voice problems, and a sore throat.

He was unable to move his limb when he was admitted to Magda Hospital and suffered a lot of mental anguish. His family had supported him very much and his relatives used to come to see him. He was very worried about his family. When he was in the ICU, his oxygen level was 82 or 83, without oxygen supply it could not reach 90. He was then given 14 injections in 15 days and stopped supplying oxygen. After 5 days he recovered. His family thought he would die. At that time his brothers supported him emotionally and financially.

He always felt thirsty while he was COVID positive. He had a speaking problem when he was in a sitting position. Feeling tired, anxious and having trouble sleeping and occasional nightmares were common problems for him.

#### Participant-3

P3 was a 25 years old female. She was a traumatic paraplegic ASIA-A patient. She got SCI through an accident on 10th June 2020 and became COVID positive on 23rd July that year. When she became COVID positive, CRP did not allow her to admit to their center. They released her and told her to stay at home. But she said, "Please, give me a separate room and I want to stay at your hospital". At that time CRP did not agree with her proposal. Then she went back home and her physical condition became very much poor and mentally unstable. She was getting support only from her family but not others. She was isolated in a separate room. At that time, she became physically very weak and lost her appetite. On the other hand, she was getting some COVID-related symptoms like mild cough, fever, loss of smell, fatigue, anxious and it lasted for 15 to 20 days. She was also very anxious about her SCI condition. She was feeling mild pain in her back because of lying for a long time and got bedsore and also had some physical weakness. Sometimes she had nightmares but that was present before the COVID-19 diagnosis.

After all, she became mentally strong though she had some SCI problems and some Long-COVID experiences.

#### Participant-4

P4 was 53 years old male. She was a traumatic paraplegic ASIA-A patient. He had SCI problems. He was injured in C5 and L3. For which his lower extremity became paralyzed. He had a grasping problem, poor sitting posture, loss of bowel bladder control, and problem in using the high commode.

He was infected with COVID-19 on August 16, 2020, when he was admitted to CRP. After being infected with COVID-19, CRP authorities released him and he went home. At that time, he had a fever and cough. There were no other symptoms. Then he was in quarantine for 23 days. His wife lived in the same room with him at that time. He was emotionally and physically broken and he suffered considerably more financially. No one came to see him when he was in the home with the COVID-19 report (Positive). His relatives, neighbors, and family were also avoiding them. One day the UNO (Upazila Nirbahi Officer) hoisted a red flag at their home to mark as quarantine. He received nothing but 10 kg of rice as help. He used to do toilet activities in bed and his wife took care of him. Then his wife had a lot of fever, cough, and cold. At the end of quarantine, he tested COVID from Upazila Health Complex. On the next day, he got an SMS which showed the negative result of COVID.

She had a fever for a week. Then he took the medicine given by CRP. Slowly he recovered. He had no bad feelings about it. He was vaccinated on February 18, 2021. Then he went to the Neuroscience Hospital. From there he was referred to CRP. After 5 days of admission to CRP, he was discharged because of his positive COVID result. He could not smell the food. Her mother and he had asthma problems for which they had difficulty in breathing. The local people locked down their house for 21 days and they were in isolation. After getting COVID positive, he did not get any support mentally and physically. People in the area were not aware. Enough, they so that became affected. After that in COVID, he was healthy but his asthma had increased a bit. He had heart problems. In 2015, he had a history of a heart attack in Qatar and had two rings in his heart.

He was vaccinated on February 18, 2021. He was very aware of the vaccine and had asked everyone to take it.

#### Participant-5

P5 was 25 years old male. He was a traumatic paraplegic ASIA-B patient. He was admitted to CRP in October 2020 due to his SCI problem for which he could not walk independently, became wheelchair bounded and had a grasping problem. Because of lying on the bed for a long time for the operation, he had bedsore. He was affected in COVID-19 after 10-15 days of admission. Then he was moved from CRP to Dhaka Medical College Hospital. Then he continued to take treatment there. He recovered after about 20-25 days. In the case of COVID-19, he had only mild flu and mild cold. Besides, there was no problem. Then he took spinal surgery at Dhaka Medical College Hospital. He didn't have much problem after recovery from COVID, just had a little stomach problem. He was shocked to hear that many people had died due to COVID infection. After recovery, he became very well and started to move in a wheelchair.

#### Participant-6

P6 was 52 years old male. He was a traumatic paraplegic ASIA-B spinal cord injury patient. For which he had weakness in the lower limb, difficulty in moving, and for this, he decided to seek treatment at CRP. He did the COVID test when he came admitted for treatment purposes at CRP. He got infected with COVID-19. Then he moved back from the CRP. He used a private car to move around. After being released from CRP got tested COVID again and it was negative. Although he was a COVID negative even before going to CRP. He did not have any symptoms of COVID-19 like fever, cold, flu, loss of smell, muscle pain, etc. When he was admitted to the hospital everyone saw them negatively and some people didn't even touch him.

#### Participant-7

P7 was 18 years old male. He was a transverse myelitis paraplegic ASIA-C patient. He got this disability same as spinal cord injury. For this condition, he had poor balance, weakness in his lower limb, as well as pain in his knees and he, could not stand alone. For this, he used an elbow crutch to move. So he wanted to take treatment in CRP. He

tested COVID-19 before being admitted into CRP and he was positive. He remained at his home at that time. He did not take any treatment. He had no mental problem. He had his family with him all the time and was not neglected even by relatives. His mother was always with him. He hid his COVID positive result from his neighbors. Only a few people knew about it but he never got any into trouble for that.

Symptoms of COVID-19 were no longer seen. After that, he was completely healthy.

#### **Participant-8**

P8 was 19 years old male. He was a traumatic tetraplegic ASIA-A patient. He had an SCI problem and was admitted into CRP. At that time he had a problem with his movement, grasping, poor bowel bladder control, and became wheelchair-bound.

On September 5, 2020, he was affected by the Coronavirus. He was discharged from the CRP for COVID positive result. He was told to have isolation in his home. But his condition was not so well. He did not go home and was admitted to the clinic in Saver. He hid his COVID positive report for his spinal surgery as there were no acute symptoms such as fever, cold, cough, body aches, etc. He had a mild fever but was mentally stable. He continued to have treatment at Savar Clinic. He did not test COVID-19 after that anymore. Then he went back to his village and continued to use the wheelchair.

After that, he got some symptoms like fever and cold and still was taking the medicine on the advice of a doctor. During the COVID situation, he had to face some financial difficulties or crises.

Table-2: COVID-19 and Spinal Cord Injury Related symptoms

Code number	SCI related symptoms	COVID related symptoms
P1	Difficulties in ambulation	Fatigue
	Wheelchair bounded	Isolation
	Weakness in lower limb	Fear
	Loss of bowel bladder control	Mental Stress
	Disability-related Fear	Anxieties
		Stigma
P2	Bed sore	Fatigue
	Physically weak	Fever
	Loss of consciousness Fear	
	Feeding by nasal tube Isolation	
	Sleeping most of the time	Mental stress
	Respiratory complication	Stigma
	Talking problem	Loss of smell
	Chest tightness	Loss of taste
		Sore throat
		Breathlessness
		Thirsty feeling
		Respiratory complication

		Headache
		Sleep disturbance
		Anxieties
		Nightmares
		Stigma
Р3	Bed sore	Fatigue
	Physically weak	Fever
	Mild back pain	Isolation
	Disability-related mental stress	Fear
	Difficulties in ambulation	Stigma
		Mental stress
		Anxieties
		Cough
		Loss of smell
		Loss of appetite
		Nightmares
P4	Loss of bowel bladder control	Fatigue
	Grasping problem	Fever
	Financial problem	Isolation
	Lower extremity paralyzed	Fear
	Poor Sitting activity	Mental stress

Difficulties in ambulation	Cough
	Loss of smell
	Loss of taste
	Sore throat
	Breathlessness
	Asthma
	Brain Problem
	Sudden anger
Difficulties in ambulation	Fatigue
Wheelchair bounded	Fever
Grasping problem	Fear
Bed sore	Anxieties
Stomach ache	Cough
Difficulties in ambulation	Fatigue
Wheelchair bounded	Isolation
Weakness in lower limb	Mental stress
	Anxieties
	Stigma
Weakness in lower limb	Isolation
Poor balance	Fear
	Wheelchair bounded Grasping problem Bed sore Stomach ache Difficulties in ambulation Wheelchair bounded Weakness in lower limb

	Unable to stand independently	
	Use elbow crutch to walk	
	Pain at knee joint	
P8	Difficulties in ambulation	Fatigue
	Wheelchair-bound	Fever
	Loss of bowel bladder control	Isolation
	Grasping problem	Fear
	Financial problem	Mental stress
		Stigma

Table-3: International Classification of Functioning, Disability, and Health (ICF) converted Spinal Cord Injury (SCI) Post-COVID symptoms

Code	Body	Activities	Participation	Environmental	Personal
No.	structure or	limitation	restriction	factors	factors
	function				
P1	Wheelchair-	Difficulties	Isolation	Public transport	Fear
	bound	in		barriers	
		ambulation			
	Weakness in		Educational		Active age
	lower limb		barrier		
	Loss of bowel				Mental
	bladder control				stress
	Fatigue				Anxieties
Code	Body	Activities	Participation	Environmental	Personal
No.	structure or	limitation	restriction	factors	factors
	function				
P2	Bed sore	Feeding by	Isolation	Public transport	Fear
		nasal tube			
	Physically		Unable to	Stigma	Mental
	weak		participate in		stress
			employment		

	Loss of			Infrastructure	Anxieties
	consciousness			barrier	
	Fatigue				Nightmares
	Sleeping most of the time				
	Talking problem				
	Chest tightness				
	Fever				
	Loss of smell				
	Loss of taste				
	Sore throat				
	Breathlessness				
	Thirsty feeling				
	Respiratory				
	complication				
	Headache				
	Sleep				
	disturbance				
Code	Body	Activities	Participation	Environmental	Personal
No.	structure or	limitation	restriction	factors	factors
	function				
P3	Bed sore	Difficulties	Isolation	Public transport	Fear

	in			
	amburation			
Physically		Education	Stigma	Active age
weak		barrier		
Mild back pain			Infrastructure	Mental
			barrier	stress
Disability-				Anxieties
related mental				
stress				
Fatigue				Nightmares
Fever				
Cough				
Loss of smell				
Loss of				
appetite				
Body	Activities	Participation	Environmental	Personal
structure or	limitation	restriction	factors	factors
function				
Loss of bowel	Difficulties	Isolation	Stigma	Fear
bladder control	in			
	ambulation			
Fatigue	Grasping	Unable to	Road	Mental
	problem	participate in		stress
	weak  Mild back pain  Disability- related mental stress  Fatigue  Fever  Cough  Loss of smell  Loss of appetite  Body structure or function  Loss of bowel bladder control	Physically weak  Mild back pain  Disability-related mental stress  Fatigue  Fever  Cough  Loss of smell  Loss of appetite  Body Activities structure or function  Loss of bowel Difficulties bladder control in ambulation  Fatigue Grasping	Physically weak Education barrier  Mild back pain  Disability-related mental stress  Fatigue  Fever  Cough  Loss of smell  Loss of appetite  Body structure or function  Loss of bowel bladder control in ambulation  Fatigue Grasping Unable to	Physically weak Education barrier  Mild back pain Infrastructure barrier  Disability-related mental stress  Fatigue  Fever  Cough  Loss of smell  Loss of appetite  Body Activities participation factors  Function  Loss of bowel bladder control in ambulation  Fatigue Grasping Unable to participate in

	Lower extremity paralyzed	Using high commode			Financial problem
	Fever	Poor sitting activity			Sudden anger
	Cough				
	Loss of smell				
	Loss of taste				
	Sore throat				
	Breathlessness				
	Asthma				
Code	Body	Activities	Participation	Environmental	Personal
No.	structure or	limitation	restriction	factors	factors
	function				
P5	Wheelchair- bound	Difficulties in ambulation	Educational barrier	Road	Fear
	Fatigue	Grasping problem	Participation restriction in sports and community life		Active age
	Bed sore				Anxieties

	Stomach ache				
	Fever				
	Cough				
Code	Body	Activities	Participation	Environmental	Personal
No.	structure or	limitation	restriction	factors	factors
	function				
P6	Wheelchair-	Difficulties	Isolation	Public transport	Active age
	bound	in		barriers	
		ambulation			
	Weakness in		Educational	Stigma	Mental
	lower limb		barrier		stress
	Fatigue		Participation		Anxieties
			restriction in		
			sports and		
			community		
			life		
Code	Body	Activities	<b>Participation</b>	Environmental	Personal
No.	structure or	limitation	restriction	factors	factors
	function				
P7	Weakness in	Use elbow	Isolation	Public transport	Fear
	lower limb	crutch to		barriers	
		walk			

	Pain at knee	Unable to	Educational		Active age
	joint	stand	barrier		
		independen			
		tly			
		ci y			
		Use elbow	Participation		
		crutch to	restriction in		
		walk	sports and		
			community		
			life		
		Poor			
		balance			
Code	Body	Activities	Participation	Environmental	Personal
No.	structure or	limitation	restriction	factors	factors
	function				
P8	Wheelchair-	Difficulties	Isolation	Public transport	Fear
	bound	in		barriers	
		ambulation			
	Loss of bowel	Grasping	Educational	Stigma	Active age
	bladder control	problem	barrier		
		proorein	builter		
	Fever		Participation	Infrastructure	Financial
			restriction in	barrier	problem
			sports and		
			community		
			life		
			1110		
	1	1	1		1

Fatigue		Road	Mental
			stress

## **Theme**

# ICF Generated five themes were given below:

- Theme-1: Adaptation to Post-COVID condition and experiencing existing disability and comorbidities.
- Theme-2: Pre-existing limitations in ambulation and activities of daily living.
- Theme-3: Gaining experience of social isolation and lack of information and resources.
- Theme-4: Experiencing negative effects and mental issues.
- Theme-5: Experiencing social barriers strongly that affect the new-normal life.

# Theme-1:

Adaptation to Post-COVID conditions and experiencing existing disability and comorbidities.

Table-4.1: Existing disability (SCI) related symptoms

Symptoms	P1	P2	P3	P4	P5	P6	P7	P8
Wheelchair-bound								
Weakness in lower limb								
Loss of bowel bladder control								
Bed sore								
Physically weak								
Loss of consciousness								
Sleeping most of the time								
Lower extremity paralyzed								
Pain at knee joint								
Mild back pain								
Stomach ache								
Disability-related Fear								
Disability-related mental stress								
Respiratory complications								
Talking problem in sitting position								
Chest tightness								
		1	1	1	1	1	1	]

All most all the participants were wheelchair-bound and they had so many major Spinal Cord injury-related problems and so many Spinal Cord Injury related minor problems.

**Table-4.2: Post-COVID related symptoms** 

Symptoms	P1	P2	P3	P4	P5	P6	P7	P8
Fatigue								
Fever								
Cough								
Loss of smell								
Loss of taste								
Sore throat								
Breathlessness								
Thirsty feeling								
Asthma								
Respiratory complication								
Headache								
Loss of appetite								
Sleep disturbance								
Brain problem								

Most of the participants' major problems were fatigue, fever, cough, and loss of smell and they also faced so many Post-COVID related symptoms.

# Theme-2:

Pre-existing limitations in ambulation and activities of daily living.

Table-4.3: Existing disability (SCI) and Post-COVID related Activities limitation

<b>Activities limitation</b>	P1	P2	P3	P4	P5	P6	P7	P8
Difficulties in ambulation								
Use elbow crutch to walk								
Poor sitting activity								
Poor balance								
Unable to stand independently								
Grasping problem								
Feeding by nasal tube								
Using high commode								

So we can say that Most of the participants needed support and they had limitations in ambulation. On the other hand, they had so many Spinal Cord Injuries related to existing disabilities.

# Theme-3:

Gaining experience of social isolation and lack of information and resources.

Table-4.4: Existing disability (SCI) and Post-COVID related participation restriction

Participation restriction	P1	P2	P3	P4	P5	P6	P7	P8
Isolation								
Educational barrier								
Participation restriction in sports and community life								
Unable to Participate in employment								

All most all the participants felt isolated in their families or the society. On the other hand here almost 80% of participants were active aged (18-40 years) that's why their main problem was the educational barrier.

# Theme-4:

Experiencing negative affect and mental issues.

Table-4.5: Existing disability (SCI) and Post-COVID related personal factors

Personal factors	P1	P2	P3	P4	P5	P6	P7	P8
Fear								
Active age (18-40 years)								
Mental Stress								
Anxieties								
Nightmares								
Financial problem								
Sudden anger								

So can say that most of the participants' had Post-COVID related fear and they were active aged, on the other hand existing disability and Post-COVID related circumstances created in their mind mental stress and anxieties.

# Theme-5:

Experiencing social barriers strongly that affect the new-normal life

Table-4.6: Existing disability (SCI) and Post-COVID related social factor

<b>Environmental factors</b>	P1	P2	P3	P4	P5	P6	P7	P8
Public transport barriers								
Stigma								
Road								
Infrastructure barrier								

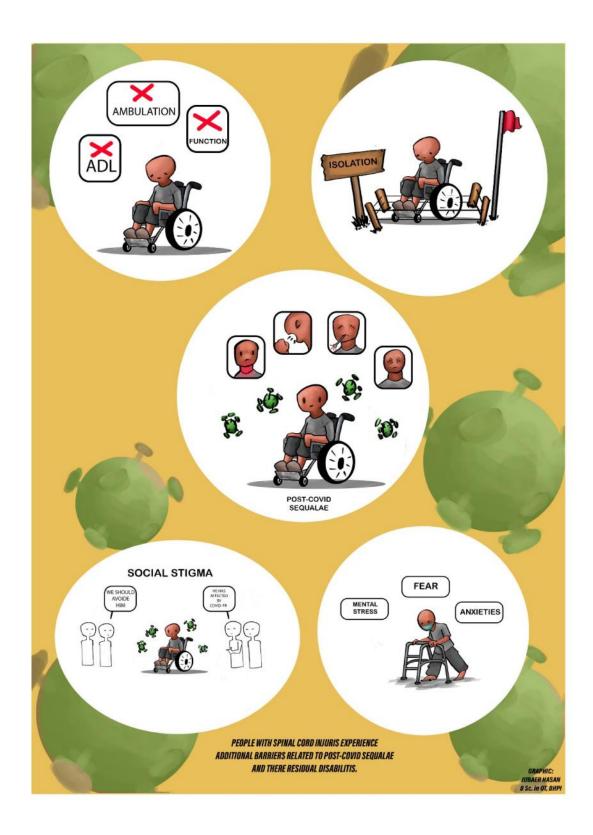
All the participants experienced existing disability-related public transport barriers and Post-COVID related stigma the society.

