

Social Support and Narrative Sensemaking Online:  
A Content Analysis of Facebook Posts by COVID-19 Long Haulers

by  
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COVID-19 has affected every one of us around the globe and changed almost all aspects of our lives. It has impacted me as well, but in a good way, as COVID-19 has inspired me to quit the job, move to the United States, and enroll in the Health Communication program at the University of Houston. Since day one, I have intended to conduct research on COVID-19. As an avid social media user, I have combined both of my interests, COVID-19 and social media, into one research topic for which I have a passion and that has practical value to the public.

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## **ABSTRACT**

Long-haul COVID-19 – the lingering effects of the coronavirus in patients – is still a mystery. After being infected with the virus, a number of COVID-19 long haulers have suffered from post-COVID-19 symptoms for days, weeks, or months. There is no explanation why people experience long-haul COVID, and at the moment, there is no known cure. This study examined the COVID-19 Long Haulers Journey Facebook group and analyzed its contents to evaluate how long haulers use narrative sensemaking online. Living with illness uncertainty, COVID-19 long haulers used social media as a virtual social support community for them to share illness narratives as they struggle to make sense of their health conditions and cope with high-stress, uncertain events. The data collected identified the significance of the sensemaking process in managing complex health situations and the value of the social media platform as a source of information and social support for wounded storytellers in the midst of uncertainty.

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## CHAPTER 1

### INTRODUCTION

*It was a year yesterday that I was admitted in the hospital with COVID.*

*During that time, I honestly thought I was going to die because I couldn't*

*breathe. Every movement I made took every little effort I had. Since then, I*

*have been diagnosed with pulmonary fibrosis, asthma, psoriatic arthritis,*

*tachycardia, memory issues, and the newest is venous insufficiency in my legs.*

*It has been a very traumatic year for me. I do thank God everyday that I am*

*still here. COVID also made me look at life differently. You only have one and*

*you need to enjoy and cherish every moment you are given. I am not the same*

*person I was a year ago. COVID changed me in a lot of ways. This is my new*

*tattoo, which represents symbols of rebirth. It also represents the continuation*

*of life in flames of change. This is what I feel COVID has done for me.*

*(member, COVID-19 Long Haulers Journey Facebook group)*

COVID-19 is a disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). It was first detected in Wuhan, China, in December 2019 and has since spread rapidly to most of the world. As of March 8, 2022, more than 440 million people have been infected worldwide, with more than 6 million deaths (Bloomberg, 2022). The United States has surpassed 79 million confirmed cases and more than 960,000 deaths (CDC, 2021a).

Even though more than 555 million doses of vaccine have been given to people in the U.S. (Bloomberg, 2022) and the country strives for return to normalcy, new variants or strains of the virus continue to emerge, linger, and evolve. For COVID-19 patients, the road to recovery is just beginning when they leave the hospital. While many patients recover, some may suffer from a range of new or

ongoing COVID-19 symptoms for weeks or months after first being infected with the virus or from the onset of first symptoms. These post-COVID conditions are known as post-acute sequelae of SARS-CoV-2 infection (PASC), long-haul COVID, long-term effects of COVID, or chronic COVID. These patients are often referred to as “COVID long haulers” (CDC, 2021a).

The Centers for Disease Control and Prevention (CDC) lists a wide range of new or ongoing symptoms for COVID long haulers that include tiredness or fatigue, difficulty thinking or concentrating, headache, dizziness on standing, fast-beating or pounding heart, chest or stomach pain, difficulty breathing or shortness of breath, cough, joint or muscle pain, loss of smell or taste, diarrhea, rash, sleep problems, depression or anxiety, mood changes, changes in menstrual cycles, and fever. Even patients who had mild or no initial symptoms may experience these post-COVID conditions. Research supports these realities. Greenhalgh and colleagues (2020), for example, found that approximately 10% of COVID-19 patients experience prolonged illness beyond three weeks. The CDC and Kaiser Permanente Georgia examined electronic record data of health care visits from 3,171 COVID-19 patients who were not hospitalized after contracting the virus and found that 69% of patients had some kind of new diagnosis between 28 and 180 days after their initial diagnosis (CDC, 2021b). In yet another study, Logue and colleagues (2021) found that 10 to 30% of COVID long haulers reported at least one lingering symptom six months after their first diagnosis.

As the numbers of COVID-19 new patients and long haulers continue to rise, the unpredictable nature and uncertain course of the disease leave individuals experiencing depression, hopelessness, fear, confusion, and anxiety (Usher et al., 2020). Uncertainty has been characterized as an “inadequate understanding, a sense of

incomplete, ambiguous or unreliable information, and conflicting alternatives” (Koffman et al., 2020, p. 211). Kingstone and colleagues (2020) found that COVID-19 patients with persisting symptoms live with uncertainty and fear, and they feel helpless and alone in managing their symptoms. Uncertainty tends to have negative impacts on patients, both physically and mentally; however, long-term data regarding patients’ health outcomes are not yet available (Leviner, 2021).

Because there are no clear answers at present, one of the most important avenues for COVID-19 long haulers to seek information, make sense of their health situation, and cope with the pandemic is social support. Social support is communication — either verbal or nonverbal — that helps individuals manage uncertain situations to enhance personal control in their life experience (Albrecht & Adelman, 1987). It is the way individuals communicate with others to demonstrate care and love, enhance esteem and value, and feel that they belong to a network of mutual obligation (Cobb, 1976). Several studies show that social support has positive impacts on mental health and physical well-being. Goldsmith and Albrecht (2011) suggested that supportive conversations and social networks can enhance health in many ways by: a) giving feedback and exercising social control, b) providing information and care referrals, c) coordinating assistance with behaviors and care, and d) sharing coping assistance. Social support can also help patients make sense of their medical situations and make informed decisions. Patients seek *problem-focused support* (informational support or advice) and *emotion-focused support* (expressions of concerns, esteem, and comfort). They can cope more effectively with stress when they have social support. Therefore, social support may be an especially important resource for COVID-19 long haulers.



To understand how COVID-19 long haulers make sense of their medical conditions, receive social support, and cope with their experiences, I draw upon communicated narrative sensemaking (CNSM) theory to explain how patients seek and provide social support (Koenig Kellas, 2018). Sensemaking is a process known to decrease fear or uncertainty when faced with difficulties or personal disruption. On a personal level, individuals have a tendency to “seek ways to make meaning of their experiences” (Horstman et al., 2016, p. 1). Individuals engage in narrative sensemaking to organize their lived events into more manageable ones (Koenig Kellas, 2015). For patients, storying illness is a natural impulse to make sense of their own experiences as “wounded storytellers” (Frank, 2013). Sensemaking helps patients “assert control when chronic or severe illness or trauma exacerbates suffering” (Harter et al., 2022, p. 50). CNSM is also a social process — it allows individuals to understand their experiences and build identity in conversations with others. In the health care context, narrative sensemaking allows patients to “express themselves publicly and construct preferred identities socially” (Harter et al., 2022, p. 51). This can be observed by interactional sensemaking behaviors, including engagement, asking and answering questions, as well as sharing encouragement and support to one another. These conversations are the vehicle for making sense of both illness and life, not just between people, but also within communities (Frank, 2013; Weick, 1995).