Table-5: ICF generated five theme described the existing disability and Post-COVID related symptoms experienced by Spinal Cord Injury people.

Theme-1		Theme-2	Theme-3	Theme-4	Theme-5
SCI	COVID	Difficulties in	Isolation	Fear	Stigma
Wheelchair- bound	Fatigue	ambulation			
Physically	Fever	Grasping	Educational	Active age	Public
weak		problem	barrier	(18-40	transport
				years)	barriers
Weakness	Cough			Mental	
in lower				Stress	
limb					
Loss of	Sore throat			Anxieties	
bowel					
bladder					
control					
Bed sore	Breathlessness				
	Loss of smell				
	Los s of taste				

So we can say that all the participants of Spinal Cord Injury survivors had major persistent symptoms or Long-COVID experiences were fatigue, fever, fear, mental stress, Anxieties, Isolation, and Stigma.

Figure-1: Thematic illustration



CHAPTER – V DISCUSSION

In this chapter, the results of the study are discussed concerning the research questions and objectives of the study. The discussion focus on persistent symptoms or long-COVID experienced by the Spinal Cord Injury survivors in Bangladesh. The description of the theme according to its category and coding is given below. Each table describes the interview findings. Under the different categories, different opinion is different codes. The tick was given only for those columns where the participant spoke about those issues. Here 'P' was used for the participant.

The interviews followed a semi-structured questionnaire format and all participants were asked the same questions. After transcripts of the entire interview were completed, the data were organized according to the interview questions. All transcripts were read several times to discover the themes and to find out what the participants wanted to say. The researcher at first appointed two category number one is existing disability-related SCI problems, number two is Post-COVID 19 related symptoms. The researcher then identified similarities from a list of categories. This procedure was repeated for all the questions. Using the topic analysis the researcher then did the second step data analysis. Each interview was segmented by this topic into categories. During analysis, the transcript was read several times and the important categories were identified. All themes were listed before they were placed into these categories according to their definition. The results obtained from these themes were written on the questionnaire. Five major categories were detected from the questions which were generated by the use of ICF.

# The General themes that have emerged from the theme

Different experiences about persistent symptoms or long-COVID experienced by the Spinal Cord Injury survivors in Bangladesh were detected.

From participants answer about persistent symptoms or long-COVID experienced by the Spinal Cord Injury survivors in Bangladesh it was clear that most of the participants existed disability-related or SCI related problems were, they were wheelchair-bound, they had difficulty in walking and grasping problem, they were physically weak, they had weakness in their lower limb and loss of bowel bladder control and they got bedsore in their body.

And Post-COVID 19 related symptoms were Fatigue, fever, cough, and loss of smell. And they were isolated in society, they felt fear of COVID -19, mental stress, anxieties, and negative stigma from society.

When an interview topic guide was used with questions focused on participants' experiences of COVID-19 and their perceptions of how it had impacted their lives. Then we found some experiences and perceptions. We conducted a thematic analysis by actively developing themes from the data.

In the result section, it has been possible to understand the patient's opinions by content analysis, where some themes have been found. Under the different themes, patients' different opinions are expressed by different codes. Five major themes were found are: Adaptation to Post-COVID conditions and experiencing existing disability and comorbidities, Pre-existing limitations in ambulation and activities of daily living, Gaining experience of social isolation and lack of information and resources, Experiencing negative affect and mental issues, Experiencing social barriers strongly that affect the new-normal life.

# Theme-1: Adaptation to Post-COVID conditions and experiencing existing disability and comorbidities.

# Major Existing disability (SCI) related symptoms:

P1, P5, P6, P8- Wheelchair-bound

P1, P6, P7- Weakness in lower limb

P1, P4, P8- Loss of Bowel bladder control

P2, P3, P5- Bedsore

# Participant-2 said,

"I was feeling...... weakness. I was not able to move. (Wife) we were a patient surviving with COVID and physical disability, which created an extra burden. I have a persistent SCI issue; I can't relate or distinguish the physical signs. I don't have bladder sensation but I can control bowel activity. (Wife) His condition was so much unstable, He was bed-bound for 5 days and we tried to change his position randomly but he had too much

breathlessness, when we tried to change his position, he refused to change. So, for that bedsore develop in a small area." [P2, male, 21 years, Appendix III]

## Participant-3 said,

"I was physically very weak at that time. I had a poor physical condition and I was getting support from my family. I had a spinal cord injury at that time and was also diagnosed with COVID-19. So, I was weak physically." [P3, male, 50 years, Appendix III]

#### Participant-4 said,

"I was already an SCI patient; I could not move anywhere. I did my toilet activities on my

bed. My wife was with me all the time. She took care of me, maintained my hygiene. Previously I had no bowel bladder control." [P4, male, 53 years, Appendix III]

#### Participant-8 said,

"I was only 19 years old when I became an SCI person. That's the main problem for me." [P8, male, 19 years, Appendix III]

So we can say that during the challenging period of the outbreaks, most of the participants have Spinal Cord Injury related physiological problems such as being wheelchair-bound, weakness in their lower limbs, physically weak, loss of bowel bladder control, and they gained bedsore.

SCI is complicated and can affect all bodily processes below the level of the lesion. A spinal cord injury (SCI) is defined as a loss or impairment of motor and/or sensory function in the cervical, thoracic, lumbar, or sacral portions of the spinal cord caused by damage to neuronal components inside the spinal canal (Biering-Sorensen et al., 2006). Pain, stiffness, pressure sores, mobility limitations, bladder control, finances, transportation, equipment, accessible housing, sexual function, and work were also noted by Cox et al as influencing the QOL of SCI patients. Furthermore, in the new study, 72 percent of participants had paraplegia and 64 percent were wheelchair-bound, compared to 61 and 65 percent of respondents in the previous study (Hossain et al., 2016)

#### **Major Post-COVID related symptoms:**

P1, P2, P3, P4, P5, P6, P8- Fatigue

P2, P3, P4, P5, P8- Fever

P3, P4, P5- Cough

P2, P3, P4- Loss of smell

#### Participant-2 said,

"We have been told to stay on the Dhaka Medical floor, but in the fear of bed-sore, we admitted to a popular hospital (Private Hospital). I was feeling chest tightness, fever, Weakness. I had breathlessness, headache, sore throat, vocal problem. I feel fatigued if I sit and talk. (Wife) Actually, at that time, they said that he (patient2) might need ICU support. Because he had breathlessness and low oxygen saturation on his, so they advised us to seek an ICU facility. (Wife) he had no consciousness and continuously had breathlessness. (Wife) Yes, he had a sore throat. Yes. I have thirsty feelings all the time. When I had COVID positive, I had a thirsty feeling also. Yes, still now I can't talk and sit at a time. I am still in bed. And yes, I experience fatigue every day." [P2, male, 21 years, Appendix III]

#### Participant-3 said,

"I had only fever and cough symptoms. The fever was mild and also had a mild cough. Fever and cold lasted for several days. I couldn't remember exactly. Maybe 5 to 6 days lasted the fever. The mild cough was lasting for 15 to 20 days. I had also a loss of appetite and I didn't have the smell. It was lasting for some days. I couldn't exactly remember. A little fatigue. Still." [P3. female, 25 years, Appendix III]

## Participant-4 said,

"I had fever and cough symptoms when I was diagnosed positive and I didn't have any other symptoms. We have mild symptoms, so I think that would save us. I had mild symptoms. I had a low-grade fever, cough. My wife had a high fever, cough, cold. I also had a sore throat but that was mild. My wife had body pain. And I did not feel any other symptoms. Yes. I had also a loss of taste in food. Also, I didn't smell anything." [P4, male, 53 years, Appendix III]

#### Participant-5 said,

"I had very mild symptoms. I had a mild cough, mild cold symptoms. I had a cough around 20 to 25 days long." [P5, male, 25 years, Appendix III]

#### Participant-8 said,

"I only felt low-grade fever." [P8, male, 19 years, Appendix III]

So we can say that during the challenging period of the outbreaks, most of the participants have Post-COVID 19 related symptoms such as fatigue, fever, cough, and loss of smell. On the other hand loss of taste, sore throat, and breathlessness were found as minor Post-COVID 19 symptoms.

The most disabling symptoms of extended COVID were recognized in a recent survey as weariness, shortness of breath, and cognitive failure. 89 percent of survey respondents also stated that mental and/or physical exertion caused a return of symptoms(Humphreys et al., 2021).Qualitative research, in addition to personal narratives, has offered vital insight into the lived experience of protracted COVID. People with protracted COVID describe a disease trajectory and varied symptomatology that did not match early assumptions and was not recognized in public health recommendations (Humphreys et al., 2021).

An unknown number of persons who had a seemingly moderate COVID-19 infection continue to experience symptoms. However, it is becoming clear that some people with COVID-19 infections, even those described as "mild," continue to experience persistent or cyclical symptoms such as chest pain and palpitations, shortness of breath, muscle, and joint aches and pains, headaches, cognitive impairment ('brain fog,' neuropathy and paraesthesia, and fatigue. Personal reports of symptoms following COVID-19 emphasize that using the term mild to characterize these difficulties ignores long-term repercussions or the persistence of symptoms, and can be perceived as diminishing pain. Following Severe Acute Retardation, patients experienced similar symptoms (chronic exhaustion, pain, weakness, sadness, and sleep disruption(Kingstone et al., 2020). Among the symptoms described by the respondents were fever, breathing problems, headaches, sleeplessness, lack of appetite, and pneumonia. These physiological experiences corroborate the clinical signs of the SARS-CoV-2 infection. The degree and kind of

symptoms experienced by survivors may vary for a variety of reasons(Olufadewa et al., 2020).

Post-acute COVID-19 'long-COVID' is described as a multi-system disease that can emerge after a very minor acute sickness, and persons who suffer from these chronic symptoms are referred to as 'long haulers.' The signs and symptoms appear to be cyclical and varied. Those may have a variety of symptoms, including respiratory, cardiovascular, neurological, dermatological, and gastrointestinal issues; how long these symptoms last is uncertain, and there is a little database to support doctors in managing people with persistent symptoms. This ambiguity exacerbates patients' anxieties(Kingstone et al., 2020).

Another study demonstrates the variety and complexity of symptoms experienced by people with persistent symptoms following suspected or confirmed COVID-19 infection; this phenomenon is known as 'long-COVID' or 'post-acute COVID-19,' and is a new disorder that is thought to affect 10% of people who have COVID-19 infection (Kingstone et al., 2020). The most often cited physiological sensations were fever, severe persistent and dry cough, difficulties breathing, cold and chill, pains and aches in the muscles, chest, and throughout the body. Other physiological experiences experienced by COVID-19 survivors but with fewer references were loss of appetite, sore throat and tonsillitis, headaches of variable severity, dizziness, voice changes, sleeplessness, and loss of smell and taste(Olufadewa et al., 2020).

Many current COVID-19 testing standards do not account for a person's altered physiology as a result of an SCI. As a result of their disrupted physiology, they may be devoid of fever, cough, and chest pain. As a result, the likelihood of missing a COVID-19 diagnosis may be enhanced in a person with an SCI (Palipana, 2020).

People suffering from comorbid, chronic, or secondary health issues, such as those affecting respiratory, cardiovascular, or immunological function. These individuals may be more seriously impacted by the COVID-19 disorder (Jesus et al., 2020). As a result, an SCI may provide the perfect storm of a patient with a compromised immune system and respiratory impairment, as well as an increased probability of additional underlying chronic comorbidities (Palipana, 2020).

# Theme-2: Pre-existing limitations in ambulation and activities of daily living.

Existing disability (SCI) and Post-COVID related Activities limitation

P1, P3, P4, P5, P6, P8- Difficulties in ambulation

P4, P5, P8- Grasping problem

#### Participant-2 said,

"(Wife) He couldn't move his limbs." [P2, male, 50 years, Appendix III]

#### Participant-4 said,

"I can't grip properly still now. My lower-extremity is paralyzed. I can't sit independently. I do my toilet activities on the high commode. I do my prayer sitting on the chair." [P4, male, 53 years, Appendix III]

So we can say that during the challenging period of the outbreaks, most of the participants had Spinal Cord Injury related physiological pre-existing ambulatory related limitations such as Difficulties in ambulation and grasping problems.

It is generally known that wheelchair-bound persons with a spinal cord injury (SCI) have a diminished physical ability, which varies based on numerous criteria such as the severity of the lesion, age, and gender (Dallmeijer et al., 1996).

Even the most fundamental ADL duties become difficult for a person with an SCI affecting the cervical level. It can make the individual reliant on others for help in many aspects of everyday life. Upper extremity function and physical capability are important conditions for ADL. Age, gender, body mass index, physical fitness, motivation, psychological state, medical issues, and socio-cultural background are all essential considerations. Previous research has demonstrated that intact motor level can predict the capacity of patients with cervical SCI to become ADL independent (Dahlgren et al., 2007).

Previous research has found that motor level is a factor of independence in ADL. Motor performance, on the other hand, is dependent on sensory feedback, which has been demonstrated to be vital in regulating arm, hand, and finger motions, and cervical SCI

patients with sensory-deficient hands must rely on visual control of the hands to be active in everyday life (Dahlgren et al., 2007).

Another study emphasizes the relevance of activities of daily living (ADLs) and outdoor activity to the normalcy and mental health of patients with extended COVID who were questioned. ADLs are core abilities necessary for independent living and are frequently used to measure physical function. Participants prioritized and chose these activities based on their meaning, balancing what was physically achievable with what gave the greatest return on investment in terms of feeling normal, active in family life, or boosting their mood (Humphreys et al., 2021). Participants detailed their extensive COVID experiences, detailing various individual disease trajectories and patterns of symptoms manifesting across the body. All of the subjects reported considerable debilitation, with their physical function severely impaired. This meant being confined to one's home for several weeks, if not months. During this time, fundamental activities of daily living (ADLs) such as self-care and cleaning became difficult or impossible, and organized exercise was out of the question(Humphreys et al., 2021).

# Theme-3: Gaining experience of social isolation and lack of information and resources.

Existing disability (SCI) and Post-COVID related participation restriction:

P1, P2, P3, P4, P6, P7, P8- Isolation

P1, P3, P5, P6, P7, P8- Educational Barrier

P5, P6, P7, P8- Participation restriction in sports and community life

#### Participant-1 said,

"Yes, when I was positive that time I was isolated, I felt mentally challenged. But after that, no other problems I felt. Just, I was afraid on the first day." [P1, male, 21 years, Appendix III]

#### Participant-2 said,

"It was a difficult time; I can't express it to anyone. (Crying) I was isolated from the family. (Wife) yes, I knew the fact the self-isolation But already I was in an isolation ward

with my Husband. (Int: In your first interview, you mentioned feeling isolated. Do you still feel isolated? P2- Yes)." [P2, male, 50 years, Appendix III]

## Participant-3 said,

"I was getting support from my family but I could not get any help from others. I was in a separate room and I was isolated. My family was isolated. My relatives didn't visit us. Yes, it was self-isolation. I was mentally broken because I couldn't get to admit myself for better treatments." [P3, female, 25 years, Appendix III]

#### Participant-4 said,

"Yes, I stayed at my home. I was quarantined for 23 days. My wife was with me. We were staying in the same room. Then my wife got affected too. She was diagnosed with COVID-19 positive and we spent 23 days quarantine in the same room. No, we decided to go self-isolation." [P4, male, 53 years, Appendix III]

#### Participant-7 said,

"I was staying at home. I did not receive any treatment." [P7, male, 18 years, Appendix III]

So we can say that during the challenging period of the outbreaks, most of the participants had gained Spinal Cord Injury and Post-COVID related social isolation, lack of information, and resource-related experiences such as isolation and educational barrier.

Unsurprisingly, participants regularly addressed their end-of-life anxieties. Several studies have found a link between social isolation and poor physical performance (Mckinlay et al., 2021). Public health professionals must convey clear, consistent information regarding the limits of masks, as well as the need of maintaining physical distance when wearing a mask. If there were more examples, this may have an impact on behavior. A culture shift is required regarding going to work while sick, and while this has begun, it will be difficult to persuade some individuals to stay at home (Benham et al., 2021).

It is highly typical for persons who are confined or secluded to suffer from severe mental illnesses while recuperating from an infection or a life-threatening catastrophe. Although it is unclear if this is related to quarantine or underlying disease, a large majority of COVID-19 survivors experienced feelings of sadness, overwhelm, and pain when

recovering from COVID-19 infection. Isolation and quarantine impede family support, which may exacerbate the poor psychological experiences of COVID-19 survivors if not addressed promptly (Olufadewa et al., 2020).

During the SARS illness epidemic, Hawryluck et al discovered comparable data to indicate the harmful impact of quarantine on patients. However, we do not advocate for the abolition of isolation or quarantine, but rather that it be made as tolerable as possible for isolated patients, which can be accomplished through psychological support, clear communication, compassionate healthcare delivery, and allowing isolated or quarantined people to use technologies such as social media and telecommunication with their familiesIsolation and are two related but separate concepts that have both been linked to illness and death.

People experience social isolation and a lack of social support as a result of lockdown. These people may be prone to the COVID-19 pandemic's negative psychological repercussions, such as mental health, disenfranchisement, occupational inequity, and social isolation (Jesus et al.,2020). Many of them faced, the circumstances at the COVID-19 treatment facility, and various unpleasant viral health disinformation that participants may have been exposed to. These negative sentiments experienced by survivors may be related not only to the virus's life-threatening nature but also to their strong anxiety about avoiding becoming an agent capable of infecting others (Olufadewa et al., 2020).

Isolation (the frequency of social connections) and loneliness (the subjective quality of social interaction) are two related but separate concepts that have been linked to illness and death. Much of this research has concentrated on mental health, demonstrating connections with greater levels of stress and depression, but there is growing interest in the consequences on physical health(Philip et al., 2020).

Furthermore, in the light of the COVID-19 epidemic, knowing the link between social isolation, loneliness, and physical performance in older persons has become critical. Because elderly individuals are more vulnerable to the disease, social distancing measures have been implemented across the world to limit their exposure to SARS-CoV-2, the virus that causes COVID-19 (Philip et al., 2020).

# Theme-4: Experiencing negative affect and mental issues.

Existing disability (SCI) and Post-COVID related personal factors

P1, P2, P3, P4, P6, P7, P8- Fear

P1, P3, P5, P6, P7, P8- Active Age

P1, P2, P3, P4, P6, P8- Mental stress

P2, P3, P5, P6- Anxieties

## Participant-1 said,

"I still remember the first day I was diagnosed. I am still afraid of the day and remember with fear. I had no symptoms but I became positive." [P1, male, 21 years, Appendix III]

#### Participant-2 said,

"I still remember the first day I was diagnosed. I am still afraid of the day and remember with fear. After that, a Chest X-ray was performed at CRP and again we were tested for COVID. And this time surprisingly I was positive again. Again we have been discharged from CRP. It was a difficult time and our relatives were supportive. I was depressed about my condition and I thought maybe I will not survive. I had so much mental stress. This is continuous mental pressure till now. I was worried if my Kids were Positive what will be fate (crying continuously). (Drinking water). (Wife) we were very worried at that time. We thought that we might be lost him. When he tested COVID negative, doctors told us to take him out of there as early as possible because it was safe for him. (Fear). So, we were very frustrated, depressed. We thought that he might not be survived. So, I thought that I didn't need the COVID at the test that time. If I tested positive, my brothers and others members would be more nervous. Yes, I have anxieties. Yes, sometimes I have nightmares." [P2, male, 50 years, Appendix III]

#### Participant-4 said,

"As I was already affected by SCI and then diagnosed COVID-19 positive so my mental status was very much unstable as well as my physical condition. It was a blessing from Allah. Allah saved my life two times from death. Yes, because I was affected by COVID-19. As it is a dangerous virus, anyone can be infected by the affected person. So, our neighbors and relatives got fear that if they came to help us then they might be infected by me. When they heard that I was infected by the coronavirus, they did not come to help.

Nor my siblings, my relative, my neighbors no one came forward to me.Yes. When I tested COVID positive, no one came to see me and help me. I couldn't get any support from them. Not even mental support." [P4, male, 53 years, Appendix III]

#### Participant-5 said,

I heard that many people died from coronavirus. I was worried at that time." [P5, male, 25 years, Appendix III]

# Participant-6 said,

"I could not understand why I was tested positive in CRP. I was tested negative before going to CRP. (Anxieties) My family members knew everything (fear). So there were not any problems." [P6, male, 28 years, Appendix III]

### Participant-7 said,

"Only a few people knew that. Might be one or two people know about that and they lived with me in the same flat." [P7, male, 18 years, Appendix III]

#### Participant-8 said,

"I was told to stay at my home from CRP. I am telling you the truth. My corona positive report was not submitted to the hospital. We did not tell the hospital authority that I was corona positive. Yes, of course. If hospital authority knew I was corona positive they did not allow me to admit there. (Int.: so you had faced financial and mental problems due to COVID-19? P8- Yes)." [P8, male, 19 years, Appendix III]

So we can say that during the challenging period of the outbreaks, most of the participants had gained Spinal Cord Injury and Post-COVID related negative effects and mental issue related experiences such as fear, mental stress, anxieties, and active age (18-40 years) related barriers.

So much research was interviewed that families and caregivers of COVID-9 pandemic patients who have psychosis(Wood et al., 2021). During the COVID-19 epidemic, a recent mixed-methods study found some critical difficulties in the delivery of mental health services(Wood et al., 2021). People who have depression or other mental health issues may have their mental health worsened by COVID-19 consequences. These include behaviors resulting from unemployment, financial stress, and other pressures

associated with the public health and economic crises(Jesus et al., 2020). According to the research, reasonable emotional responses to the pandemic include concerns about the virus, the future, and mortality(Kckinly et al., 2021).

Another study's participants were stated that Employment is related to improved physical and mental health, enhanced quality of life, and gives structure and regularity to everyday life for persons with intellectual disabilities. The unexpected loss of a job as a result of the COVID-19 epidemic may have had a substantial impact, particularly on those with intellectual disabilities, who are known to have very tiny social networks(Embregts et al., 2020). Participants often remarked that their fear over the anticipated implications of catching COVID-19 was having a significant negative impact (Fisher et al., 2021).

Living with an LTC during the COVID-19 epidemic has a significant influence on several elements of mental health and wellbeing (Fisher et al., 2021). The major findings indicate that COVID 19 has a psychosocial and behavioral influence on these persons, based on the data. These people were feeling worried and anxious. Addressing these people's psychosocial and behavioral issues can aid in better adapting to the epidemic. Similarly, qualitative measures might be created to produce objective data on the of **COVID** 19 behavioral influence on people's psychological and characteristics(Chakrawarty et al., 2021).

According to the study's reported experiences, many of these individuals had a bad mental health experience. They discovered that anxiety, panic, terror, and a fear of death were typical mental health experiences among many COVID-19 survivors during their recovery. This might be owing to the disease's ambiguity (Olufadewa et al., 2020). Some participants also expressed concerns and feelings of guilt, maybe because they were concerned that their family might become infected with the fatal virus as a result of them. The research that reveals certain SARS survivors' bad mental health experiences (Yan et al., 2020)

Long-term psychological issues such as PTSD and depressive disorders were found in studies of SARS-CoV and MERS-CoV survivors. The long-term effects of COVID-19 sickness on survivors may be similar to SARS and MERS. Without early help, COVID-19 survivors' mental health problems during the healing process may progress to long-term PTSD. Thus, symptoms of anxiety, despair, paranoia, guilty emotions, rage, and

other mental health-related clinical manifestations should be detected early, and appropriate intervention for improvement in symptoms should be done to increase the mental health resilience of COVID-19 survivors(Olufadewa et al., 2020).

The physical and psychological effects of extended COVID were intertwined. For other individuals, lengthy and unexpected physical incapacity had emotional consequences, including dread, mental tension, and anxiety over not being able to fulfill daily obligations. Some individuals stated that mental tension and worry were a particular cause of physical symptoms (Humphreys et al., 2021).

# Theme-5: Experiencing social barriers strongly that affect the new-normal life.

Existing disability (SCI) and Post-COVID related social factors:

P1, P2, P3, P6, P7, P8- Public transport barriers

P2, P3, P4, P6, P8- Stigma

P4, P5, P8- Road

P2, P3, P8- Infrastructure barrier

#### Participant-1 said,

"My parents were aware and we didn't tell the news to anyone, so I experienced no challenge. CRP's people told us that this is not a problem and we thought we would not let it be known to society. Also, it was locked down period, if we let it known to the society, the civil-administration would impose locked down to us and nobody could go out of the house." [P1, male. 21 years, Appendix III]

#### Participant-2 said,

"(Wife) Negative stigma is common in people for COVID testing. Because it is a communicable virus and it can transmit." [P2, male, 50 years, Appendix III]

#### Participant-3 said,

"When I got my positive result, CRP did not want me to stay here. (Stigma) But I couldn't get any support from my neighbors even from my relatives. They didn't contact us. There

was pressure on my family. People had a negative stigma for COVID-positive patients because of the nature of viruses." [P3, female, 25 years, Appendix III]

#### Participant-4 said,

"When I came back with my COVID-19 positive report, nobody came to see me. My relatives, my neighbors everyone avoided us, avoided my family. One day, UNO came to my home, and issue me a home quarantine notice, and mounted a red flag on my home. Then our local Chairman, Member lockdown our house because me and my wife was COVID at that time. So, they lockdown my house. Yes, UNO issued the lockdown. And they put a red flag in my main gate." [P4, Male, 53 years, Appendix III]

#### Participant-6 said,

"When I was in the hospital, some people negatively saw me. Some were not wanted to touch me." [P6, male, 28, years, Appendix III]

So we can say that during the challenging period of the outbreaks, most of the participants had gained Spinal Cord Injury and Post-COVID relatedsocial or environmental barriers such as public transport barrier and stigma, and that affect the new normal life.

According to the World Health Organization, societal stigma in the context of health refers to a negative link between a person or group of individuals who share particular qualities and a certain condition (Chopra and Arora, 2020). This opinion examines social stigma as a barrier to COVID-19 community well-being responses in Bangladesh (Mahmud & Islam, 2021).

Myths and misunderstandings frequently shape stigmatizing attitudes to Covid-19. Even though SARS-CoV-2 is a unique virus, which implies that no one is immune and thus everyone is at risk of developing the disease (Schmidt et al., 2020). Stigmatizing responses to Covid-19 demonstrated that certain groups believe they are resistant to the virus while condemning others for being responsible (and more vulnerable) for illness transmission (Schmidt et al., 2020).

Participants in one research drew parallels between HIV-related stigma and stigmatizing responses to Covid-19 as the epidemic spread in South Africa(Schmidt et al., 2020). Quarantined individuals have their freedom restricted to contain transmissible infections. This has a significant impact on the individual(Hawryluck et al., 2004). COVID-19 has resulted in stigma and prejudice among many demographics and groups of individuals (Chopra and Arora, 2020). To the general public, the social stigmatization of the isolated looks to be typical behavior. It obtains societal acceptability. Institutional isolation of persons affected by an illness, in this case, COVID-19, reinforces the stigma (Bhattacharya et al., 2020).

The stigma is directed not just at people who have recovered from COVID-19, but also at those who are undergoing treatment, are suspected of being affected, or have succumbed to it, as well as their relatives. They were forced to leave the area, were denied access to their homes, and their families were intimidated. The stigma is having a significant impact on the mental health of frontline workers as well as individuals who are healing or have survived the sickness. Social stigma may jeopardize the fundamental framework upon which a society is built. In times like these, when "physical detachment" and "physical isolation" are necessary procedures to keep oneself and loved ones safe and healthy (Bhattacharya et al., 2020).

Stigmatization may generate a negative motivation for people to hide sickness symptoms and crucial medical history, postpone seeking healthcare, and discourage communities from adopting healthy practices(Peprah & Gyasi, 2020).

Growing research reveals that COVID-9 stigma is a substantial source of mental discomforts such as stress, anxiety, and depression among frontline health providers and afflicted persons, with serious implications for their wellbeing. COVID-19induced stigma can drastically isolate and devalue individuals, particularly health workers, due to their failure to successfully contribute to the pandemic's fight (Peprah & Gyasi, 2020).

## **Limitations:**

Regarding this study, there were some limitations or barriers to consider the result of the study as below:

- The research interview was taken over the phone, which would have been nice to have a face-to-face interview.
- The researcher did the research manually, he did not use any software.
- Most of the participants were unwilling to share their experiences of survivorship.
- The researcher is a novice and his experience is so little in this field.

# CHAPTER – VI CONCLUSION AND RECOMMENDATION

#### **CONCLUSION**

During this study, I discovered Spinal Cord Injury and Long-COVID related so many bio-psycho-social problems. The biological Long-COVID and SCI-related problems were fatigue fever, wheelchair-bound, difficulties in ambulation, and physical week. The Psychological problem was fear, anxiety, and mental stress. The Psychosocial problem was isolation. And the Social problem was the stigma.

## RECOMMENDATION

A further study might aim to reduce this bio-psycho-social problem and encourage selfmanagement approaches for their quality of survivorship in the community on a larger scale.

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## Appendix I

Date: 16th June, 2021.

The Chairman

Institution Review Board (IRB)

Bangladesh Health Professions Institute (BHPI).

CRP, Savar, Dhaka-1343, Bangladesh.

Subject: Application for review and ethical approval.

Dear Sir.

With due respect, I am Md. Obayadur Rahman Noman, student of 4<sup>th</sup> professional B.Sc. in physiotherapy at Bangladesh Health Professions Institute (BHPI), academic institute of Centre for the Rehabilitation of the Paralyzed (CRP) under the faculty of medicine of University of Dhaka. This is a four-year full-time course. Conducting thesis project is partial fulfilment of the requirement for the degree of B.Sc. in physiotherapy. I have to conduct a thesis entitled, "COVID-19 Survivorship: A Qualitative Study of Persistent Symptoms or Long-COVID Experienced by Spinal Cord Injury Survivors in Bangladesh" under the supervision of Kazi Md. Amran Hossain, Lecturer, Department of Physiotherapy, BHPI, CRP, Savar, Dhaka-1343. The purpose of this study is to gain research knowledge on the experiences of people living with Spinal Cord Injury, who have survived COVID-19 and to contribute to building research knowledge on post COVID-19 syndromes also known as "Long-COVID". I would like to assure that anything of my study will not be harmful for the participants. Informed consent will be received from all participants, data will be kept confidential.

I, therefore pray and hope that your honor would be kind enough to approve my thesis proposal and give me permission to start data collection and oblige thereby.

Sincerely,

Md. Obayodur Rahman Noman

Md. Obayadur Rahman Noman

4th professional B.Sc. in Physiotherapy

Roll No: 16

Session: 2015-16, ID: 112150287

BHPI, CRP, Savar, Dhaka-1343, Bangladesh.

Recommendation from the thesis supervisor:

Kazi Md. Amran Hossain

Lecturer of the Physiotherapy Department, BHPI

CRP, Savar, Dhaka-1343, Bangladesh.



# বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) Bangladesh Health Professions Institute (BHPI)

(The Academic Institute of CRP)

Ref:

Date:

CRP/BHPI/IRB/06/2021/476

17/06/2021

To, Md. Obayadur Rahman Noman 4<sup>th</sup> year B.Sc. in Physiotherapy Session: 2015-2016, Student ID: 112150287 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "COVID-19 Survivorship: A Qualitative Study of Persistent Symptoms or Long-COVID Experienced by Spinal Cord Injury Survivors in Bangladesh" by ethics committee.

Dear Md. Obayadur Rahman Noman,

Congratulations.

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, as the principal investigator. The following documents have been reviewed and approved

#### Sr. No. Name of the Documents

- 1. Dissertation proposal
- 2. Questionnaire (Bengali & English version)
- 3. Information sheet and consent form

The purpose of this study is to gain research knowledge on the experiences of people living with spinal cord injury, who have survived COVID-19 and to contribute to building research knowledge on post COVID-19 syndromes also known as "Long-COVID". The study involves use of a questionnaire to explore that may take 30 to 45 minutes to answer the questionnaire and there is no likelihood of any harm to the participants. The members of the Ethics committee have approved the study to be conducted in the presented from at the meeting held at 8.30AM on 1st March, 2020 at BHPI (23rd IRB Meeting).

The Institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964-2013 and other applicable regulation.

Best regards

Muhammad Millat Hossain

Assistant Professor, Dept. of Rehabilitation Science

Member Secretary, Institutional Review Board (IRB)

BHPI, CRP, Savar, Dhaka-1343, Bangladesh

CRP-Chapain, Savar, Dhaka-1343, Tel: 7745464-5, 7741404 E-mail: principal-bhpi@crp-bangladesh.org, Web: bhpi.edu.bd, www.crp-bangladesh.org

#### Permission letter

Date: 16th June, 2021

The Head of Department

Department of Physiotherapy

Centre for the Rehabilitation of the Paralysed (CRP)

Chapain, Savar, Dhaka-1343.

Through: Head, Department of Physiotherapy, BHPI

Subject: Seeking permission for data collection of 4th year physiotherapy research project.

Respected Sir,

With due respect and humble submission to state that I am Md. Obayadur Rahman Noman, student of 4th Professional B.Sc. in Physiotherapy at Bangladesh Health Professions Institute (BHPI). The ethical committee has approved my research project entitled on "COVID-19 Survivorship: A Qualitative Study of Persistent Symptoms or Long-COVID Experienced by Spinal Cord Injury Survivors in Bangladesh" under the supervision of Kazi Md. Amran Hossain, Lecturer (BHPI), Department of Physiotherapy, CRP, Savar, Dhaka-1343, Bangladesh. Conducting this research project is partial fulfillment of the requirement for the degree of B.Sc. in Physiotherapy. I want to collect data for my research project from the patients of Spinal Cord Injury (SCI) unit, Department of Physiotherapy, CRP-Savar. So, I need permission for data collection from the Spinal Cord Injury (SCI) unit of Physiotherapy Department of CRP-Savar. I would like to assure that anything of my study will not be harmful for the participants.

May I, therefore pray and hope that you would be kind enough to grant my application & give me permission for data collection and oblige thereby.

Approved

Yours obediently,

M. Obayadure Rahman Neman

Md. Obayadur Rahman Noman

4<sup>th</sup> professional B.Sc in Physiotherapy
Roll: 16, Session: 2015-16, ID No: 112150287
Bangladesh Health Professions Institute (BHPI)
(An academic Institute of CRP)
CRP, Chapain, Savar, Dhaka-1343.

Forwarded to Head of PT. BAHPI

Kazi Md. Amran Hossain Lecturer Dept. of Physiotherapy BHPI, CRP, Savar, Dhaka-1343 Recommended

Md. Shofiqui Islam
Associate Professor & Read
Department of Physiotherapy
Bangiadesh Health Professions institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343

MOHAMMAD ANWAR HOSSAIN
MOHAMMAD ANWAR HOSSAIN
Senior Consultant 8

# **Appendix II**

## সম্মতিপ

আসসালামুয়ালাইকুম/ নমস্কার,

	মো ওবায়েদুর রহ	নোমান,	হেলং	থ প্রফেশনস	ইনস্টিটিউট (	)	চতুর্থ বর্ষের
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টেলিফোনে মৌখিকভাবে সম্মতি গ্রহন

# কোভিড-১ বেঁচে থ স্থায়ী উপসর্গের একটি গুনগত অধ্যায়ন স্পানাইল কর্ড ই থেকে বেঁচে থ দীর্ঘ-কোভিড অভিজ্ঞত।

মোঃ ওবায়েদুর রহ নোমান

জন্য ব্রহনকারীর শনাক্তকর নম্বরঃ .....