Illness narratives and the shared co-construction of meaning between storytellers and storylisteners is a prolific area of health communication scholarship (Harter et al., 2022). In recent years, research has paid increased attention to sensemaking amidst the ongoing uncertainty of chronic illness. In one study, Ellingson (2017) explored the reality of long-term cancer survivors who suffered from late effects of treatment, arguing for the disruption of the “happily ever after” myth

touted publicly in favor of a “realistically ever after” story. In another study, Reynolds and colleagues (2020) examined the meaning-making and treatment-seeking journeys of older adults with mental health challenges. Given the new realities of COVID-19 long haulers, narrative attention to the ways they make sense of their illness is warranted.

Health communication scholarship has also examined social media in depth. Researchers have conducted and published a number of studies on the ways online engagement can contribute to the well-being of community members after a crisis (Tandoc & Takahashi, 2016). Some studies have focused on the ways people come together virtually to exchange information and make sense of their various health issues. For example, Naveh and Bronstein (2019) explored how online communities serve as a source of information for pregnant diabetic women.

While physically distancing themselves from one another, COVID-19 long haulers virtually connect to exchange experiences, information, and support with one another. Hacker et al. (2020) studied the use of web-based technologies and applications during the COVID-19 outbreak and found that, as social distance became the norm, individuals became more social especially in an online environment. Moreover, online communities serve as an open space for patients to share information and experiences, ask questions, provide comments, and react to other patients’ concerns. With these conversations and engagement, members of this particular community can co-construct a common reality that helps them understand and make sense of their common illness and difficulties (Naveh & Bronstein, 2019).

Given the above, the goal of the current study is to examine how COVID-19 long haulers seek and share social support as they work to make sense about and give meaning to their COVID-19 experiences. To do so, I examine the content created and

exchanged by COVID-19 long haulers in a public Facebook group devoted to their condition. Facebook is “the fastest and the most constant growth” and has the highest number of users worldwide (Ahmed et al., 2017, p. 301). Facebook’s monthly active users, as of December 2020, were 2.8 billion, with more than 1.4 billion having joined Facebook groups (Facebook, 2021). By focusing on the experiences of COVID-19 long haulers, this study can identify the significance of the sensemaking process in managing complex health situations and the value of the Facebook group as a source of information and social support for wounded storytellers in the midst of uncertainty.

In the next chapter, I review the literature on the chaos of long-term illness, illness uncertainty as a call for narratives, and coping with uncertainty through narrative sensemaking. I end with a proposed research question to guide this study.

## **CHAPTER II**

### **REVIEW OF LITERATURE**

#### **The Chaos of Long-Term Illness**

A long-term or chronic illness persists with conditions or symptoms “that usually last for three months or longer and may get worse over time” (National Cancer Institute, 2021). The National Center for Chronic Disease Prevention and Health Promotion (2021) defines chronic illness as conditions that last one year or more, need ongoing medication or treatment, and limit an individual’s ability to perform daily activities (National Center for Chronic Disease Prevention and Health Promotion, 2021). They tend to be managed and controlled for extended periods of time, but not cured (Brown et al., 2020). Chronic conditions may be visible to others (such as physical disabilities), be invisible to others (such as diabetes), or have both visible and invisible conditions (such as HIV/AIDS) (Joachim & Acorn, 2000).

Chronic illnesses, such as heart disease, stroke, cancer, HIV/AIDs, and diabetes, have shifted from life-and-death problems to extended long-term journeys. These diseases have an impact on and transform patients’ lives (Benkel et al., 2020). Current treatments have resulted in a decrease of mortality rate and an increase in the number of survivors living longer; however, patients with long-term illnesses end up with long-term disabilities that require ongoing care and support (Pizzoli et al., 2019). For patients, survival means living with a complex condition and late effects of treatment. After the diagnosis, many patients or “survivors” experience significant physical and psychological burden (Phillips & Currow, 2010). As chronic conditions become part of their lives, these long-term conditions can affect their freedom and sense of self (Benkel et al., 2020). Researchers have suggested that, while patients strive to restore a sense of normalcy, they experience illness uncertainty and

confusion. These chronic illnesses can disrupt patients' quality of life and threaten their identity and self-esteem; hence, patients strive and thrive to find meaning out of illness uncertainty, find ways to live with the changed situation, develop coping strategies, and restore a coherent sense of identity (Benkel et al., 2020; Whitehead, 2006).

### **Illness Uncertainty**

Illness uncertainty is a major source of chaos for many individuals living with chronic conditions (Dong et al., 2021). As defined by Mishel and Braden (1988), illness uncertainty means the failure to give illness-related events meaning. It is "the inability to determine the meaning of events and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcome" (Mishel, 1988; Mishel & Braden, 1988, p. 98). Uncertainty in illness has four characteristics: 1) the state of illness is vague and ambiguous; 2) treatment and healthcare systems are complex; 3) information about diagnosis and seriousness of illness is scarce; and 4) course of illness and prognosis are unpredictable (Mishel & Braden, 1988; Simpson et al., 2021). Illness uncertainty increases when information about the disease process and treatment is insufficient; for example, patients with cancer who undergo chemotherapy may experience unexpected loss of appetite and weight loss (Detprapon et al., 2009). With these unexpected and uncontrollable conditions, the lack of information and experience increases, as well as the degree of illness uncertainty (Dong et al., 2021).

The concept of illness uncertainty has been used in studies of patients with several chronic conditions, and a number of results have shown that illness uncertainty can cause negative effects towards patients' lives, especially increased emotional tension (Sajjadi et al., 2015). A number of factors contribute to stress, such

as unpredictable conditions, ambiguous pattern of symptoms, and a lack of knowledge on treatment options and health outcomes (Brown et al., 2020). Patients also feel that they lack a sense of control over their future as cures for their chronic conditions are not yet known. And a sense of losing control can occur in any stage of the disease, from disease confirmation stage and on-treatment stage, to survival stage (Dong et al., 2021).

Apart from stress, living with uncertainty about disease progression and recurring symptoms, and trying to manage life with chronic conditions, can lead to high levels of anxiety, depression, fear, and anger. In turn, poor mental health can lead to more severe symptoms (Simpson et al., 2021). Illness uncertainty can create abrupt changes in daily routines, quality of life and well-being, as patients adjust to their new normal and the uncertainty it brings (Hurt et al., 2017). It also affects family life and contributes to inability to maintain relationships (Kurita et al., 2013).