গ্রহনকারীকে নিম্নলিখিত প্রশ্নগুলি জিজ্ঞাসা করুনঃ উত্তরটি হ্যা : বক্সে হ্যা

## বক্সে ।

I	নিশ্চি	ত যে		পর্যাপ্ত ব্যাখ্যা দেওয়া	?	
	তথ্য	, প্রা	জিজ্ঞাসা	পেয়েছেন এ	সন্তোষজনক	
	উত্তর	?				
I		পেরেছেন যে	অংশঃ	গ্ৰহণ স্বেচ্ছায়	কোন	
	যে কোন	:	থেকে:	?		
I		পেরেছেন যে বি	ঞ্লেষণের অ	ব্যক্তিগত তথ্য	প্রতিক্রিয়া গুলি	
	বেনামী :	?		বেনামী প্রতিক্রিয়া গুলি	লতে প্রবেশের	
		?	পেরেছেন (	য প্রকাশনার জন্য নির্বাচি	ত হলে প্রত্যক্ষ	
	উক্তিগুলি গোপন	1₹ ?				
I	স	াক্ষাৎকারটিতে স	শ্মত	সাক্ষাৎকারটি	-রেকর্ড ব	
	I সমস্ত	ইলেকট্র	নিক ডেটা সংগ্ৰ	এটি	কেজেল ডেটা	
	সেটে সংরক্ষণ		হেলথ প্র	ফেশনালস ইনস্টিটিউ (	),	
	-	স	ংরক্ষণ I			
I			সম্মত?			

#### অংশগ্রহনকারীর তথ্য পত্রক

#### অধ্যয়নের লক্ষ্য

মেরুদন্ডে আঘাত প্রাপ্ত বেঁচে থাকা ব্যক্তিদের অভিজ্ঞতা সর্ম্পকে জ্ঞান অর্জন করা, যারা কোভিড-১৯ এ বেঁচে গেছেন৷

. পোস্ট কোভিড-১৯ সিন্ড্রোম সম্পর্কে গবেষণা জ্ঞান তৈরিতে অবদান রাখতে, যা "লং-কোভিড"

#### আপনাকে কেন অংশ নিতে আমন্ত্রন জানানো হয়েছে?

আমরা আপনাকে এই গবেষনায় অংশ নিতে আমন্ত্রন জানিয়েছি কারন আপনি অধয্যনের জন্য সমস্ত যোগ্যতার মানদণ্ড পূরন করেন৷

## সম্ভাব্য সুবিধা

তদন্তকারীরা প্রতিশ্রুতি দেয় না বা গ্যারান্টি দেয় না, যে আপনি অধ্যয়ন থেকে সরাসরি সুবিধা পাবেন৷ এমন সুবিধাগুলিও জড়িত থাকতে পারে যা এই সময়ে গবেষকের কাছে অজানা৷

#### আপনি কি এই গবেষণায় অংশগ্রহণ করবেন?

এই গবেষণা অধ্যয়নে আপনার অংশগ্রহণ সম্পূর্ণরূপে স্বেচ্ছায় এবং আপনি অংশ নিতে চান কি না তা সম্পূর্ণরূপে আপনার পছন্দ। এই অংশগ্রহণকারী তথ্য পত্রক (পিআইএস) ব্বর্ণীখ্যা করে এবং কী জড়িত তার পটভূমির তথ্য দেয়। কোনো কারণ না জানিয়ে আপনি চাইলে যেকোনো সময় অধ্যয়ন থেকে সরে যেতে পারবেন।

## এই গবেষণায় আমার অংশগ্রহণ কিসের সাথে জড়িত?

সকল অংশগ্রহণকারী টেলিফোনে একটি আধা-কাঠামোগত সাক্ষাৎকারে অংশ নেবে৷ ইন্টারভিউর তারিখ অগ্রিম একটি পারস্পরিক সুবিধাজনক সময়ে নির্ধারন করা হবে৷

# এই গবেষণা কি অর্থায়ন যুক্ত?

এই গবেষনাটিতে অর্থায়ন করা হয় নি এবং এই গবেষণায় অংশগ্রহণের জন্য আপনাকে কোন অর্থ প্রদান করা হবে না৷ এটা সম্পূর্ণ স্বেচ্ছাসেবী৷

#### অংশ নেওয়ার গোপনীয়তা এবং পরিচয় গোপন রাখা

ষণাটি সমস্ত অংশগ্রহণকারীকে আশ্বস্ত করে, সমস্ত ডেটা অ-শনাক্ত করা হবে, সংরক্ষণ করা হবে এবং বেনামে পরিচালনা করা হবে৷

# সম্মতি বিবৃতি

আপনার মৌখিক সম্মতি নির্দেশ করে যে, আপনি এই গবেষণায় অংশগ্রহণ করার সিদ্ধান্ত নিয়েছেন এবং আপনি উপরে দেওয়া তথ্যের সাথে সম্মত এবং আপনাকে প্রশ্নের উত্তর দেওয়ার সুযোগ দেওয়া হয়েছে৷

# প্রশ্নপ

# কোভিড-১ বেঁচে থ স্থায়ী উপসর্গের একটি গুনগত অধ্যায়ন স্পানাইল কর্ড ই থেকে বেঁচে থ দীর্ঘ-কোভিড অভিজ্ঞত।

ব্যক্তিগত তথ্যঃ										
শনাক্ত করন না	শনাক্ত করন নাম্বার:									
করোনা শনাক্তে	র তারিখ:									
সাক্ষাৎকারের ত	ারিখ:									
আৰ্থ-ভ	তথ্যঃ									
		বৎসর								
	লিঙ্গ	<b>্ৰ</b> পুরুষ								
	(√ চিহ্ন দিন )									
। মেরুরজ্জু	তথ্যঃ									
	রোগ নির্ণয়									

# ।কোভিড-১: দীর্ঘ-কোভিড সম্পর্কিত তথ্যঃ

প্র :	সাক্ষাৎকার	প্রতিক্রিয়া
	অনুগ্রহ করে আপনি আমাদের কে বলেন যে, কোভিড-	
	এ আক্রান্ত হওয়ার পর আপনার অভিজ্ঞতা কেমন	
	l l	
	?	
	ব্যক্তিকে কথা বলা শুরু করতে উৎসাহিত করার জন্য বিরতি	
	ঐচ্ছিক প্রনোদিত প্রশ্ন যদি ব্যক্তি কথা বলা শুরু না করেঃ	
	1	
	- শনাক্ত হয়েছিল এবং ঐ অভিজ্ঞতা কেমন	
	?	

-প্রয়	সাক্ষাৎকার	প্রতিক্রিয়া
	আপনার কী কী লক্ষণ ছিল এবং সময়ের সাথে সাথে	
	সেগুলির কি কোন পরিবঁতন হয়েছিল?	

ব্যক্তিকে কথা বলা শুরু করতে উৎসাহিত করার জন্য বিরতি
 ঐচ্ছিক প্রনোদিত প্রশ্ন যদি ব্যক্তি কথা বলা শুরু না করেঃ
আপনি কি অনুভব করেন যে আপনি পুরোপুরি সুস্থ হয়ে
উঠেছেন অথবা সুস্থ হয়ে উঠেন নাই?

প্রশ্ন:	সাক্ষাৎকার	প্রতিক্রিয়া
	এমন কোন উপসৰ্গ আছে যা আপনি এখনও অনুভব	
	করেন যা আপনার জন্য সমস্যা সৃষ্টি করে?	
	ব্যক্তিকে কথা বলা শুরু করতে উৎসাহিত করার জন্য বিরতি	
	ঐচ্ছিক প্রনোদিত প্রশ্ন যদি ব্যক্তি কথা বলা শুরু না করেঃ	
	कार्या के कार करियंग कार्य स्वीती विभाव कार्य	
	আপনি কি কোন অবিরাম অথবা স্থায়ী উপসর্গ অনুভব ?	
	·	

-প্রঃ	সাক্ষাৎকার	প্রতিক্রিয়া
	আপনার কাছে কোভিড-১ থেকে বেঁচে থাকার অর্থ	
	?	
	ব্যক্তিকে কথা বলা শুরু করতে উৎসাহিত করার জন্য বিরতি	
	ঐচ্ছিক প্রনোদিত প্রশ্ন যদি ব্যক্তি কথা বলা শুরু না করেঃ	
	কোভিড-১ থেকে বেঁচে যাওয়ায় এখন আপনার জীবন	
	?	

প্রায়	সাক্ষাৎকার	প্রতিক্রিয়া
	ভবিষ্যতে আপনার মতো বেঁচে থাকা হাঁ	হাঁ 📗
	ব্যক্তিদের সাহায্য করার জন্য একটি সহায়ক চিকিৎসা না হস্তক্ষেপ বিকাশ এবং স -উৎপাদনে সহায়তা করতে	
	প্রস্তুত হবেন?	

সাক্ষাত্কারের সহ , প্রয়োজন ই	ı	
প্রনোদিত প্রশ্নগুলি ব্যবহার	:	
?		
এটি	কেমন	
?		
তে সত্যিই আগ্ৰহী,	প্রসারিত	
?		

# সংক্ষিং পত্ৰ

কো	ভিড-১ বেঁচে গ	থ স্থায়ী উপস	ার্গের একটি গুনগত অধ	<b>গ্রায়ন</b> <sup>হ</sup>
স্পানাইল কর্ড	ই থেকে বেঁ	চৈ থ	দীৰ্ঘ-কোভিড অভিজ্ঞ	চ।
	নেয়ার জন্য ্	ধন্য	বাদ ও	
প্রশংসা I				
অংশগ্ৰহন শেষ	ı	দিচ্ছি,	কোন প্রশ	থকে
1				
সম্পর্কে	নিশ্চিত	?	কোন প্রশ	
	মো	হোসাইন, প্র	ভাষক,	, ,
, -	, যোগা	যাগ কর	I	
সংক্ষিপ্ত বিবরনিটি মৌখিব	<b>চ</b> ভ	-		
স্বাক্ষরঃ·				
গ্রহনকারীর	ননাক্তকরন নম্বরঃ			

#### **CONSENT FORM**

Assalamualaikum/Namasker,

My name is Md. Obayadur Rahman Noman, student of 4th Professional B.Sc. in Physiotherapy in Bangladesh Health Profession Institute (BHPI). I am conducting research that is included in my course and the title is "COVID-19 Survivorship: A Qualitative Study of Persistent Symptoms or Long-COVID Experienced by Spinal Cord Injury Survivors in Bangladesh". Because of that, I would like to know some information, which will not take more than 15-20 minutes. It also guarantees that your provided information will be remained confidential.

You can participate in this study voluntarily. If you want, you can withdraw your participation or skip any question at any time from the list. Also, if there is any problem or as a participant in this study, if you have any queries, you can contact me or my research supervisor Kazi Md. Amran Hossain, Lecturer, Department of Physiotherapy, BHPI, CRP, Savar, Dhaka-1343.

Do you l	have a	ny	questions	before	starting	the	research?	Can	I	start	this	interview?
Yes	•••••											
No												
Signature	of Inte	ervie	ewer									
Date												

Consent taken verbally by the researcher via telephone.

Research Title: "COVID-19 Survivorship: A Qualitative Study of Persistent Symptoms or Long-COVID Experienced by Spinal Cord Injury Survivors in Bangladesh".

Name of Researcher: Md. Obayadur Rahman Noman			
Name of participant:			
Date of informed consent process:			
Participant Identification Number for this research:			
Please ask the participant the following questions: If the answer is YES – write YES in			
the box and If the answer is NO – write NO in the box.			
1. Are you sure you have been adequately explained in this study?And			
you have the opportunity to consider the information, ask questions,			
and answer satisfactorily.			
2. Do you understand that your participation is voluntary and that you			
can withdraw from this study at any time withoutgiving any reason?			
3. Do you understand that your data responses will be anonymized			
before analysis? Did you permit the researcher to have access to your			
anonymized responses? Do you understand that any direct quotes if			
selected for publication, will be anonymized?			
4. Do you agree to the interview and this interview will be audio-			
recorded.All audio and electronic data will be collected so that it is			
stored in the Kegel data set and stored securely by researchers from			
Bangladesh Health Professionals Institute (BHPI), CRP.			
5. Do you agree to take part in this study?			

#### PARTICIPANT INFORMATION SHEET

#### Aim of this study

- 1. To gain research knowledge on the experiences of people living with spinal cord injury, who have survived COVID-19
- 2. To contribute to building research knowledge on post-COVID-19 syndrome also known as "Long-COVID".

#### Why have you been invited to take part?

We have invited you to take part because you meet all the eligibility criteria for the study.

#### **Possible Benefits**

The investigators do not promise or guarantee that you will receive direct benefit from being in the study. There also may be benefits involved that are not known to the researcher at this time.

#### Will you participate in this research study?

Your participation in this research study is entirely voluntary and it is entirely your choice as to whether or not you wish to take part. This Participant Information Sheet (PIS) explains the research and gives background information on what is involved. You would always be free to withdraw from the study at any time if you wanted to, without giving a reason.

#### What would my participation involve?

All participants will take part in a semi-structured interview on the telephone. The interview date will be agreed upon at a mutually convenient time in advance.

#### Is this research funded?

This research is not funded and there is no payment for taking part in this research. It is entirely voluntary.

#### Confidentiality and anonymity of taking part

The research can assure all participants that all data will be de-identified, stored, and handled anonymously.

#### **Consent Statement**

Your verbal consent indicates that you have decided to participate in this study and you are agreeing to the information provided above and you are allowed to answer the questions.

# Questionnaire

Research Title: "COVID-19 Survivorship: A Qualitative Study of Persistent Symptoms or Long-COVID Experienced by Spinal Cord Injury Survivors in Bangladesh".

Bangladesh".			
Personal d	etails:		
Identification	on number:		
Date of CO	VID-Positive:		
Date of Inte	erview:		
1. Socio-demographic information:			
1.1	Age	years	
1.2	Gender (Put on your answer)	Male Female	
2. SCI Information			
2.1	Diagnosis		

# 3. COVID-19 and Long-COVID related information:

# **Question-1:**

3.1	Interviewer	Response
3.1.1	Please could you tell us about your experience with COVID-19?  Please pause to encourage the person to begin speaking.	
3.1.2	Optional prompt question if the person does not start talking:  Could you tell us when you were diagnosed with COVID-19 and what this experience was like?	

# **Question 2:**

3.2	Interviewer	Response
3.2.1	What were your symptoms and did they change over time?	
	Please pause to encourage the person to begin speaking.	

3.2.2	Optional prompt question if the person does	
	not start talking:	
	Do you feel that you have fully recovered or	
	not?	

# **Question 3:**

3.3	Interviewer	Response
3.3.1	Are there any symptoms that you still experience that cause problem for you?  Please pause to encourage the person to begin speaking.	
3.3.2	Optional prompt question if the person does not start talking:  Do you experience any persistent symptoms?	

# **Question 4:**

3.4	Interviewer	Response
3.4.1	What does it mean to you to have survived COVID-19?	
	Please pause to encourage the person to begin speaking.	

3.4.2	Optional prompt question if the person does	
	not start talking:	
	How has your life changed now that you have survived COVID-19?	

# **Question 5:**

3.5	Interviewer	Response
3.5.1	Would you be prepared to help develop and co-produce a supportive treatment intervention to help survivors like yourself in the future?	Yes No
	During the interview, if needed, you can use these general prompt questions:What happened next?	
	How did you feel when that happened?  I am interested in that, can you expand on it?	

# **Debriefing Sheet**

Thank you very much for kindly taking part in this research study and I appreciate your
time and help.
Now that your participation has finished, I would like to allow you to ask any questions you might have.
Is there anything that you are not sure about? If you think of any questions later on, then
you can contact me or my research supervisor Kazi Md. Amran Hossain, Lecturer,
Department of Physiotherapy, BHPI, CRP, Savar, Dhaka-1343.

This debrief document was provided in a verbal format by –	
Name of the Researcher:	
Signature of Researcher:	• • • • • • • • • • • • • • • • • • • •
Date:	
Participant Identification Number:	

## **Appendix III**

#### **Participant-1**

Patient Gender: Male

Age: 21 years

Diagnosis: Traumatic Tetraplegic ASIA A

Date of COVID-Positive: 23/07/2020

Date of Interview: 04/03/2021

Int: Assalamualaikum (Greetings)

P1: Walaikumassalam (Greetings)

Int: I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI).

I am interviewing you to know about your long COVID experience. You have been

called earlier about the interview and you have given consent to interview and record.

P1: Yes

Int: You had COVID-19, how was the experience?

P1: I can't remember the exact date. When I was affected I have been tested from CRP. I

was positive but I had no symptoms like fever, cold, or cough nothing. Just I was positive

in a routine check.

Int: When did you attend CRP?

P1: The test was nearly 5-6 months ago. June or July. I had no symptoms. I was normal.

Int: You have been tested –

You said you had no symptoms, what was your feeling that time? When did you test

negative?

P1: Yes, it was a routine check for all patients. I was released after being positive, I

returned home and re-tested after 16 days and I was negative. After being negative, I

have returned to CRP.

Int: So, you were not admitted at CRP, you came for admission and after being tested

positive, you returned home and were later admitted to CRP?

P1: Yes

Int: What type of physical illness you have experienced?

P1: No, no symptom, no physical or emotional challenge.

Int: You said you had no physical problem but were there any other challenges you faced? Physical, psychological, or social barriers?

P1: Yes, when I was positive that time I was isolated, I felt mentally challenged. But after that, no other problems I felt. Just, I was afraid on the first day.

Int: Did you experience any stigma from family or relatives or society?

P1: My parents were aware and we didn't tell the news to anyone, so I experienced no challenge.

Int: You didn't share the news, was there any reason?

P1: CRP's people told us that this is not a problem and we thought we would not let it be known to society. Also, it was a locked-down period, if we let it known to the society, the civiladministration would impose locked down to us and nobody could go out of the house.

Int: Do you have any effect of that particular event till today, like a physical problem, illness, psychological issues, or any other effect?

P1: I still remember the first day I was diagnosed. I am still afraid of the day and remember with fear. I had no symptoms but I became positive.

Int: As we are interviewing you as a part of the research, If we ask for any further assistance or contact you for any research purpose, are you willing to be contacted?

P1: Yes, I will.

Int: Thank you so much for the interview, stay well.

P1: Thank you, keep well, too.

### Participant-2

Patient Gender: Male

Age: 50 Years

Diagnosis: Traumatic Tetraplegic ASIA A

Date of COVID-Positive: 15/11/2020

Date of Interview: 04/03/2021

Int: Assalamualaikum (Greetings)

P2: Walaikumassalam (Greetings)

Int: How are you?

P2: I am fine, Alhamdulillah

Int: I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI). I am interviewing you to know about your long COVID experience. You have been called earlier about the interview and you have given consent to interview and record.

P2: Yes

Int: You had COVID-19, how was the experience?

P2: I had an accident on 27<sup>th</sup> October 2021. I attended CRP for treatment, CRP refused to treat me and advised me to take treatment anywhere (where ICU support is available); because I have dysphonic and SOB. And the ICU facility is not available at CRP. From that moment I attended many places for treatment with my family. Dhaka Medical College, Mugdha Medical (Wife added and continued---

We have been told to stay on the Dhaka Medical floor, but in the fear of bed-sore, we were admitted to a popular hospital (Private Hospital). We were there for 5 days, I had no other way (husband continued). I need ICU support, and at that time finding ICU was critical, after 5 days we were admitted to HDU, in an isolation unit. Then, we thought the Neuroscience hospital will be a suitable place. We were at Neuroscience hospital for 10 days, after admitting to neuroscience hospital, the respiratory complication gradually decreased.

Int: When did you attend CRP?

P2: 3 days after admitting HDU. (Wife continued--- he was unconscious)

After that we attended CRP.

Int: When did you test positive?

P2: We were negative at the neuroscience hospital. After admitting to CRP for 7 days, I was feeling chest tightness, fever, weakness. After that, a Chest X-ray was performed at CRP and again we were tested for COVID. And this time surprisingly I was positive again. Again we have been discharged from CRP.

Again we were admitted to Dhaka Medical College. And then again referred to Magda medical college (specialized COVID hospital) and they said you have SCI that is not a common case for us. So they again referred to the ICU facilities of Dhaka Medical College.

Indeed. It was a difficult time and our relatives were supportive. I was depressed about my condition and I thought maybe I will not survive. But I want to fight for the last time. Finding ICU was not easy. I thought if I need ICU support I have to manage anyhow.

Int: You have been tested –

You said you had no symptoms, what was your feeling that time? When did you test negative?

P2: After 15 days the oxygen level improved and self-feeding started. But we stayed at Dhaka Medical. We were admitted there 5 days after testing COVID negative for the second time. Again we were referred to CRP. My wife also had COVID symptoms and she didn't test because if she is tested positive, noone would be allowed to stay with me.

Int: So for many days, you were referred to many places?

P2: yes

Int: What type of physical illness you have experienced?

P2: I had breathlessness, headache, sore throat, vocal problem. I had so much mental stress, I was not able to move, this is continuous mental pressure till now. In the COVID-hospital, we were a patient surviving with COVID and physical disability, which created an extra burden.

Int: Your family members were supportive, what was about others?

P2: My relatives were working hard; they were not saying anything but I understood they are being fatigued (crying).

Everyone was very helpful. All of my relatives visited me and my brothers-in-law helped me when my wife became sick (cried)

Int: Do you have any effect on that particular event till today?

P2: I still remember the first day I was diagnosed. I still afraid of the day and remember with fear. I can't relate to any of the symptoms of COVID now. Also, I have a persistent SCI issue; I can't relate or distinguish the physical signs.

Int: You are now COVID negative, how do you feel now?

P2: I feel fatigued if I sit and talk. Which is the problem, I can't relate. I want to go to the bed now.

It was a difficult time; I can't express it to anyone. (Crying) I was isolated from the family. I was worried if my Kids were Positive what will be fate (crying continuously). (Drinking water)

CRP is helping us and supporting us with the utmost care.

Int: Last question

Thank you for sharing your experience. As we are interviewing you as a part of the research, If we ask for any further assistance or contact you for any research purpose, are you willing to be contacted?

P2: Yes, I will. If it opens a scope for people like us I will certainly help.

Int: Thank you so much for the interview, stay well.

P2:Thank you, keep well, too. Thank you so much.

#### Participant-2 (2nd)

Interviewer (Int.): Assalamualaikum (Greetings). I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI). I am interviewing you to know about your long COVID experience though we talked before and thank you for your kindness in giving us consent to interview you on a second occasion for more information in detail. We will record this interview for our study purposes. Have you any problem with this?

Patient 2 (P2): No, I don't have any problem. I agree.

Int: Please could you tell us what level your spinal cord injury is at?

P2: No, I can't tell.

Int: Okay. Can you control your bowel and bladder? Do feel your bladder pressure?

P2: I don't have bladder sensation but I can control bowel activity.

In the first part of your interview, you informed us that you were advised to seek ICU treatment in many places because you had problems with your voice and shortness of breath. What kind of problems did you have with your voice at that time?

P2: I couldn't remember anything at that time.

Int: Are your wife with you now? You can turn on your phone's loudspeaker so that your wife can help you.

P2: (wife) Actually at that time they said that he (patient2) might need ICU support. Because he had breathlessness and low oxygen saturation on his, so they advised us to seek an ICU facility.

Int: How low was the oxygen saturation at that time?

P2: (wife) Sometimes the oxygen saturation rate decreased to 82 or 83. And after the oxygen supply, the oxygen saturation rate increased to 90 to 92. But without the oxygen supply, the oxygen saturation could not reach 90.

Int: Could he speak at that time?

P2: (wife) He could speak very slowly. He was given medical treatment. For this, he was sleeping most of the time. But he could speak. He spoke with me very slowly. When I sat beside his bed, he spoke with me very slowly and gently.

Int: How long did he need oxygen support?

P2: (wife) 15 days. Doctors prescribed 14 injections on 15 days. After 15 days, they advised us to partially remove the oxygen supply to check that what was his responses. They also warned us never to decrease the oxygen saturation rate below 90. So, we continue this procedure as we sometimes remove the oxygen supply and when the oxygen saturation is decreased to below 90, we again give him the oxygen supply. Then after 5 days, gradually he improved and his oxygen saturation level was 97 or 96 most of the time.

Int: So, at last, you did not need the ICU support?

P2: (wife) No, at last, we didn't need to take him to ICU. Then, we went to Mugdha Medical College & hospital [a government-selected COVID dedicated hospital in Dhaka city], they told us that because he had an injury in the spinal cord, so they couldn't treat him both for spinal cord injury and COVID-19. So, they advised us to take him to the Dhaka Medical College & hospital [a tertiary hospital in Dhaka city]. So, we took him to Dhaka Medical College & Hospital.

Int: How did it make you feel when you were advised to do this?

P2: (wife) We were very worried at that time. We thought that we might be lost him.

Int: Have you ever had ICU treatment before?

P2: (wife) No, but he had CHD before. So, when he was diagnosed with CHD at Popular hospital, they told us he might need to transfer to ICU. But then we didn't need to do it.

Int: Have you ever been inside an ICU place before?

P2: (wife) No

Int: You mentioned being fearful of developing bedsores, where did this fear come from?

P2: When he was admitted toPopular hospital. His condition was so much unstable. He was in bed bound for 5 days. We tried to change his position randomly but he had too much breathlessness, when we tried to change his position, he refused to change. So, for that bedsore develop in a small area.

Int: So, you didn't need to take him to ICU. Where did you need to put him onto a ventilator machine?

P2: No. And he was unconscious all that time.

Int: From the Intensive care unit, we understand that you went into an HDU isolation unit. Do you remember anything about that time? Were you conscious? Could you speak? Int: Did you have a tracheostomy tube? Or were you breathing via your nose and mouth? P2: (wife) No, he didn't have a tracheostomy tube. But he was feeding by nasal tube.

Int: From the HDU, we understand that you went into the Neuroscience hospital. How was your breathing at that time? Did you have any shortness of breath? Could you talk

normally?

P2: (wife) Yes, from the first day at neuroscience hospital he had oxygen support. At first, he needed 5 liters of oxygen per day. Gradually it decreased to 2 liters. Then they advised us to take him CRP.

Int: So, you told us that when he was in Dhaka medical college hospital, he had an oxygen supply, and also, he had a low oxygen saturation level. Then you took him popular hospital and then a Neuroscience hospital?

P2: (wife) No, at first, we took him to CRP from Khulna hospital. Then we took him to Neuroscience hospital from CRP because his condition was very critical. But Neuroscience hospital refused to admit him because they had no seat. Then we went to Dhaka medical college hospital. They gave us a seat there on the ground floor. So, we took him out there and then admitted him toPopular hospital. We stayed at Popular hospital for 5 days. After that, we managed to admit him to Neuroscience hospital. We were in 10 days there. Then we admitted him to CRP. At that time, he has diagnosed with COVID-19. So, we took him to the Mughda medical college hospital. They (doctors from Mughda medical college hospital) told us he would be in ICU support because he had a spinal cord injury in the cervical region and was also affected by COVID. So they advised us to take him to Dhaka medical college hospital. So, we admitted him again to

the Dhaka medical college in the COVID unit. He was in there for 21 days. After 14 days, he tested COVID negative and his oxygen saturation level was gradually at good level. When he tested COVID negative, doctors told us to take him out of there as early as possible because it was safe for him. Then after 6 to 7 days, we released him from there and again admitted him to CRP.

Int: In your first interview, you mentioned that at one stage, you felt depressed and were not sure if you would survive. Could you explain why you thought you might not survive? What was it that made you think that?

P2: (wife) he had no consciousness and continuously had breathlessness. He couldn't move his limbs. And then he was affected by COVID-19 also. So, we were very frustrated, depressed. We thought that he might not be survived.

Int: You also made a comment that you wanted to fight. What made you take that attitude? Were there some particular aspects that made you choose to "fight"?

P2: (wife) Yes, my 4 brothers were with us all the time. My other relatives also supported us. They encouraged us. And my brothers helped me both mentally, physically, and financially.

Int: When you (wife) developed some typical covid symptoms – what were those symptoms?

P2: (wife) Yes. I had a mild fever, weakness, I didn't smell anything.

Int: When this happened, we understand that you chose not to have a COVID test, because if the result was positive, then you would not be able to stay with him and help him. Was it commonplace and well known by other people at that time, that if a test came back positive at that time, then the person would be advised not to have contact with any others and have to self-isolate?

P2: (Wife) after he was admitted to COVID unit Dhaka medical college, then some days I have also had COVID-like symptoms. It was COVID dedicated ward. There was a total of 5 patients' capacity per ward. Yes, I knew the fact the self-isolation. But already I was in an isolation ward with my Husband (patient 2). So, I thought that I didn't need the COVID test at that time. If I tested positive, my brothers and others members would be more nervous. After 14 or 15 days when my husband tested negative then I gave my COVID sample and I got negative results. Then I decided to admit him to CRP again.

Int: Do you think that there was a negative stigma toward people who received a positive covid test result at that time? If so, do you think that this is still the case?

P2: (wife) Negative stigma is common in people for COVID testing. Because it is a communicable virus and it can transmit. Those who helped us at that time were very courageous.

Int: In your first interview, you commented on a range of covid symptoms that you experienced. Could you please give a little more detail on these?

P2: (wife) He has shortness of breath. He has a spinal cord injury in the cervical region. After coming to CRP, I came to know that it was common for spinal cord injured people in the early stages. Other's symptoms were not persisting now.

Int: You mention a headache – where did you feel the pain? Could you describe how it felt? Did anything help?

P2: (wife) No, he doesn't have a headache now.

Int: You mention a sore throat, how did that feel? Did it last a long time?

P2: (wife) Yes, he had a sore throat. But I couldn't remember the exact days. It might be lasting for 10 to 12 days after he tested COVID positive. After getting negative results, it might last for some days but not as severe as before.

Int: Can you tell your husband to speak to us?

P2: (wife) Yes.

Int: Do you have any symptoms after getting negative?

P2: Yes. I have thirsty feelings all the time. When I had COVID positive, I had a thirsty feeling also.

Int: You mentioned fatigue and that you felt fatigued if you sat and talked and that it made you want to go to bed. Could you describe how the fatigue felt? Where did you feel the fatigue in your body? Was it a physical and /or mental fatigue? Both?

P2: Yes, still now I can't talk and sit at a time. I am still in bed.

Int: Did you experience fatigue all day? Did it come and go? Did it vary? Did you experience fatigue every day? Do you still experience fatigue? Does it stop you or interfere with you doing tasks?

P2: Yes.

Int: Do you experience any new anxieties that perhaps you did not have before?

P2: Yes, I have anxieties.

Int: Do you experience any new difficulties with sleep that you did not have before?

P2: Yes, I have difficulty sleeping.

Int: This been happening since your COVID testing?

P2: No, When I was sick. I didn't remember.

Int: Do you experience any new difficulties with your mood that you did not have before?

Int: In your first interview, you mentioned feeling isolated. Do you still feel isolated? Or

has this changed?

Int: Also, you mentioned that you were worried about whether your children might catch COVID-19, are you still worried about this now?

P2: Yes.

Int: Have you or your wife, and/or members of your family been offered the vaccine against COVID-19?

P2: No.

Int: If offered, would you take the vaccine? Do you think that vaccination will help make social situations safer?

P2: Yes. It is good.

Int: Have you experienced any problems with sleep since being diagnosed positive with COVID-19?

Int: Have you experienced any nightmares that you think may be related to your experience during your recovery?

P2: Yes, sometimes I have nightmares.

Int: Do you have any new fears since you recovered that you didn't have previously?

P2: Yes. I feel pressure on my chest sometimes.

Thank you very much for your kindness in supporting this research.

## Participant-3

Patient Gender: Female

Age: 25 Years

Diagnosis: Traumatic Paraplegic ASIA A

Date of COVID-Positive: 23/07/2020

Date of Interview: 04/03/2021

Interviewer (Int.): Assalamualaikum (Greetings).

P3: walaikumassalam (Greetings)

Int.: I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI). We are conducting a study about the experience of COVID-19 positive participants among people with SCI. At first, I have to ask you, when did you diagnose COVID-19 positive? And what was the experience?

P3: Actually, I couldn't remember the exact date of my COVID-19 positive. But when I have SCI, 20 to 25 days later I was diagnosed COVID-19 positive. In these 20 to 25 days I was suffered a lot.

Int.: So, you diagnosed COVID-19 positive 20 to 25 days after your SCI.?

P3: I have SCI on 10<sup>th</sup> June 2020 and I was diagnosed with COVID-19 positive in July.

Int.: So you have SCI in June and got the COVID-19 positive test in July?

P3: Yes.

Int.: What happened after you diagnosed COVID-19 positive?

P3: when I got my positive result, CRP did not want me to stay here. I offered to keep myself in a separate room. But the answer, if they did this, they had to answer to the government. They suggested Igo to the Kurmitola Specialized Hospital. But I didn't agree to go to the Kurmitola hospital and went back to my home.

Int.: okay, then you didn't get any treatment from others' side during this time?

P3: No, I received treatment at my home.

Int.: when you went back to your home from CRP after being diagnosed with COVID positive, what were your physical symptoms, and what kinds of mental problems you faced from your surroundings?

P3: As I was already affected by SCI and then diagnosed COVID-19 positive so my mental status was very much unstable as well as my physical condition. I had a poor physical condition and I was getting support from my family.

Int.: Did you get support from your family and others like neighbors or relatives?

P3: I was getting support from my family but I could not get any help from others. I was in a separate room and I was isolated.

Int.: what were the physical symptoms you experienced?

P3: I was physically very weak at that time. I lost my appetite and I had a fever. But I didn't have any cough or cold-like symptoms.

Int.: and what about your family support you want to tell earlier?

P3: I was mentally broken at that time. My parents, my siblings support me very much.

Int.: when you diagnosed COVID-19 positive, you faced a lot of bitter experiences like a stigma. Do you face any family or social stigma till now?

P3: No, I was physically very weak at that time. My husband was away from me at that time. My parents and my siblings helped me a lot. But I couldn't get any support from my neighbors even from my relatives. They didn't contact us. There was pressure on my family. My family was isolated. My relatives didn't visit us. Now we recovered from this. I do not face any previous experiences now. Because I have the COVID antibody in my body. Now if I want, I can save others.

Int.: How do you feel now after getting recovered from COVID-19?

P3: It was a blessing from Allah. Allah saved my life two times from death. My parents and my well-wishers might pray for me a lot.

Int.: As we are interviewing you as a part of the research, If we ask for any further assistance or contact you for any research purpose, are you willing to be contacted?

P3: Yes, I will.

Int.: Thank you so much for the interview, stay well

P3: Thank you.

### Participant-3 (2nd)

Interviewer (Int.): Assalamualaikum (Greetings). I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI). We talked before. Thank you for your kindness in giving us consent to interview you on a second occasion for getting more information.

Please could you tell us do you have bowel bladder control?

Patient 3 (P3): Yes, have bowel bladder control. I removed my catheter on 10<sup>th</sup> April. And now, I can control my bladder also.

Int: In your first interview, you mentioned that when you received a positive COVID test result, you were asked to leave CRP. Could you explain this a little more? Why was this?

P3: When I got my positive result, CRP did not allow me to stay there. I offered them to keep me in a separate room. I had my family members take care of me, they didn't take care of me. I just asked me to keep me in a separate room. But they told me, they didn't have the facility to keep the COVID patients. Yes, I know, that COVID is dangerous but they could allow me in a separate room there. They suggested I to go to the Kurmitola Specialized Hospital. I am an SCI patient and it was difficult for me to go there. So, I went back to Chittagong my home.