Given the long-term challenges of illness uncertainty in unpredictable physical and emotional conditions, it is crucial to address the uncertainty associated with long-term conditions and find optimal ways to manage this illness uncertainty. However, there is a lack of literature on how those with chronic illness manage uncertainty and live their lives with long-term illness.

Some scholars studied the lived experiences of patients with chronic conditions related to cancer. Ellingson (2017), for example, explored the lives of long-term cancer survivors (LTS), their “next chapter” after a series of treatment, and a post-cancer “new normal” — their new challenging realities of ongoing late effects. She found that LTS face a series of late effects after treatment, for example, ongoing conditions and damage caused by chemotherapy, radiation, and other treatments; hence, LTS encounter difficulties in maintaining physical and physiological health

and well-being. Not knowing when and how their chronic conditions reoccur and having intensive treatments impact their work, family life, and social relationships.

Living in uncertainties and complexities of survivorship has an impact on patients' perceptions of self (Ellingson, 2017; Ellingson & Brofka, 2020). Relatively, the realities of the long-term conditions of patients with chronic illnesses beyond the initial transition from acute life-saving treatment to enduring survivorship are absent in extant research.

### ***Illness Uncertainty and COVID-19***

Since the end of December 2019, the COVID-19 pandemic has made people's lives uncertain and unpredictable globally. Countries with high quality healthcare systems and economic stability have also encountered higher degrees of uncertainty compared to other pandemics, with widespread illness and death, economic instability, and long-term challenges (Simpson et al., 2021).

Similar to other chronic diseases such as cancer, diabetes, and heart disease, COVID-19 is an infectious disease associated with significant uncertainty for the general public, health care systems, health care professionals, and especially patients. As characterized by Koffman and his colleagues (2020), COVID-19 uncertainty is associated with "an inadequate understanding, a sense of incomplete, ambiguous or unreliable information, and conflicting alternatives" (p. 211). The spread, persistence, and evolution of COVID-19 cause the high degree of uncertainty and feelings of uncontrol over the illness-related event (Dong et al., 2021).

At the time of writing this paper, several aspects of virus transmission, infection and symptoms are still unclear (Wiersinga et al., 2020). As a global pandemic, COVID-19 leads to an overload of data and sometimes-contradictory information regarding the disease, the symptoms, the testing, the treatment, and the

vaccines. According to the Centers for Disease Control and Prevention, the symptoms of COVID-19 vary. Patients report various types of symptoms such as dizziness, chest pain, diarrhea, fatigue, cough, depression, insomnia, to name a few (CDC, 2021). Researchers also found that millions of people around the globe have been infected and a number of patients suffering from symptoms after SARS-CoV-2 infection or “long-haulers” are increasing (Fernández-de-las-Peñas et al., 2021). Current therapies for COVID-19 available are still in the exploration stage and for supportive care such as pain and fever control and breathing treatment. Ambiguity and uncertainty extends to an insufficient clarification and understanding of patients’ health status. At the moment, little is known about long-term survival and health outcomes of long-haul patients after being diagnosed with COVID-19, including patients’ physical disability, cognitive state, and overall quality of life and well-being (Koffman et al., 2020).

While communication surrounding diagnosis, treatment, and prevention for chronic diseases such as cancer has been widely studied in health communication research (e.g. Ellingson & Borofka, 2020), relatively little attention has been paid to studying COVID-19 patients living with long-haul conditions. This raises questions of COVID long haulers’ narrative sensemaking, social support, and a sense of self in regard to illness uncertainty in the times of pandemic. As the pandemic involves illness uncertainty that is continually evolving, studying the management of uncertainty regarding the issue of long-haul survivorship and COVID-19 late effects by health communication scholars has become paramount.

### ***Illness Uncertainty as a Call for Narrative***

Engel and colleagues (2008) defined narratives as “a universal way of giving meaning to experience” (p. 42). They wrote:



[Narratives] are a primary way in which we understand ourselves and the world we inhabit, and they are a primary means of influencing others. Once heard, a story initiates for the listener a search for possible meanings. Stories are dynamic, and evolve as people tell them and as they are listened to. (p. 42)

Kreuter and colleagues (2007) defined narrative as “a representation of connected events and characters that has an identifiable structure, is bounded in space and time, and contains implicit messages about the topic being addressed” (p. 222).

Additionally, narratives can raise questions and provide solutions, as Hinyard and Kreuter (2007) stated “a narrative is any cohesive and coherent story with an identifiable beginning, middle, and end that provides information about scene, characters, and conflict; raises unanswered questions or unresolved conflict; and provides resolution” (p. 778).

Storytelling is a universal practice used to convey information, knowledge, wisdom, and opinions, and focuses on individuals’ collective experiences (Fakunle et al., 2021). It allows storytellers to structure their lived experiences and organize them into meaningful units. Storytelling is “a natural way of recounting experience, a practical solution to fundamental problems in life, creating reasonable order out of experience” (Moen, 2006, p. 56). Storytellers can connect their past and current situations, interpret problems, and identify their own solutions (Harter et al., 2022).

Scholars have used narratives to understand patients, their experience of illness, and their attempts to deal with life (Whitehead, 2018). As defined by Hyden (1997), illness narratives “are concerned with illness, illness episodes, or illness experiences, and even with experiences considered to be unhealthy. Narratives can be constructed and presented by the person who is ill, by his or her family, or by the medical professional. The common denominator is the narrative’s theme, namely,

illness,” (p. 53). Illness brings with it a sense of disruption of the patient’s life, as well as the sense of self and identity (Engel et al., 2008). As patients are coping with their chaotic conditions, they also try to deal with the problems of identity, and narrative can be one of the powerful tools for patients to express their feelings, pain, experiences, and cope with their situations (Hyden, 1997). Narratives, therefore, provide an enthralling way for patients to make sense of their illnesses, and learn from experiences of recovery (Harter et al., 2022).

Illness narratives can take several forms — triumph, restitution, tragedy, chaos, and quest (Ednew, 2018; Frank, 1995). Triumph stories portray a happy-ending narrative where patients recover from their illnesses and suffering. In these narratives, patients defeat the illness and are able to share the experiences of hope and positivity, and highlight the process of coping or overcoming health challenges (Fitzgerald et al., 2020). Tragedy narratives, on the other hand, entail patients’ struggles of loss or death (Liao & Wang, 2021). Restitution narratives highlight patients’ ability to restore their health to normal and return to a pre-illness self (Roher et al., 2017). Stories of chaos show a patient's narrative that reflects a loss of control over an illness event, such as the experience of living with chronic conditions with no cure and trying to understand unexplained symptoms (Malcolm et al., 2017). In the quest stories, patients accept the illness, live with it, treat it as a challenge and transformation, and see it as an experience (Spillmann et al., 2017). Simply put, illness narrative can be described as patients trying to make sense of their illnesses (Mathieson & Stam, 1995).

A number of health communication scholars have used narratives in studies of patients living with chronic illnesses. Nettleton and colleagues (2005), for example, explored the narratives of patients living with medically unexplained symptoms and

identified the chaotic experiences of the patients, including their concerns of their ongoing symptoms. They found that patients expressed significant distress, uncertainty and confusion regarding diagnosis and prognosis. Malcolm and colleagues (2017) studied how patients living with chronic obstructive pulmonary disease (COPD) depicted their illness experiences through a set of narratives, and defined how the patients found their experiences chaotic and challenging as they were trying to make sense and cope with their illness situations. Mathieson and Stam (1995) studied how cancer survivors used narratives to make sense of their illnesses, provide their lives with meaning, reconstruct their identity, and give them a sense of future direction.

Through storytelling, patients can gain important benefits. Sharf and Vanderford (2003) identified five benefits of illness narrative. It helps patients (1) make sense of their illnesses; (2) assert control amidst uncertainties; (3) transform their identities and social roles as a result of altered health and disease; (4) make decisions about their health; and (5) build social support communities with other patients. Narrative also addresses emotional and existential issues (Kreuter et al., 2007). Storytelling has an ability to express deeper understanding of emotional and existential aspects of health problems and can portray stories from different angles and from many people — allowing to portray the complex processes that lead to an enlightened resolution. When patients describe and share their lived experiences, they can feel more heard. As patients experience uncertainties of illnesses, they share their questions and ambiguities regarding ongoing symptoms or treatments to others, other patients may share information or knowledge that may lead patients to a new or greater meaning (Engel et al., 2008) and be able to interpret their experiences and restore a sense of self (Whitehead, 2005).

## **Coping with Uncertainty by Narrative Sensemaking**

Coping is defined as the process of trying to manage, reduce, or lessen the demands created by stressful events (Taylor & Stanton, 2007). Jin (2009) stated that individuals' attitude and perception towards a crisis involves their personal interpretation of the crisis. When individuals face an uncertain situation, fear, anxiety, stress, and uncertainty tend to develop and increase. Hence, to control and manage these emotions, people actively participate in coping efforts to make sense of the situation, comfort themselves, and reduce negative emotions (Jin, 2009).

In order to cope with a significant life event, like a chronic illness, individuals employ sense making to construct and describe meaning to their experience. Narrative sensemaking allows patients to organize uncertain, complex and confusing events into more manageable ones (Horstman et al., 2016). According to sensemaking theorist Karl Weick (1995), sensemaking simply means making sense of an environment or situation. It is the process of organizing and structuring the unknown events that involves "an articulation of the unknown, because, sometimes trying to explain the unknown is the only way to know how much you understand it" (Ancona, 2012, p. 4). The sensemaking process can be "accomplished by assigning narrative structures such as setting, scene, agency, and plot to the experience" (Horstman et al., 2016, p. 1).

Narrative sensemaking has two forms: individual narrative sensemaking and communicated narrative sensemaking (Horstman et al., 2016). Individual narrative sensemaking is the psychological process for individuals to understand, reflect on, and make meaning from their life experiences by creating stories (Bute & Jensen, 2011; Horstman et al., 2016). By recalling their experiences and creating their stories, patients can interpret the illnesses, make sense of the situations that have disrupted their lives, develop control over the event, cope with their problems, and reconstruct

their own identities (Horstman et al., 2016; Whitehead, 2005). Communicated narrative sensemaking, however, states that humans are social creatures who create stories and share with others. It is “the use of narrative structures to understand experiences and build identity in conversations with others” (Horstman et al., 2016, p. 2). Through “interactional sensemaking” or “joint storytelling” (Horstman et al., 2016, p. 4), individuals engage, collaborate, and share stories together to make sense of their common situations.

According to Horstman and colleagues (2016), four sensemaking behaviors occur in communicated narrative sensemaking — “engagement, turn-taking, perspective-taking, and coherence.” They wrote:

*Engagement* refers to the partners’ verbal and nonverbal responsiveness, liveliness, and warmth during a jointly-told stories; *turn-taking* identifies the partners’ dynamism, politeness, and distribution of turns during the storytelling; *perspective-taking* assess the partners’ tendency to confirm each other’s ideas and emotions, and incorporate the other’s experiences into their own stories; and *coherence* is the way partners collectively organize their perspectives about the event and integrate them into a whole story. (pp. 4–5)

Unexpected situations can form interpersonal relationships either by strengthening family and friend relationships or individuals within the communities (Harter et al., 2022). Communicated narrative sensemaking allows patients or “wounded storytellers” (Frank, 1995) living in a similar circumstance to enhance their health and well-being by sharing social support to one another; thereby creating a sense of belonging and community among the members (Harter et al., 2022). Researchers have found links between communicated narrative sensemaking and patients’ better control of their unexpected events. Communities such as online

support groups, where members share their stories of lived experiences, enable patients to access a wide range of information, enable coping mechanisms, and empower patients to make their own medical decisions (Sharf&Vanderford, 2003). Additionally, sharing stories to one another can cultivate a shared emotional understanding and empathy within the community (Harter et al., 2022). Exemplary narrative research by Naveh and Brongstein (2019) demonstrated how diabetic pregnant women received information and emotional support in online communities and made sense of their critical medical condition. Charvat and colleagues (2021) explored the role of narrative sense making and social support for pregnant women during the COVID-19 pandemic. They found that pregnant women created and told their stories with others in their community to organize their unsettled emotional events and cope with their experiences.

### **Virtual Communities as Sources of Social Support**

Online communities provide their participants with social support (Naveh& Bronstein, 2019). It's a platform where members can share their lived experiences, ask for advice, react to other members' information and opinions, and cope with their problems. Relatively, patients can "co-construct a common reality that helps them make sense of the common challenges they face" (Naveh& Bronstein, 2019, p. 780).

Scholars explored how socially supportive communication can reduce complexity in crisis and help people manage their challenges. Apker (2012) divided social support into three forms: (a) instrumental, (b) informational, and (c) emotional. Instrumental support refers to tangible or physical help such as money, goods, and services. Informational support refers to knowledge, data, facts, and advice. Emotional support is to display compassion, care, empathy, and concern. Cutrona and Suhr (1992) developed the Social Support Behavior Codes and identified five

categories of social support: (a) informational support (facts and advice), (b) emotional support (sympathy, comfort, and concern), (c) esteem support (compliments), (d) social network support (sense of belonging to a group), and (e) tangible support (practical, physical support). Some studies used the five categories of the Social Support Behavior Codes to study the role of Facebook on social support and coping. For example, Coulson and Greenwood (2012) used the five categories of social support to analyze the use of online communities as support groups among families affected by childhood cancer. Eghdam et al. (2018) also used the five categories of social support behavior codes to examine the use of Facebook as communication support for persons with cognitive impairment.