Int: When you went home, you mentioned that you were in a separate room and were isolated. How did the isolation work? Were you alone and noone came into the room? How did you manage to eat? Could you speak with anyone? Did you use a phone?

P3: Yes, it was self-isolation. I am educated so I knew when I need to do that. I was in a separate room in my home. My family came to visit me every day. They provided me with food, medicine, and other necessary things. Yes, I could also contact them when I need them. I had a phone to talk.

Int: You mentioned that you received support from your family but not others like neighbors and relatives. Do you know why this might have been? We understand that your neighbors and relatives did not contact you to offer support. Do you have any ideas why they did not offer support to you and your family?

P3: Yes, because I was affected by COVID-19. As it is a dangerous virus, anyone can be infected by the affected person. So, our neighbors and relatives got fear that if they came to help us then they might be infected by me.

Int: Do you think that there was there any negative reaction and/or stigma towards someone with a positive COVID test result?

P3: Yes, it was very common for COVID-positive patients in our country at that time. People had a negative stigma for COVID-positive patients because of the nature of viruses.

Int: In your interview, you mention that you were physically very weak. Can you give any more details on this?

P3: I had a spinal cord injury at that time and was also diagnosed with COVID-19. So, I was weak physically, because my condition was good at that time.

Int: In your interview, you mention that you were mentally broke at that time. Can you describe what you mean by this?

P3: I was mentally broken because I couldn't get to admit myself for better treatments.

Int: In your interview, you mention that your husband was away at that time. Where was he? Do you think that you would have felt better if he had been around at that time?

P3: He works in a foreign country as a remittance worker. On that, he was in his working country. He was not present with me at that time. If he was with me, it would be supporting. He phoned me every time.

Int: You mentioned some symptoms in your interview. Apart from those symptoms, did you experience any shortness of breath at all? If so, when? How long did it last? Did it interfere with any activities?

P3: I had only fever and cough symptoms. The fever was mild and also had a mild cough. Fever and cold lasted for several days. I couldn't remember exactly. Maybe 5 to 6 days lasted the fever. The mild cough was lasting for 15 to 20 days. I had also a loss of appetite and I didn't have the smell. It was lasting for some days. I couldn't exactly remember.

Int: Did you experience fatigue? If so, what did it feel like? When?

P3: A little fatigue. Still

Int: Do you still experience any symptoms like shortness of breath?

P3: No, I don't.

Int: Do you experience any new anxieties that perhaps you did not have before?

P3: Yes, I am anxious that when I will get improvement from this spinal cord injury.

Int: Do you experience any new difficulties with sleep that you did not have before?

P3: No. But when I was in bed for a long time, I felt mild pain in my back.

Int: Do you experience any new difficulties with your mood that you did not have before?

P3: No, I don't have that.

Int: Have you or your husband, and/or members of your family been offered the vaccine against COVID-19?

P3: Yes, my others family members got the vaccine. But I couldn't get the vaccine.

Int: If offered, would you take the vaccine? Do you think that vaccination will help make social situations safer? Do you think that people are aware of the benefits of vaccination or not?

P3: Yes, of course. Vaccines keep people safe.

Int: Have you experienced any problems with sleep since being diagnosed positive with COVID-19?

Int: No. I haven't experienced this.

Have you experienced any nightmares that you think may be related to your experience during your recovery?

P3: No, sometimes had nightmares but that was present before diagnosed COVID-19

Int: Do you have any new fears since you recovered that you didn't have previously?

P3: No, I am mentally strong.

Thank you very much for your kindness in supporting this research.

### Participant-4

Patient Gender: Male

Age: 53 Years

Diagnosis: Traumatic Paraplegic ASIA A

Date of COVID-Positive: 18/08/2020

Date of Interview: 04/03/2021

Interviewer (Int.): Assalamualaikum (Greetings)

P4: walaikum assalam (Greetings)

Int.: I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI). We are conducting a study about the experience of COVID-19 positive participants among people with SCI. Please tell us when you were diagnosed with COVID-19 and what were your experiences?

P4: I have been diagnosed with COVID-19 probably on 18<sup>th</sup> August. I can't remember the exact date but might be 18<sup>th</sup> August I gave my sample in CRP for COVID-19 testing, and the next day I got my positive report. After that CRP released me. I went back to my home. I had fever and cough symptoms when I was diagnosed positive and I didn't have any other symptoms.

Int.: what had you done when you went back to your home?

P4: yes, I stayed at my home. I was quarantined for 23 days. My wife was with me. We were staying in the same room. Then my wife got affected too. She was diagnosed with COVID-19 positive and we spent 23 days quarantine in the same room. We have mild symptoms, so I think that would save us.

Int.: when you diagnosed COVID-19 positive what were the physical symptoms and as well as what were the mental problems you had faced?

P4: I had faced more financial problems rather than mental or physical. When I came back with my COVID-19 positive report, nobody came to see me. My relatives, my neighbors everyone avoided us, avoided my family. One day, UNO came to my home, and issue me a home quarantine notice, and mounted a red flag on my home. I only got 10kg of rice as a relief. Then by the grace of Allah, I gradually recovered from that.

Int.: so, you and your wife both were in quarantine at the same time?

P4: yes. My son lived here in a separate room. He cooked for us. But no one came to my home to help us. I felt very sad at that time. When they heard that I was infected by the coronavirus, they did not come to help. Nor my siblings, my relative, my neighbors no one came forward to me.

Int.: Please tell us what was the symptoms at that time?

P4: I had mild symptoms. I had a low-grade fever, cough. My wife had a high fever, cough, cold. I also had a sore throat but that was mild. My wife had body pain. And I did not feel any other symptoms. I was already an SCI patient; I could not move anywhere. I did my toilet activities on my bed. My wife was with me all the time. She took care of me, maintained my hygiene.

Int.: So you were in 23 days quarantine when you diagnosed COVID-19 negative?

P4: After completing my quarantine time, I phoned the Upazilla Health Complex to test me again. The next day, they came to my home and took the sample. 3 days later I was informed that I was diagnosed with corona negative. I was informed via SMS.

Int.: did you have the same symptoms all the time or did they change over time?

P4: yes. I had a fever for around one week. I continued my prescribed drugs from CRP. And I am also an L.M.A.F (rural health alliance). So I continued my prescribed drugs, and then I am recovered gradually.

Int.: are there any symptoms that you still experience those cause problems for you?

P4: I can't grip properly still now. My lower-extremity is paralyzed. I can't sit independently. I do my toilet activities on the high commode. I do my prayer sitting on the chair.

Int.: Once you were in isolation from others. You faced many mental problems at that time. Do you still experience the problem?

P4: No, I am fully recovered now. I do not have any negative feelings for those. I have the vaccine last 18<sup>th</sup> February.

Int.: As we are interviewing you as a part of our study, so If we ask for any further assistance or contact you for any study purpose, are you willing to be contacted?

P4: Yes, I will.

Int.: Thank you so much for the interview.

P4: Thank you.

### Participant-4 (2nd)

Interviewer (Int.): Assalamualaikum (Greetings). I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI). We talked before and thank you for your kindness in giving us consent to interview you on a second occasion for more information in detail. We will record this interview for our study purposes. Do you agree?

Patient 4 (P4): yes, I agree.

Int: Please could you tell us what level your spinal cord injury is at?

P4: I had an injury in C5 and L3. At first, I went to a neuroscience hospital after my injury. From there they referred me to CRP. 5 days after my admission to CRP, I was tested COVID positive. They released me from CRP.

Int: okay. Do you have bowel bladder control?

P4: Previously I had no bowel bladder control. But now I am improving.

Int: In your first interview, you mentioned that you had a fever and cough as symptoms?

P4: Yes. I had also a loss of taste of food. Also, I didn't smell anything

Int: How long did it be lasting?

P4: More than a week.

Int: Did you have any shortness of breath?

P4: No, I didn't have shortness of breath when I was COVID positive. I have asthma. My mothers also had asthma. Though I have mild asthma and mild shortness of breath nowadays I had no shortness of breath when I was COVID positive.

Int: In your first interview, you mention that you went home from CRP. We understand that your wife became infected and was staying in the same room at your home. Can you remember if you were given any advice about how to quarantine and self-isolate?

P4: No, we decided to go self-isolation. Then our local Chairman, members lockdown our house because I and my wife were COVID at that time. So, they lockdown my house.

Int: You mention that when you went home, noone came to see you and they avoided you. Was this because you had been diagnosed with COVID-19 positive? You mention that your siblings, relatives, and neighbors did not come forward to offer help. Do you think that this is because of a negative attitude/stigma toward someone with a positive diagnosis of COVID-19?

P4: Yes. When I tested COVID positive, no one came to see me and help me. I couldn't get any support from them. Not even mental support. Then when my friends came to know that, they helped me both mentally and financially.

Int: You also mentioned that UNO put a red flag on your home. Where did they put the flag?

P4: Yes, UNO issued the lockdown. And they put a red flag in my main gate.

Int: What was the purpose of the flag?

P4: Red flags mean COVID-affected people are living here. No one can enter the house.

Int: How long did it remain there? Has it been removed now? What effect did it have at that time?

P4: My house was in lockdown for 14 days. They advised me to remove the flag after 21 days. So after 21 days, I removed the flag from my main gate.

Int: What was the effect of that red flag on you and your family whilst it was there?

P4: I took it positively. Because the people in my area are unconscious about health safety. When they saw the red flag, they could not dare to enter. One of my neighbors was affected by COVID and then died 6 months later. Though he had heart and kidney problems before.

Int: In your interview, you mention that you faced financial problems and only got 10kg

of rice as a relief. Can you give us more detail on the financial problems? How frequently did you receive the relief of rice?

P4: I had received the relief just one time from our local Union Parishad Office.

Int: Did you experience any physical or mental fatigue?

P4: No, I don't have any physical problem. Just I have felt that my asthma symptoms are increased rather than before. Not too much.

Int: Do you have any other physical problems?

P4: I had 2 rings in my heart. When I went to Qatar in 2015, I had a heart attack. Then I got 2 rings in my heart from there.

Int: Do you experience any new anxieties that perhaps you did not have before?

P4: No.

Int: Do you experience any new difficulties with sleep that you did not have before?

P4: No.

Int: Do you experience any new difficulties with your mood that you did not have before?

P4: I think I may be having some brain problem nowadays. Like I get suddenly angry, that was not present before.

Int: Have you or your wife, and/or members of your family been offered the vaccine against COVID-19?

P4: Yes, I was vaccinated on Feb 18. My mother also got the vaccine. My wife couldn't get the vaccine because her age is not over 60 years. When she gets an offer, she will get the vaccine also.

Int: Do you think that vaccination will help make social situations safer? Do you think that people are aware of the benefits of vaccination or not?

P4: Yes, I am positive about vaccination. Because it is pandemic time. Others also get the vaccine. It will be good for us.

Int: Have you experienced any problems with sleep since being diagnosed positive with COVID-19?

P4: No, I don't have a sleeping problem.

Int: Have you experienced any nightmares that you think may be related to your experience during your recovery?

P4: No.

Int: Do you have any new fears since you recovered that you didn't have previously?

P4: No, I don't have any fear now.

Int: Thank you very much for your kindness in supporting this research.

### Participant-5

Patient Gender: Male

Age: 41 Years

Diagnosis: Traumatic Paraplegic ASIA B

Date of COVID-Positive: 21/08/2020

Date of Interview: 04/03/2021

Interviewer (Int.): Assalamualaikum (Greetings). How are you now.?

P5: walaikumassalam (Greetings). I am fine now by the grace of Allah

Int.: I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI).

We are conducting a study about the experience of COVID-19 positive participants among people with SCI. You had been diagnosed COVID-19 positive once a few months earlier, we want to know about your experiences at that time.

P5: yes, I understand.

Int.: First, tell us when you diagnosed COVID-19 positive, how was your experience at that time?

P5: I was diagnosed with COVID positive after 10 to 15 days of admission in CRP.

Int.: when you admitted to CRP?

P5: in October.

Int.: then what happened?

P5: after 10 to 15 days of my admission to CRP, I was tested positive. Then I was referred to Dhaka Medical College Hospital. I was getting my treatment there.

Int.: what were the symptoms that you experienced at that time?

P5: I had very mild symptoms. I had a mild cough, mild cold symptoms. I did not have diarrhea or a sore throat. But I had cough problems.

Int.: How long have you had to face the problem?

P5: I had a cough around 20 to 25 days long. Then I recovered from it.

Int.: then what had you done?

P5: then I went to Dhaka medical college hospital. I had my spine surgery there.

Int.: Do you still experience any symptoms that cause problems for you?

P5: no, I have not anything symptoms like that. But now I have a stomach ache. And I am worried about this.

Int.: so what were your feelings when your recovery from COVID-19?

P5: I heard that many people died from coronavirus. I was worried at that time. After recovery, now I am feeling good.

Int.: As we are interviewing you as a part of our research, so If we ask for any further assistance or contact you for any research purpose, are you willing to be contacted?

P5: Yes, I will.

Int.: Thank you so much for the interview.

P5: Thank you.

### Participant-6

Patient Gender: Male

Age: 28 Years

Diagnosis: Traumatic Paraplegic ASIA B

Date of COVID-Positive: 13/08/2020

Date of Interview: 04/03/2021

Interviewer (Int.): Assalamualaikum (Greetings).

P6: walaikum assalam (Greetings).

Int.: I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI). We are conducting a study about the experience of COVID-19 positive participants among people with SCI. You had been diagnosed COVID-19 positive once. You have been called earlier about the interview and you have given consent to interview. First please tell us when you diagnosed COVID-19 positive. Can you share with us how was

your experience?

P6: when I went to CRP for admission, then I was tested for. I got a positive report from that test. Then I came back from CRP. After returning from CRP, I was tested again for

COVID-19 but I got a negative result. I could not understand why I was tested positive in CRP. I was tested negative before going to CRP.

Int.: that means before your admission in CRP, you were tested COVID-19 negative?

P6: Yes.

Int.: then when you were admitted in admission, you tested COVID-19 positive?

P6: yes.

Int.: when you went back to your home, then you tested again and got a negative result?

P6: yes.

Int.: what were your symptoms?

P6: I did not have any physical symptoms like fever, cold or cough, sore throat.

Int.: when you tested COVID-19 positive did you experience mental problems?

P6: No.

Int.: Okay. Did you feel any upset about your surroundings people's behaviors towards you?

P6: No, I did not feel any of these.

Int.: did feel hurt by any of your family members?

P6: No. My family members knew everything. So there were not any problems.

Int.: So, did you have any impact on yourself when you diagnosed COVID positive?

P6: No. there was not much impact on me. When I was in the hospital, some people negatively saw me. Some were not wanted to touch me.

Int.: so that experiences hurt you?

P6: yes.

Int.: As we are interviewing your recording as a part of our research, so If we ask for any further assistance or contact you for research purposes, are you willing to be contacted?

P6: Yes, I will.

Int.: Thank you so much for your time.

P6: Thank you.

### Participant-7

Patient Gender: Male

Age: 18 Years

Diagnosis: Transverse Myelitis Paraplegic ASIA C

Date of COVID-Positive: 15/09/2020

Date of Interview: 04/03/2021

Interviewer (Int.): Assalamualaikum (Greetings)

P7: walaikumassalam (Greetings)

Int.: I amMd. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI).

We are conducting a study about the experience of COVID-19 positive participants among people with SCI. Please tell us when you were diagnosed with COVID-19 and can you share with us what were your experiences?

P7: After going to CRP for getting admission, I was tested COVID-19. From there I was diagnosed COVID-19 positive.

Int.: when you diagnosed COVID-19 positive, then what had you done at that time?

P7: I was at home.

Int.: that means you were in your village home or other places?

P7: we rented a flat close to the CRP area.

Int.: did you receive any kinds of treatments?

P7: No, I was staying at home. I did not receive any treatment.

Int.: did you feel any symptoms at that time?

P7: No, I did not feel any physical problems.

Int.: so you did not have any physical symptoms. But many people faced some mental stress at that time. Did you feel any kinds of mental stress or problems?

P7: No.

Int.: did you face any stigma from your family, your relative, or your neighbors that you are still experiencing?

P7: No, I did not have any.

Int.: when you diagnosed COVID positive, your family members were with you?

P7: No. Only my mother stayed with me at that time.

Int.: did your neighbors know that you were COVID-19 positive?

P7: No.

Int.: Didn't you tell anybody that you were COVID-19 positive? Did nobody know about it?

P7: Only a few people knew that. Might be one or two people who know about that and they lived with me in the same flat.

Int.: did you face any problems from them?

P7: no.

Int.: do you want to tell anything about the coronavirus?

P7: No.

Int.: Do you still experience any symptoms?

P7: no

Int.: As we are interviewing you as a part of our research, so If we ask for any further assistance or contact you for any research purpose, are you willing to be contacted?

P7: Yes, I will.

Int.: Thank you so much for the interview.

P7: Thank you.

### Participant-8

Patient Gender: Male

Age: 19 Years

Diagnosis: Traumatic Tetraplegic ASIA A

Date of COVID-Positive: 01/09/2020

Date of Interview: 04/03/2021

Interviewer (Int.): Assalamualaikum (Greetings). How are you?

P8: walaikum assalam (Greetings). I am fine now.

Int.: I am Md. Obayadur Rahman Noman, B.Sc in Physiotherapy 4<sup>th</sup> year student (BHPI).

We are conducting a study about the experience of COVID-19 positive participants among people with SCI. You have been called earlier about the interview and you have given consent to interview and record. At first please tell us when you diagnosed COVID-19 positive. Can you share with us how was the experiences?

or the positive can you share with as now was the emperiores.

P8: Probably it was  $4^{\text{th}}$  or  $5^{\text{th}}$  September I was diagnosed corona positive.

Int.: where did you had done your test?

P8: in CRP hospital. Then they release me from there.

Int.: where did you refer from CRP?

P8: I was told to stay at my home from CRP. But my physical condition was very bad. So I was admitted to a Clinic in Savar and continued my further treatments from there.