### ***Role of Social Media for Coping***

Informational and emotional coping efforts can particularly help individuals control their unexpected events, and social media features a unique communication platform for individuals who experience stress and fright to cope with the unexpected situation (Zhang & Shay, 2019). Moorhead et al. (2013) identified six benefits of social media for health communication — particularly for patients, healthcare providers, and general public: (1) users have more interactions with others; (2) users can generate more health information; (3) users have access to resources and deal with their own health issues; (4) social media provides social and emotional support; (5) social media tracks the outbreak, monitors users' opinions on health issues, and identifies any misinformation; and (6) information on social media may contribute to health policy. Yan et al. (2016) also added that informational and emotional aids on social media can satisfy patients' unmet needs with traditional, face-to-face medical services. Patients can understand more about their health conditions, and learn about medication options, health outcomes, as well as positive behavioral change from their

peers in the virtual community. While the general public might be concerned about their privacy, patients in the virtual community see these personal knowledge and experiences as valuable and can share them freely to other community members (Yan et al., 2016).

Social media engagement has been conceptualized into many dimensions. Lim and colleagues categorized engagement into functional engagement, emotional engagement, and communal engagement (Lim et al., 2015). Functional engagement can be defined as “a social media user’s interactions with other users in the process of co-creating, conversing and sharing the content” (p. 159). Emotional engagement occurs when audiences are emotionally engaged toward other people’s posts and opinions and relate to appreciation and attachment (Lim et al., 2015; Guo & Sun, 2020). Communal engagement occurs when audiences feel the sense of belonging and value social connection (Guo & Sun, 2020). Among other types of engagement, emotional engagement can play a vital role in shaping an individual’s behaviors (Ji et al., 2019). The emotional aspects of a message can also influence the shareability of the message in the online setting and attract more attention. By consuming emotional messages, viewers can also regulate their own emotional states and create emotional experiences with others (Ji et al., 2019).

Zhao et al. (2019) identified functions of Facebook communication during crisis: information gathering and dissemination, support exchange, emotional coping, opinion discussion, and collaborative problem-solving and decision-making. Unlike traditional media that only supports one-way communication, social media features a higher level of communication. Information can be spread and shared widely and rapidly with a massive number of users. During a crisis or pandemic, people tend to search and share information about the event, as well as the content they experience,



witness, or learn from other sources. This practice allows users access to information and to engage in the conversation in real time (Imran et al., 2015). User engagement is a distinctive feature of social media. It involves “exploring and examining, delineating and demystifying, contesting and countering persistent problems facing a community, and affording possible solutions” (Bin Jwain, 2020, p. 332). Social media platforms such as Facebook, therefore, is particularly useful as it engages people by eliciting ideas and concerns to help one another solve problems. Facebook does not limit users to connect with only friends and family, but provides ways for users to communicate with others to seek information and help, as well as to assist others. Hence, it is evident that Facebook can be an effective and practical platform in health and pandemic situations (Jurgens &Helsloot, 2017).

### ***Facebook Groups as Social Support Platforms***

Although there are many types of social media sites, from Twitter and TikTok to Instagram, Facebook is the most popular social network platform, with more than 1.8 million daily active users worldwide (Facebook, 2021). One special feature of Facebook which differentiates it from other social media platforms is its “Facebook group,” which serves as a community of people with common interests to join as members and exchange conversations. Within their groups — either public or private groups, individuals can seek information and share resources (Athanasopoulou&Sakellari, 2015). Members can post information, photos, or videos on their groups’ walls, and be able to comment and use reaction features such as like, love, care to share support to one another. Facebook also allows users to share long-form content with up to 63,206 characters in regular posts, enhancing users to communicate their personal stories (Hinson & Sword, 2019).

With these distinctive features, Bender and colleagues (2011) stated that Facebook is one of the widely used platforms for health purposes. Unlike other platforms, Facebook allows patients to actively connect with other patients who might be in similar health situations and learn from their lived experiences. Patients share informational support on symptoms, treatments, recovery journey, lived experiences, and medical services, as well as emotional support such as encouragement, hope, and care. They use Facebook groups as their social support communities to make sense of their health conditions, learn about treatment options, and improve their health outcomes, both physically and mentally (Mirzaei & Esmailzadeh, 2021; Yan et al., 2016). The illness narratives within the group are created by the patients for the patients. This patient-centered community allows patients to be both “actors and agents” trying to understand their chronic conditions (Hinson & Sword, 2019, p. 4).

Oh and colleagues (2013) studied the effects of Facebook for health purposes, including the impacts on Facebook users’ social support behavior and health self-efficacy. They looked at the emotional (encouragement and sympathy), information (facts about disease and treatments), tangible (willingness to offer physical assistance), and esteem (positive messages to help patients restore self-esteem) dimensions of social support and found that emotional support is the most significant element that patients require. Emotional support includes encouragement, empathy, and sympathy which aim at lessening their fear, stress, and anxiety (Oh et al., 2013).

Past studies have shown Facebook groups to be a communication tool used by patients seeking information or support for breast cancer and diabetes. For example, Bender and colleagues (2011) studied 620 breast cancer groups with over one million members on Facebook and found that Facebook groups were a popular tool for awareness-raising, fundraising, and support-seeking. Stellefson and colleagues (2019)

analyzed 34 public Facebook diabetes groups and found that most groups were created to provide instrumental and emotional support among the patients. Yan and colleagues (2016) stated that sharing health-related knowledge and experiences within the groups allow users to identify patients with similar symptoms, make sense of their own conditions, and find appropriate treatment for themselves.

Additionally, social support seeking and providing on Facebook allow individuals to empower one another to go through difficult times or grieve over their loss (Tandoc & Takahashi, 2016). For example, in Tandoc and Takahashi's (2016) research on the use of social media in the Typhoon Haiyan crisis in the Philippines, Facebook was found to be the most significant platform where affected people informed their friends and family they survived and served as a venue for them to manage their feelings. They also shared their experiences and how they moved on with their lives.

There is emerging evidence that Facebook groups have been used for community building. Partridge and colleagues (2018) explored the use of Facebook groups for the management of chronic diseases and community building. They found that Facebook groups enhanced peer-to-peer information exchange and provided individuals and groups support and advice regarding type 2 diabetes mellitus and coronary heart disease care. The group provided opportunities for members to exchange detailed information, patient discussions, emotional support, and support for behavioral change. Wang and Lund (2019) also explored the features of Facebook groups and how the Facebook community can serve as a major source of information and support for individuals with rare genetic disorders.

Past studies have shown Facebook groups' great potential for promoting health. Zhang and colleagues (2013), for example, analyzed messages posted to a

Facebook diabetes group and found that members' conversations were related to information, emotion, and community building. Within their Facebook groups, patients who have suffered from long-term conditions like diabetes have been actively engaged in their virtual conversations and provided social support to one another. Hence, it is evident that Facebook can be an effective and practical platform in unexpected situations (Jurgens &Helsloot, 2017).

### **Research Question**

Relatively little is known about the use of Facebook in the context of COVID-19 because the pandemic recently emerged at the end of 2019. Some recent studies address issues related to COVID-19 on social media such as self-reported symptoms on Twitter (Sarker et al., 2020) and COVID-19 misinformation on Twitter (Shahi et al., 2020); however, few studies explore the illness narratives of patients living with COVID-19 long haul conditions or analyze the types of social support that COVID-19 long haulers seek and share on Facebook.

Therefore, to contribute to the existing knowledge of illness narratives, communicative narrative sensemaking, and social support in virtual communities, this research seeks to explore how COVID-19 long haulers engage with others to make sense of their long haul conditions. The main objective of the research is to gain a deep understanding of the role of Facebook as a supportive community and how the narratives develop collaboratively and coherently within the group. Hence, I would like to explore the following research question: How do members of COVID-19 Long Haulers Journey make sense of long-haul COVID?

## **CHAPTER III**

### **METHODS**

To answer the research question, I conducted a content analysis of posts from the Facebook public group named COVID-19 Long Haulers Journey. Established in October 2020, the group serves as a virtual venue for members to exchange COVID-19-related information, research, and lived experiences. As of March 8, 2022, the group consisted of approximately 78,000 members. The majority of group members are COVID-19 long haulers who share their illness journeys, as well as exchange information with and provide emotional support to one another. The group, as stated in its “about” section, serves as a platform for COVID-19 long haul education, research, and resources.

I have conducted several research projects related to COVID-19 for my professors at the Valenti School of Communication and actively stayed up to date on COVID-19. Hence, I have become members of several Facebook groups related to COVID-19 to stay informed on the topic. However, I found the COVID-19 Long Haulers Journey group most informative and active, with the focus specifically on long haulers. Hence, I joined the COVID-19 Long Haulers Journey group in June 2021 and immersed myself in the scene to understand the phenomenon, and later, as I myself became a COVID-19 long hauler, I decided to conduct my research on long-haul COVID to take a deep dive into this topic. I was aware that my personal biases and assumptions would influence how I approached this study, and I acknowledged them for lending perspective and credibility to my research (Tracy, 2020). However, as my research goal was to better understand the phenomenon without proving, judging, or confirming anything, I conducted research as a complete observer (Tracy,

2020). Doing so meant watching the scene unfold without interacting with members or making members aware that they were being studied.

Because this is an online public Facebook group that is accessible to anyone regardless of group membership, University of Houston's Committee for the Protection of Human Subjects declared the study exempt from IRB review. Still, the group name used in this research is a pseudonym to protect the identity of the group and its members.

### **Data Collection**

Because this group is the largest community for COVID-19 long haulers available on Facebook and is quite active with members' posts and comments, I chose to collect data from January 2021 to January 2022, a period of 13 months. I selected the five most engaging posts and all associated comments of each month to analyze. In total, I collected 65 posts with a total number of 24,767 comments within this timeframe.

The collected data included member interactions such as wall posts, comments, and reactions to posts (e.g., like, love, care, haha, wow, sad, and angry emoticons), as well as any photos and video links. Although I read and made note of all posts during the determined time period, I focused primarily on posts with high engagement (i.e., more than 50 comments). Since this was a highly engaged and active group, 13 months' worth of data provided me with rich and deep insights, as well as enough data to reach saturation for this project.

I collected data without including any identifiers from the members' Facebook profiles (e.g., username and location), and I do not use names or pseudonyms to differentiate members in my results. Further, I refrained from adding, deleting, changing, or formatting text in order to maintain the authenticity of the content and

preserve member voices. Thus, the initial posts or comments appear in Chapter 4 with misspellings, grammar errors, and abbreviations.

### **Data Analysis**

To understand how members of the group make sense of the COVID-19 uncertainty through narratives and what the types of support members of the group seek and provide, I conducted a textual analysis, which is associated with “rhetorical methods which refers to the description and interpretation of the content, structure, purposes, and consequences of existing verbal or visual texts” (Tracy, 2020, p. 80). The content analysis began with reading all posts on the Facebook group and then selecting the top five posts with the highest numbers of comments and reactions per month. After I copied and pasted all of the posts and comments to the Excel file, I added one column for the “primary-cycle coding” process (Tracy, 2020, p. 219) to examine the data and assign words that were relevant to their essence. I analyzed the language, symbols, and pictures presented on the posts to understand how they made sense of the situation and exchanged support with one another.

To ensure reliability, I worked with another researcher to code the data. Once the first-level preliminary codes were completed (see Table 1), both coders coded the same set of data and worked together on the secondary-cycle coding. We reviewed all of the codes, modified them until we reached agreement, and collapsed them into emergent categories and themes. I discuss the three primary themes in the next chapter.

**Table 1. Preliminary Codes**

<b>Definitive Answers</b>		
Finally felt heard	Group gave me a voice	I was crying out to doctors
No one listened to me	Doctors didn't ask	Doctors don't know
Nothing can be done	It's all still unknown	Not alone
No longer feel alone	In this together	Not crazy
<b>Negative Emotions</b>		
Struggle w/ lingering effects	Scared/fear	Anxiety/depression
Feeling down	Driving me crazy	Just want to be normal
Never felt this bad in my life	Frustrated	Exhausted
<b>Advice</b>		
Doctors	Treatments	Reading
Be aware	Take help from others	Take care of yourself
Tips for specific tests		
<b>Questions or Requests</b>		
Same symptoms	Relapse	Information
<b>Hope / Inspiration</b>		
We get the help we need	We get answers	There is no hope/losing hope
Good news/progress	Shared stories	Reassurance
Full recovery	To be normal	To be back to old self
<b>Perspective</b>		
Be patient	Personal healing journey	Success stories
Don't give up/hang in there	Thankful to still be alive	Thankful it gets better
Keep fighting/keep working	Covid changed my life	Covid robbed me
Stay strong	Look at life differently now	Same situation/similar path
Will never be the same	Encouragement	Positive vibes/stay positive
Celebrate small wins	Survivor	Warrior
<b>Faith</b>		
God let me live	God is bigger than Covid	Prayers
<b>Loss</b>		
Shared stories	Support	Pray for you



## CHAPTER IV

### RESULTS

In this exploratory study, I aimed to understand how members of the COVID-19 Long Haulers Journey group use this platform to seek and exchange support as they work to make sense of their illness conditions. The content analysis of Facebook posts and comments led me to identify three emerging themes: 1) group gave me voice, 2) group gave me community, and 3) group gave me perspective. These themes, along with subthemes, are presented in Table 2. In this chapter, I elaborate on each theme with a number of examples from the COVID-19 long haulers' posts and comments.