Int.: Okay. So when you diagnosed COVID-19 positive, what were the physical and mental problems you had faced?

P8: I did not feel severe symptoms. I had no high-grade fever, cold, cough, or sore throat. I only felt a low-grade fever.

Int.: so, you had only a mild fever. But did you feel any mental problems? Because stigma was a very common familial problem that the COVID-19 survivors experienced?

P8: No, I did not have any of these problems. Because the doctor assured me that I would get recover from that.

Int.: What were the experiences you face from your family members, relatives, or neighbors during that time?

P8: I was only 19 years old when I became an SCI person. That's the main problem for me.

Int.: Which kinds of treatment did you receive from the clinic in Savar, that you admitted at that time?

P8: I treated my SCI there. I had my spine surgery there.

Int.: So, when you had your spine surgery, you were COVID-19 positive at that time. How does the hospital authority allow it?

P8: actually, I am telling you the truth. My corona positive report was not submitted to the hospital. We did not tell the hospital authority that I was corona positive.

Int.: so that was your interesting experience. You hid your corona positive report because you need surgery at that time. If hospital authorities came to know that, then they would not allow it?

P8: yes, of course. If hospital authority knew I was corona positive they did not allow me to admit there.

Int.: have you done your COVID-19 test again?

P8: No, I did not do any test again. After my surgery, I came back to my village and started using a wheelchair. I visited the doctor here. The doctor prescribed me medicine and I am continuing these drugs.

Int.: okay. Are there any symptoms that you still experience that cause problem for you?

P8: no, no. I have no physical symptoms like fever, cough, cold right now.

Int.: how were your experiences that you have survived COVID-19? Do you face any mental problems till now?

P8: yes, of course. If I was not diagnosed positive at that time, I might be getting admission to CRP. And I could continue my treatment there. It was very costly for me to get treatment from a private clinic. If I was not tested positive, I could admit to CRP and could receive better cost-effective treatment.

Int.: so you had faced financial and mental problems due to COVID-19?

P8: yes.

Int.: As we are interviewing your recording as a part of our study, so If we ask for any further assistance or contact you for any study purpose, are you willing to be contacted?

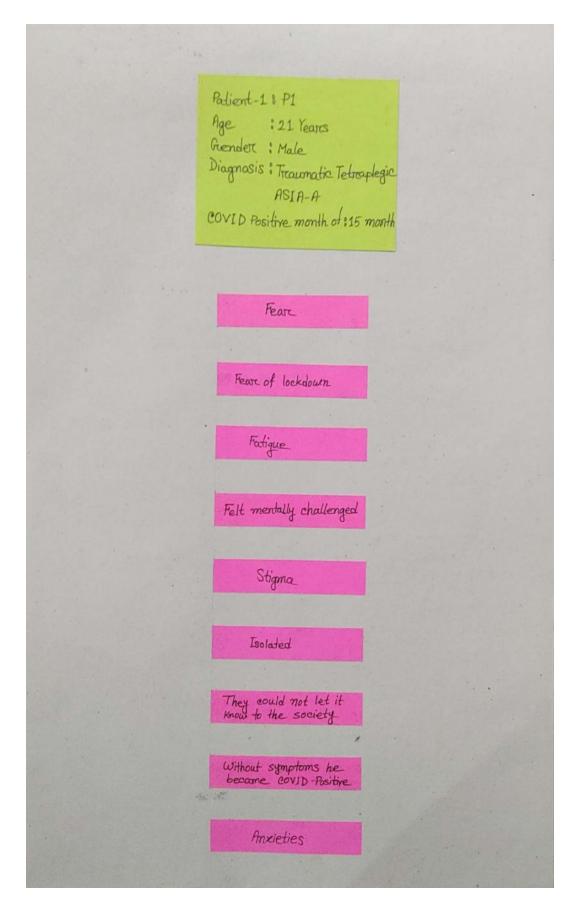
P8: Yes, I will.

Int.: Thank you so much for the interview. Take care

P8: Thank you.

# **Appendix IV**

# Covid-19 Survivorship: A Qualitative Study of Persistant symptoms on Long-COVID Experienced by Spinal Cored Injury Survivors in Bangladesh".



Patient - 2: P2

Age: 50 Years

Gender: Male

Diagnosis: Traconatic Tetraplegic

ASIA-A

COVID Positive month of: 11 month

-		
Fever	Anxieties	
Breathlessness	Mental stress	
A STATE OF THE STA		
Chest tightness	Negative stigma on COVID	)
Loss of smell	Bed some	
Low oxygen saturation	Sleeping most of the time	
Vocal problem	weakness	
Dysphonic	Physically disable	
Respircatory complication	- Loss of consciousness	

Required 5 liter oxygen per day	Loss of bladder sensation
	74 1 1 1 1 h
Speak very slowly and gently	Unable to move his limb
Feeling pressure on his chest	Fear of COVID test
Feeding by nasal tabe	Nightmarres
Some thomat	Sleep disturbance
Headache	In sitting position he can't talk
11 Oliverie	talk
Fatigue &	Have some persistant ScI issue
Thirosty Jeelings	Self isolation
Shortness of breathing	No vaccination due to severity

	-31 P3
Ondon	:25 Years : Female
Diognos	is: Tramatic Paraplegia
0	ASIA-A
COVID F	bsitive month of 115 month

Fever.	Physically very weak
cough	Poore physical condition
Loss of smelling	Now mentally strong
Falique	Self-isolation
Loss of appetite	Mentally unstable
Bed some	She was mentally broken, her parcents and siblings support here
Anascious	Montally unstable couldn't get to artmit here fore bettere treatment
She didn't get support from here neighbours and reclatives	long-time in bed, I selt mild pain on my back
Batoria diagnosed coviding the had nightmores	

Padient-4: P4	
Age:53 Ye	ATC.
Gender : Male	
Diagnosis : Treasm	natic Paraplegic.
ASIA- COVID Positive more	th od : 14 month
Mild cough	P. 19. 1
The cough	Positive In Vaccination
loss of smell	thigh commode
Some throats	Lower extremity is paralyzed
Loss of teste	UNO put a ned flag at
Loss of teste	his home
Mild Astlona	Nobady came to see him
Mild shortness of breadhing.	Brain Problem
- Love-grade Feren	Did toilet activities on his bed
0	
Mentally unstable	Social stigma of COVID®
8	
Can't grip properly	Sudden angere
- Can't sit independently	Fully recovered no negative feelings
,	Ticyative the op
No bowel bladders	His falends helped him
control	mentally & financially
Self isolation	

Patient-5: P5 Age : 41 Years Grender : Male Diagnosis: Troumatic Paraplegic ASIA-B COVID Positive month of \$12 month Mild cough Mild cold Cough lasting 20 to 25 days SCI Related Problem Dying of people due to covid made him wornied Stomach Ache Spinal 'surgery

Patient 6: P6 : 28 Years Gender : Male Diagnosis : Traumatic Paraplegic ASIA-B COVID Positive month of: 14 month Incorrect COVID positive result pressurized him months Negative impression at cpp and society Social isolation at CRP and society Physically and mentally stable No symptoms

Patient-7: P7

: 18 Years

Age: 18 Year Greender : Male

Diagnosis: Transverse Myelitis

Paraplegic ASIA-C COVID Positive month of:13 month

They didn't let to know the society as he was covID4) Patient

Did not face cony stigma from the society

Self isolation (He and his mother)

Patient 8: P8

Age: 19 Years

Grender: Male

Diagnosis: Tramatic Tetraplegic

ASIA-A

COVID Positive month of: 13 month

Only mild Sever

Hide COVIDAND report

Social stigma of COVID positive report

-Spinal surgery

Mental problem

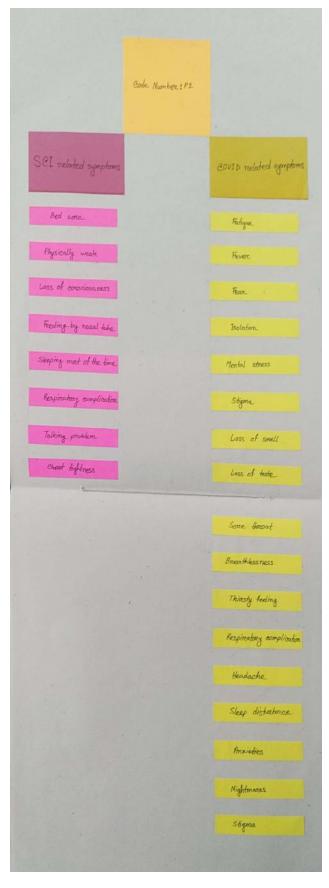
SCI was his main problem

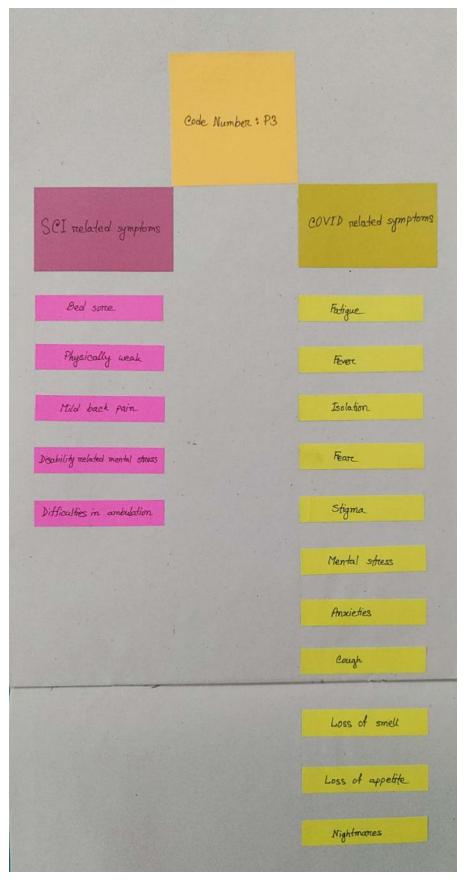
Financial problem

Wheelchain bounded

No cough , cold , some throat









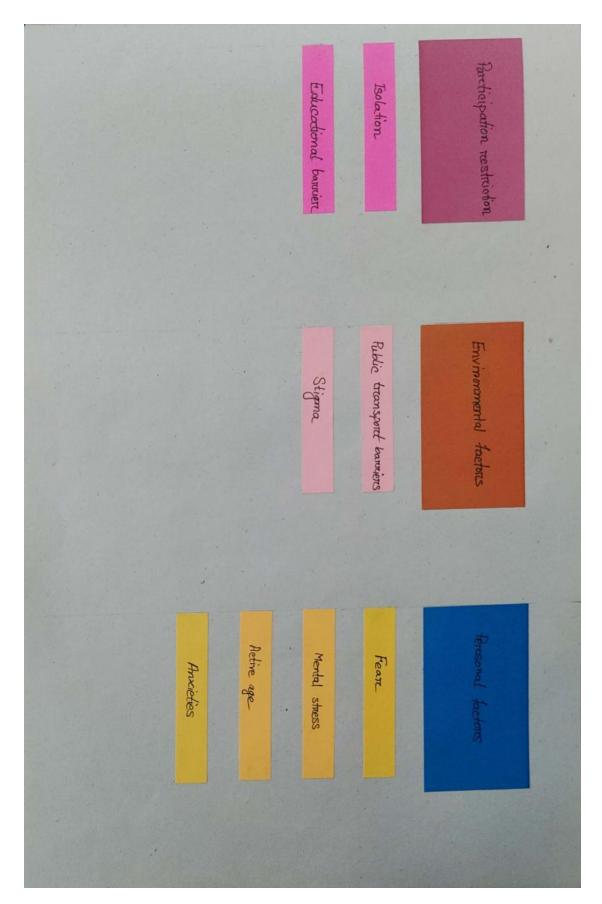
	Code Numbert: P5	
SCI related symptom	2.	COVID related symptoms
Difficulty in walking		Factique
Wheelchain bounded		Feverc
Genesping Problem		Feare
Bed some		Anxieties
Stomach ache		Cough
Difficulties in ambulation		

	Code Number: P6	
		The state of the s
SCI related symptoms		COVID related symptoms
SCI HEIGHES GRAPIONS		8,1
Difficulties in ambulation		Fotique
Wheelchair bounded		Isolation
P. C		Mental stress
Weakness in lower limb		region areas
		Anxieties
		Myseucs
		Chinese
		Stigma

	Code Number: P7	
SCI related symptoms		COVID related symptoms
Weakness in lower limb		Isolation
Poor balance		Fearc
Unable to stand independently		
Use elbow crutch to walk		
Pain at knee joint		

	Code Number: P8	
SCI related symptoms		COVID related symptoms
Difficulties in ambulation		Fatigue
Wheelchaire bound		Fevere
Lioss of bowel bladder confiol		Bolation
Greasping problem		Feare
Financial Problem		Mental stress
		Stigma

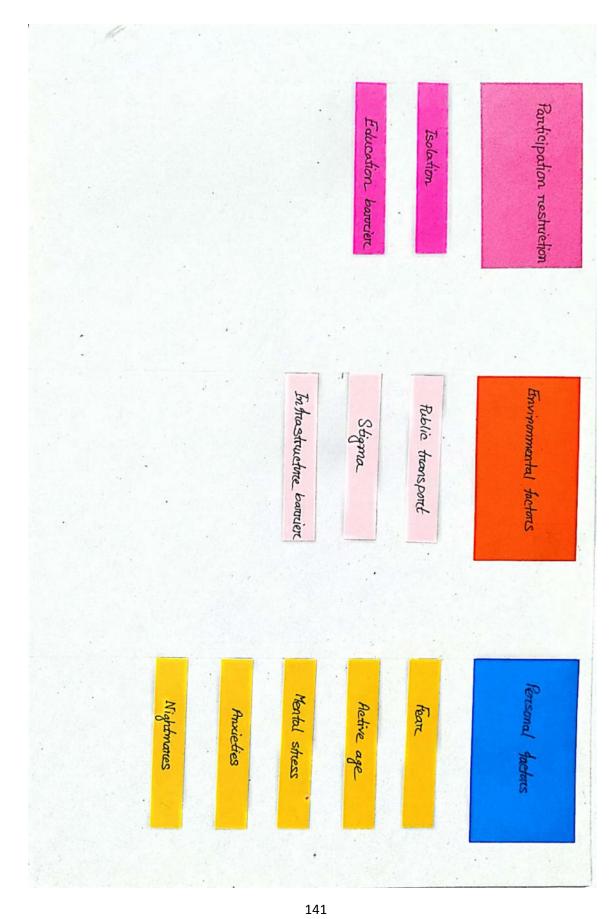
Body Shuestone or Activities in a (IEF)—Remerched SCI  COVID positive peoples survivanship  Lass of bowel bladen embal  Fadigue  Fadigue						
			(ICF)-Generated SCI COVID positive peoples survivorship	Coole Number - P1		
Activities in a difficulties in a	Fadgue	Loss of bowel bladden embrol	Weakness in lower limb	Wheelshair bound	Body Structure or	
Activities in a						
mirlachin				difficulties in ambulation	Activities limitation	



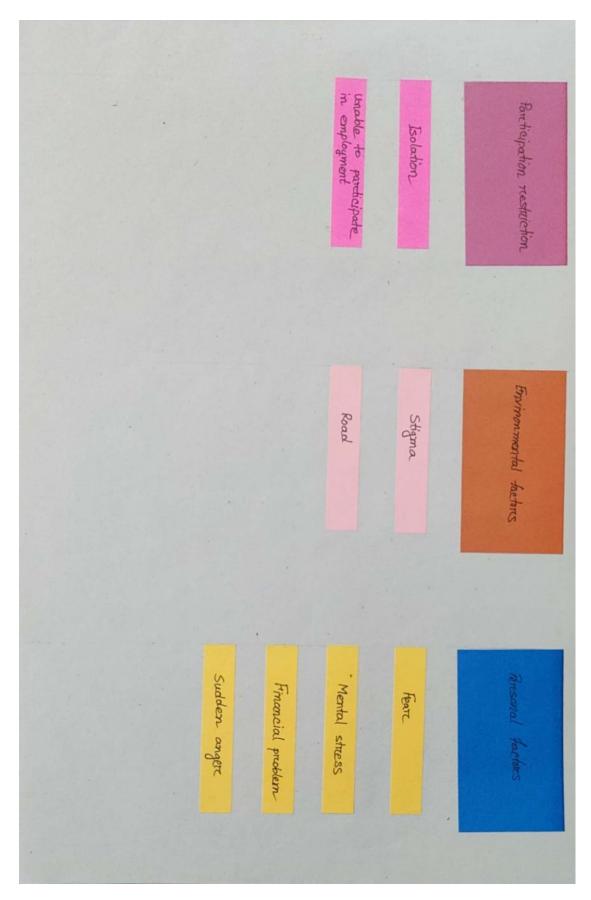
	0 1:1-1	FI	
	Headache	Cuest tightness	
	Respireatory complication	Talking problem ?	
	Thirtsy feelings	Sleeping most of the time	
. 1	Breaklessness	Fabigue -	
			SUTEVIYOTISHIP
	Some throat	Loss of consciousness	could positive peoples
			(ICF) Generaled SCI
	Loss of teste	Physically weak	Cade Number-P2
feeding by nasal tube	Loss of smell	Bed some	
Activities Limitation	Body structure on two-tion	Body st	

		unable to periticiple in employment	Isolation.	Pareticipation restruction
	Intrastructure basusier	Stigma	Rublic transport	Environmental tactors
Nightmattes	Anxieties	Mental stress	Fear	Pensonal factors