**Table 2. Primary Themes**

<b>Theme 1: Group Gave Me Voice</b>	
Sharing negative emotions	Struggle/battle with lingering effects Scared/depressed/exhausted/crazy Loss of self
Seeking definitive answers	Finally felt heard No definite answer
<b>Theme 2: Group Gave Me Community</b>	
Informational support	Lingering symptoms Relapse
Emotional support	Shared stories Patience / positivity Prayers
<b>Theme 3: Group Gave Me Perspective</b>	
Hope	Good news/progress/small wins Full recovery/normality/back to old self
Journey	Life transformation Survivors/warriors/fighters

## **Group Gave Me Voice**

The COVID-19 Long Haulers Journey group enabled its members to cultivate a safe space to make their voices heard. Within this group, members could openly share their negative emotions and, because COVID-19 affected them in unpredictable ways, seek definitive answers to their problems.

### ***Sharing Negative Emotions***

COVID-19 long haulers mostly shared their physical struggles and expressed their feelings about pain and stress they had with the new, recurring, or ongoing symptoms of COVID-19. The constellation and duration of symptoms varied among them. Collectively, the members experienced night sweats, higher heart rate, shortness of breath, body pain, headache, fatigue, loss of taste and smell, high blood pressure, high blood sugar, change of vision, and many more.

For many long haulers, fatigue and body pain were common signs and symptoms that lingered over time. Thus, some members lamented the frustration of having no cure. “I’m still dealing with the muscle fatigue or weakness in arms and legs almost 3 months out and can’t do anything,” wrote one. “Very frustrating. Wish I could at least exercise.” Another member shared that she experienced muscle pain “all the time.” She wrote, “One day I’ll be fine and the next I struggle to stay awake or even walk around.” Another long hauler agreed, sharing that she suffered pain “when walking and standing.” One fully vaccinated group member stated that she was “terrified,” describing her body aches as if “there is a truck on my back.”

Another most unusual symptom of post-COVID is olfactory dysfunction. Many long haulers could regain their sense of smell a few weeks after their initial COVID-19 infection, but some still suffered with the loss and distortion of smell and taste for months and still could not fully regain their senses. One long hauler, for

example, said she had lost her sense of smell and taste for three months and it was “just coming back at about 25%.” After one year following infection, another long hauler still had not regained her sense of taste and smell. “All foods taste weird these days. Nothing smells right,” she wrote. Because of the chronic symptom, she refused to attend family events as she could not enjoy any flavors of food. “This year I absolutely refused to do anything with family for Thanksgiving,” she said. “I’ll make my own then have my break down in private because I know I’ll not be able to taste stuffing or pumpkin pie. My two favorites.”

Long periods of ongoing symptoms with no cure could lead to psychological dysfunction such as stress, anxiety, and depression. For example, one long hauler who lived with post-COVID symptoms for 21 months described depression as a “symptom of the beast.” She wrote:

Early in the disease, when I couldn’t think my way out of a paper bag, I would feel the black fog of depression come rolling in every day like clockwork at 2PM. Mornings were rough physically, but not depressed so I knew it was just another symptom of the beast. 21 months later PTSD/agoraphobia and a hole inside me that wants to start living again.

Similarly, another long hauler suffered from panic attacks and anxiety, things she never experienced prior to the COVID-19 journey. “The anxiety attacks with no reason..... I’d never had anything like it before,” she wrote. “I’m a year in and have worked through so many things but the sudden flood of anxiety, fear, unbridled emotion with no provocation is still a battle that I intend to eventually win!”

Another participant developed severe anxiety. He wrote, “All I do is worry about it and when I’m gonna get better .. driving freaking nuts.” One member describing her COVID-19 recovery wrote that “everyday seems to be harder,” and the

ongoing symptoms had dragged her down in the dumps. “I appear to be on a downward slide myself,” she wrote. “My muscles and joints hurt. It feels like I am coming down with the flu or hung over, which I am not. It started happening just in the afternoon and night now it’s constant. Crazy thing is I will have a normal daily randomly, but those are becoming few. This sucks! I have so many other symptoms but this is getting me down.”

She wasn’t alone. Another group member said she struggled with panic, nausea, and a “feeling of bugs running on the back of my head!!! Just praying the doctors aren’t missing something! Don’t know what I did to provoke it today!” One member described feeling as “a non thinking zombie with pain!,” while another mother of a long hauler expressed her distress regarding her daughter’s symptoms. “My daughter seems to be letting fear control her. It worries me,” she wrote.

Apart from anxiety and depression, several long haulers experienced insomnia and decreased quality of sleep, despite feeling tired. Some shared that “insomnia kicks in every night,” “it’s maddening,” and “it’s never ending.” Sleep disturbances also exacerbated the symptoms of many physical and mental conditions like exhaustion and depression. “I’m exhausted all the time 11 months post covid... No matter how much sleep I get,” one long hauler commented. Similarly, another group member replied, “Me too! You feel so exhausted but sleep just doesn’t come. Getting maybe 4-5 hours a night on a good night!”

Some long haulers took sleeping pills or supplements such as melatonin and lavender to improve their sleep quality. However, for some, nothing seemed to help. “All day everyday but idont sleep well at all even with pills,” wrote one long hauler. “I hear and feel my heart beat in my whole body and the burning sensation is

insane it makes me so sad and depressed! I was a lil better for a few weeks but it always comes back.”

A number of long haulers worried whether they would ever recover from COVID-19 symptoms and return to normal. Some long haulers expressed their experiences living with the chronic illness as “a roller coaster ride of symptoms.” For example, one woman wrote:

10 months out and it’s been a roller coaster ride of symptoms, headaches,fatigue,leg and foot pain, high blood pressure,weight gain, face tingling, food allergies..it’s been intense to say the least but I’m finally feeling human. All my symptoms are finally subsiding.I definitely have more good days than bad.

Loss of control also presented for COVID-19 long haulers. Some group members expressed that chronic symptoms have driven them “crazy” as they lost control of their lives. One long hauler wrote, “Just want my life back....I need control,” while another member commented, “I can’t wait until the damage no longer controls my life.”

### ***Seeking Definitive Answers***

It is still unclear why some people infected with COVID-19 are plagued with symptoms for weeks and months. A number of long haulers strove to understand the mysteries of COVID-19 in this support group as they could not find the answers anywhere else. Some long haulers also complained that even though they were able to see the doctors, they did not receive a clear treatment for the lingering symptoms. For example, one member wrote, “I am experiencing hair shedding to the point that I think I may need a wig. Did anyone with hair loss symptom experience itching of the scalp? I went to dermatologist. No real answer. ?????”

Another 25-year-old member with no known health conditions pre-COVID had suffered from a range of persistent symptoms such as constant shortness of breath, back pain, chest tightness and pain, vivid dreams, bad sleep, weight gain, and fatigue. It had been seven months and yet she could not find answers from doctors on how to treat this long-hauler misery. “Any positive recovery stories out there? I am really down lately,” she wrote. “I have had blood tests and ct scans. Everything looks normal. The doctors have no answers for me. I don’t know what to do for myself. I am exhausted.”