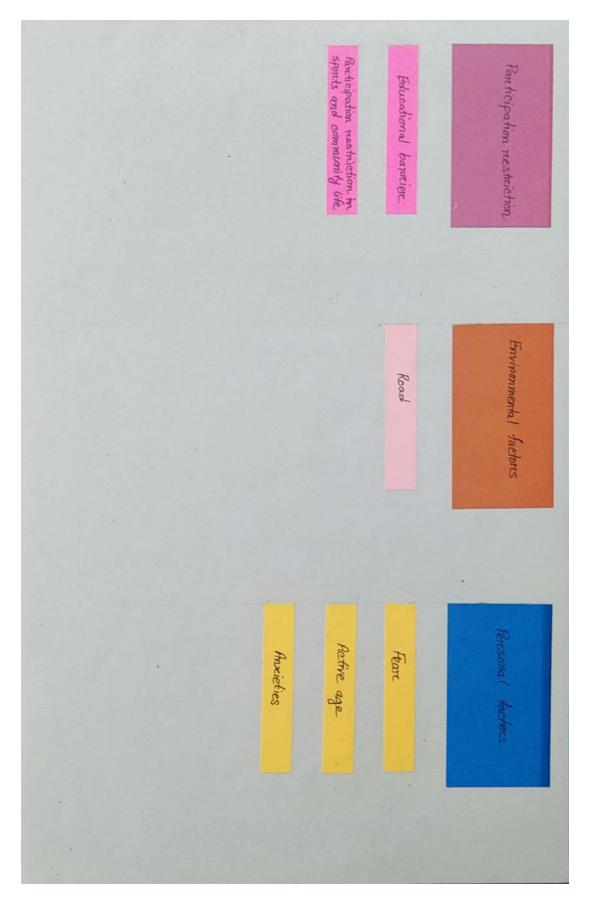
		Smannousub	(ICF)- Generaded SCI COVID positive peoples	2 2 20		
Fafique	Disability related mental stress	Mild back pain	Physically weak		Bed some	Body stur
	Loss of appetite	Loss of smell	Cough		Fever	Body sture-tune on
					Difficulties in ambulation	Activities limitation



	Astlana		
	Breadhlessness		
Pont sitting activity	Some threeat	Febrer	
Using high commode	Loss of teste	Lower extriently paralyzed	COVID positive peoples surrivoriship
bacsping-problem	Loss of smell	Fatigue	Code Number - P4
difficulties in ambulation	cough	Loss of bowel bladder control	
Activities limitation	ture on	Body structure or	



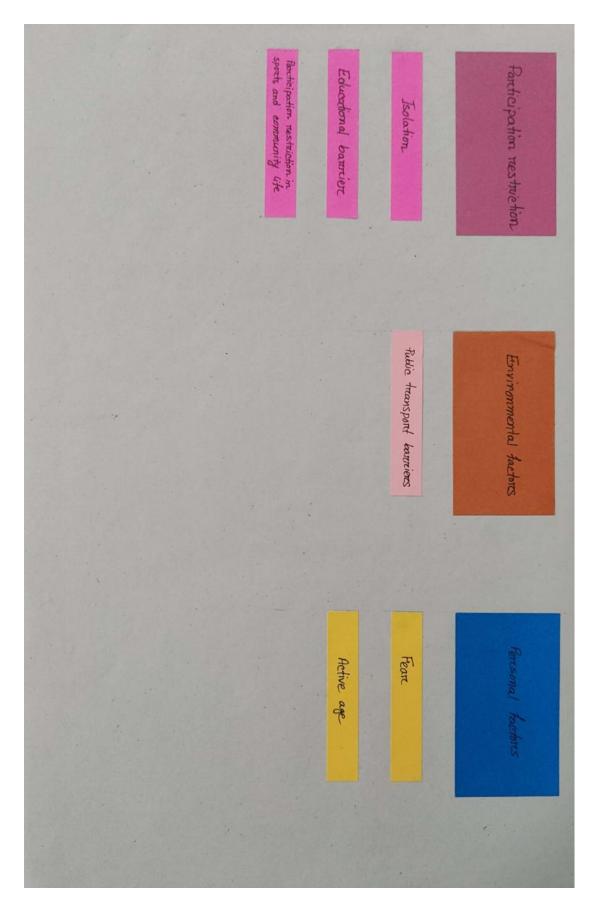
	COVID Positive peoples survivoreship	Cook Number-95 (ICF) Georgraded SCI		
Stomach ache  Bed some	Fever Cough	Fatigue	wheelchair bound	Body structure or
		bussping problem	Difficulties in ambulation	Activities limitation

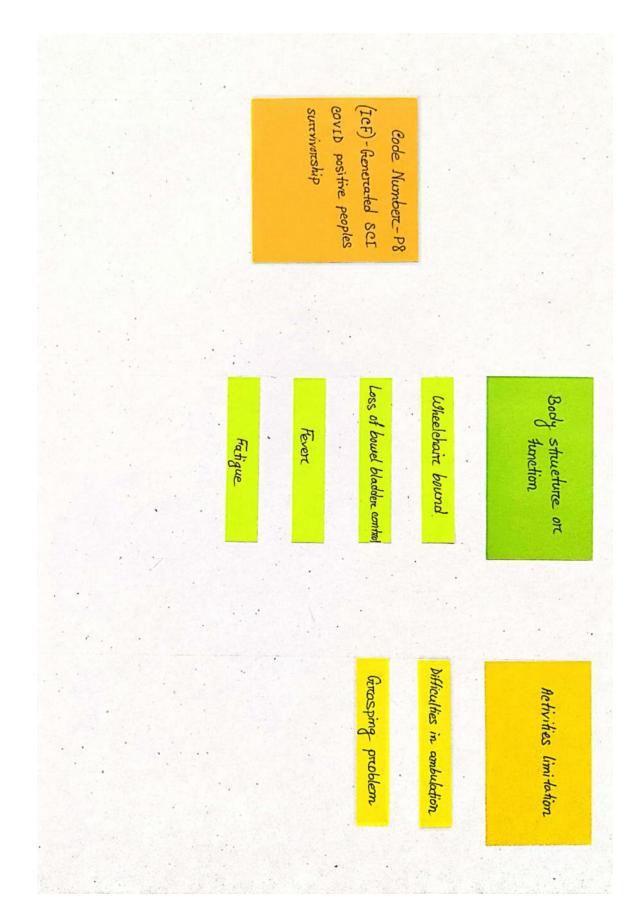


C. C.		
Code Number - P6 (ICF)-Renemated SCI COVID positive peoples survivoriship		
Code Number - P6 2F)-Premercaled SC: WID positive people arrivoriship		
fed So people		
23		
3		
ealoness Fa	Wheel	Body
wealoness in buen limb Fatique	Wheelchair bound	Body structure on tweetien
er limb	prond	n on
	HIA	P.
	iculties	tivities
	חי פחי	Retivities limitation
	Difficulties in ambulation	tation



	COVID positive peoples	Code Numbers:P7		
		Pain of knee joint	Weokness in lower limb	Body structure on function
Poor balance	Use elbows oxuden to walk	Unable to stand independently	use abour orwich to walk	pativities limitation





	Barticipation reestriction in sports and community life	Educational bosocier	Isolation	Participation restriction
Road	Intrastructure barrier	Stigma	Rublic transport barriors	Environmental factors
Mental stress	Financial problem	Active age	Fear	Rensonal Factors

## THEME

ICF Generated Long-covID and SCI peoples survivorship

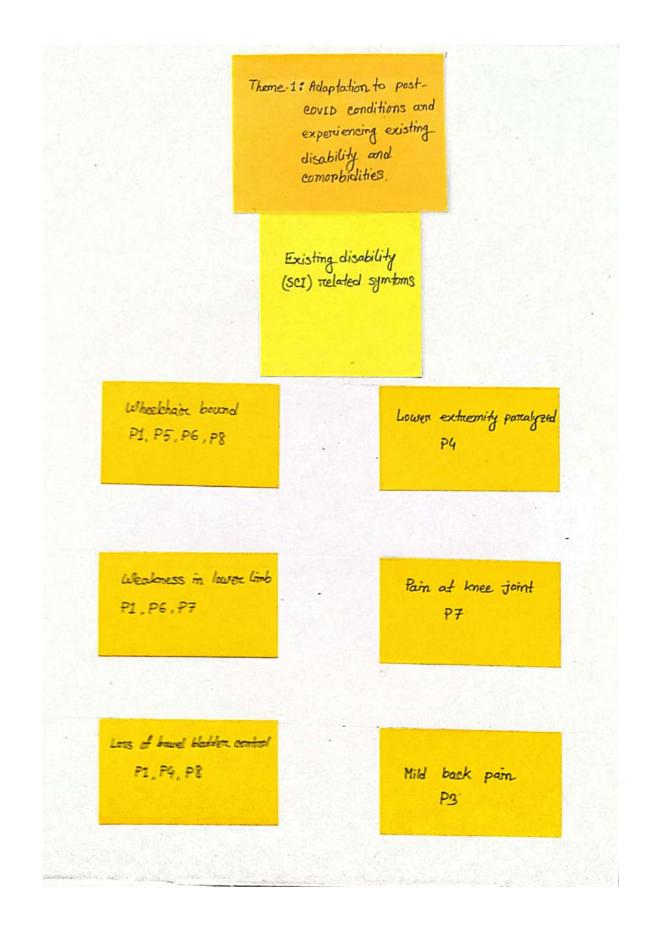
Theme-1: Adaptation to PostcoVID conditions and expertiencing existing disability and commonbidities.

Theme-2: Pre-existing limitations in ambulation and activities of daily living.

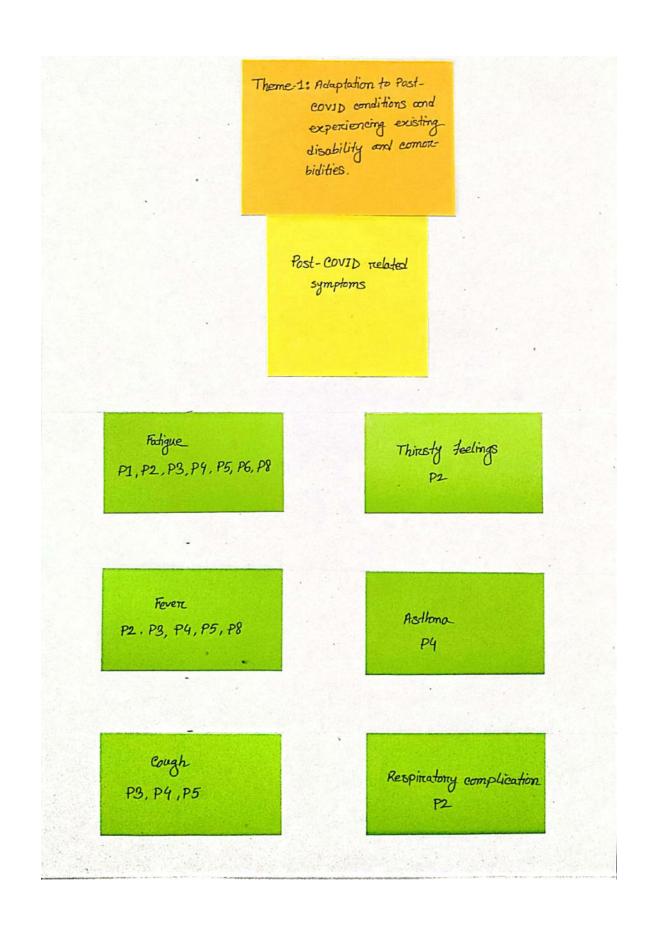
Theme-3: Graining experience of social isolation and lack of information and resources.

Theme-4: Experiencing negative effect and mental issues

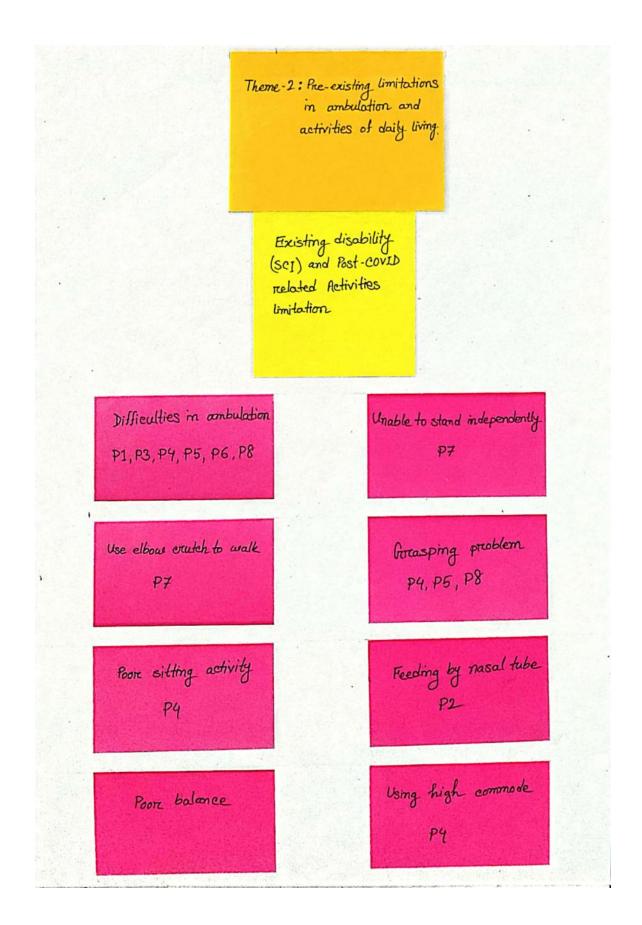
Theme-5: Experiencing social barriers strongly that effect the new-normal life.



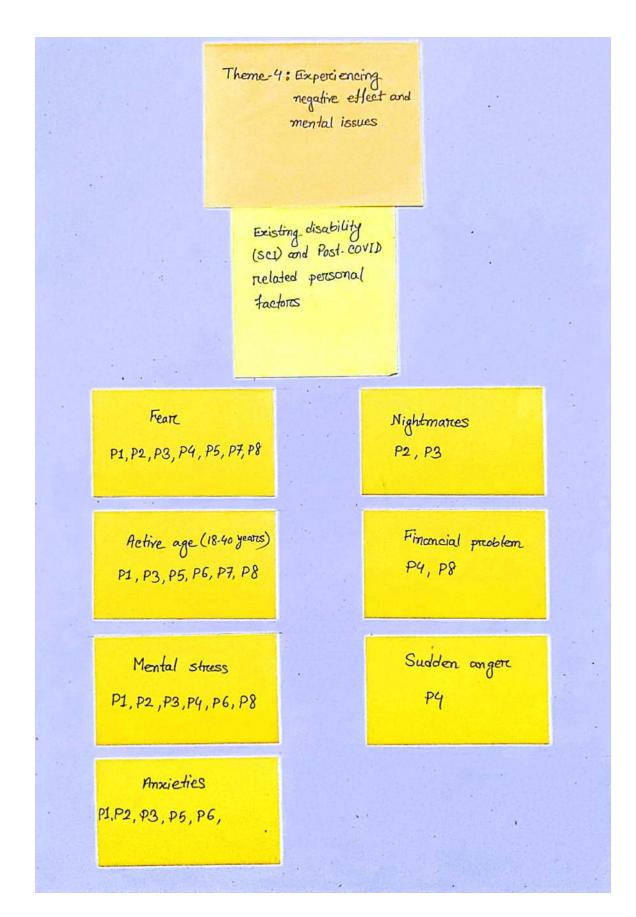
Bed some Stomach ache P2, P3, P5 P5 Disability related fear Physically weak P2, P3 Loss of consciousness Disability related mental stress P2\_ P3 Sleeping most of the time Respiratory complications Talking problem in sitting Position chest tightness P2 P2

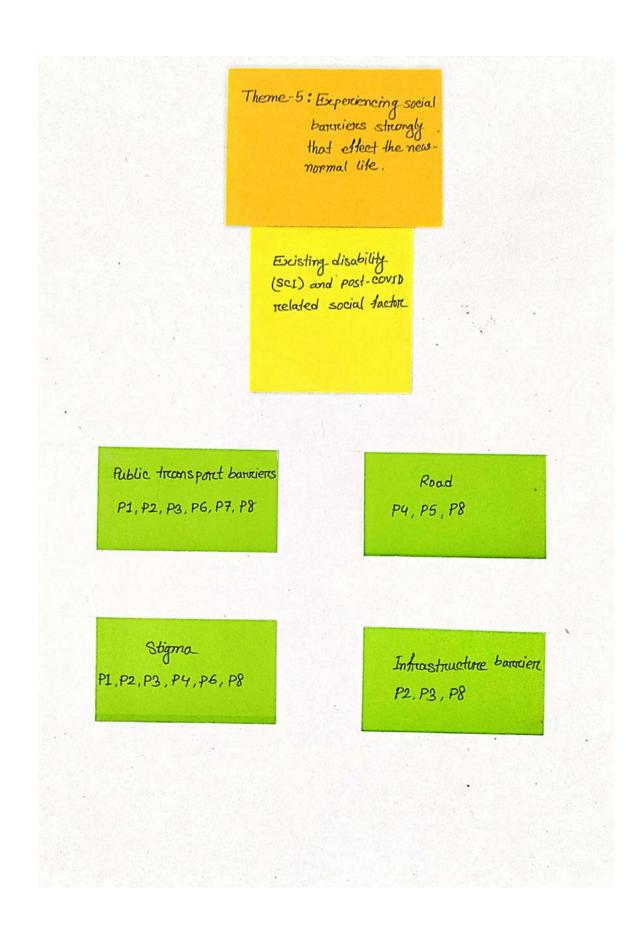


Loss of smell P2, P3, P4 Headache P2 Loss of teste Loss of appelite P2, P4 P3 Some throat Sleep disturbance P2, P4 P2\_ Breathlessness Brain problem P2, P4 P9



Theme-3: Gaining experience of social isolation and lack of inforcmation and resources. Existing disability (SCI) and Post-COVID related participation restriction. Pareticipation restriction Isolation in sporets and community P1, P2, P3, P4, P6, P7, P8 life P5, P6, P7, P8 Unable to participate Educational barrier in employment P1, P3, P5, P6, P7, P8 P2, P4,





	Bed some	Loss of bowel bladder control	Weakness in bower limb	Physically weak	Wheelchair bound	SCI	
Loss of smell Loss of teste	Breathlessness	Some throat	Cough	Fever	Fatigue	COVID	Theme-1
					Guasping prublem	Difficulties in ambulation	Theme - 2