A number of members provided comments to her post, stating they were in similar situations or even worse. One member commented, “YES SAME AND MORE. Haven’t been able to have a bowel movement it’s been going on for months and Drs think I’m crazy I have inflammation weight gain severe swelling weird looking veins in my legs now and blue hands and feet and constantly cold.” Other members agreed, stating doctors do not seem to understand long-haul COVID-19 and the condition’s lingering symptoms. “Unfortunately doctors live in these boxes. And they can’t think outside of it. And that’s unfortunate because our bodies aren’t like cars,” wrote one member. “They are infinitely more complicated and diverse. One is not like the other and to fix things you can’t just think one way.”

Some long haulers shared that some healthcare providers had not even heard of long-haul COVID. “Went to the er this morning and the nurses never heard the term long covid. They only knew the official name,” wrote one member. “They looked officially startled and even stood back when I first told them. I was just as confused about that as they were at me. Lol.”

Another group member who had suffered from ongoing symptoms such as shortness of breath, muscle and joint pains, heart enlargement, and blood pressure for

13 months and been to a few doctors agreed that long-haul COVID is a mysterious syndrome and doctors do not seem to know how to treat it:

I do not believe that many doctors know about the treatment of long haul symptoms of COVID. The latest specialist that I saw was a pulmonologist. He said my problems were all minor and treatable. I wish he had walked in my shoes for the last year. I almost died and it was not minor, and so far no one can alleviate my fatigue and shortness of breath. My heart is what it is and I am followed by a cardiologist. No, it is not minor and so far, it has not been treatable.

One member stopped visiting doctors or having any tests, stating long-haul COVID was “still in the unknown zone. Nothing can be done about it anyways.” Another long hauler recommended that others stop searching for answers and let time heal:

Honestly you should stop searching for answers from doctors.... They don't know... I know this sounds crazy but when you let go of the search and accept where you are it all seems to come together...my Doctor suggested crossword puzzles and as bazaar as that sounds it has actually helped... I went to a neurologist, immunologist, cardiologist..etc... nothing, so I thought ok crossword puzzles???... and I'm actually getting better, that plus exercise and a lot of good understanding friends... I'm sorry you're going through this... I am right there with you... but believe me every month you will see improvement, get lots of rest, enjoy when you can and do your puzzles!

Some long haulers felt they were not being heard as doctors failed to show care and compassion towards them and thought that they were “crazy.” As one participant wrote, “All the drs think we are crazy. It almost makes me want to make a career change to become a dr that actually cares for the people.” Another group

member, however, wrote that COVID-19 long haulers were not crazy, but “feeling like crazy” as they tried to find answers and made progress. “We are not crazy, we are feeling like crazy and doctors don’t want to be bothered. This is a real thing,” she wrote. “Doctors don’t know anything about what is happening, so they brush it off! Keep your chin up and keep looking for someone that will listen to you. I am doing the same, looking for a doctor that will listen to me.”

Similarly, another participant experienced a range of post-COVID symptoms like vertigo, chronic fatigue, blurry vision, and joint pain. She visited several doctors and felt that they disbelieved her. “I’m dizzy all the time, having balance issues, chronic fatigue, and nystagmus in my eyes. I’ve lost the ability to drive. Joint pain. Nerve pain. Heart races for no reason,” she wrote. “Drs don’t really believe me. Tests show nothing, so they assume I’m crazy. Tried all kinds of meds. Nothing works, or has a lot of side effects. I’ve gained 25lbs, too. I was super active before. Now I struggle to get through the day.”

Some long haulers mentioned that doctors believed new and lingering symptoms, such as ache and pain, were subjective and could not be quantified. “Yes I am over a year out and still get new symptoms. Of course all of my doctors around here just say it’s in my head,” shared one group member. “All my tests are coming back fine. Unfortunately I am not one to complain about every ache and pain and run to the doctor every time I get sick or something. So I can truly tell you this is not in my head and I am having these issues.”

While many COVID-19 long haulers could not receive definitive answers from their doctors and tended to give up, some shared their positive experiences. One member who had suffered from post-COVID symptoms for two years and visited nine



different doctors finally received some definitive answers regarding her hearing loss problem. She wrote:

I received some answers finally at an audiologist appointment. I have nerve damage in my inner ear and severe to profound hearing loss in that ear. That explained everything. He diagnosed it as neuritis. I'm pretty sure it's the vagus nerve. The cause is from a virus. Which we all know was covid. I was experiencing all of the symptoms this past 2 years. BP and HR going way up. Digestive issues. My carotid artery throbbed for several months. I felt like I was crying out to all these 9 Drs. And no one listened to me. I understand long haul was not heard of, but post viral syndrome is not new to the planet. This audiologist was amazing.. he sat and talked with me for over an hour.

Conducted his hearing tests and went through the results. He knew my history before I walked in the door. So now I need hearing aids. Finally I have some definitive answer!

Some long haulers facing similar challenges found this post hopeful and the support group gave them a voice to express their opinions. One long hauler experienced loss of hearing, tinnitus, and fluid leaking out of her ears for a year. She had tried to find the answers to the symptoms, and after reading this post, believed she could someday have the answer she had been searching for. "That's great news you are getting answers!! I hope we all do eventually and get the help we need," she commented. "Healing light to you all. This group gave me a voice and i finally felt heard, thank you."

### **Group Gave Me Community**

COVID-19 long haulers faced constant health challenges weeks or months — and counting — after their initial infection. Several members had recovered but still

dealt with persistent symptoms that simply would not go away. While cures remained elusive, members of the Facebook group sought and provided information and emotional support to one another, in order to make sense of their own health conditions. The group served as a virtual community for long haulers who were going through or had gone through similar situations to exchange conversations. This virtual support group provided COVID-19 long haulers an opportunity to ask questions about their health conditions, share advice based on personal experiences, give firsthand information about treatments, and provide encouragement, reassurance, and emotional support to one another.

### ***Informational Support***

Long-haul COVID members posted a number of questions related to their persistent symptoms on the group wall. One member who had suffered from loss of smell and taste raised a question: “Did anyone get their sense of taste and smell back, only to reuse one or both a few months later? My sense of smell and my taste a completely returned and this week I noticed my sense of smell is gone again.”

The replies offered reassurance that other long haulers had experienced similar. One wrote, “Yes. 19 months and it comes and goes,” while another member said, “Comes and goes all the time..day by day it’s different and hour by hour. I have learned just to live with it.” One member had lived with this symptom for 18 months and commented, “I STILL cannot smell most EveryThing and my tastes are so messed up. It really sucks.” Another long hauler who had experienced the loss of taste and smell for nine months agreed, saying that “I can taste and smell about 10 percent now.” Another long hauler experienced strange smell and taste distortions, describing that “everything smells or taste like burnt garlic.. that smell when youve over cooked the garlic and now its bitter and gross.”

Some members were concerned that, in addition to persistent symptoms, new conditions occurred. One of the long haulers posted a question: “I’m almost 8 months out ...anyone else still getting new symptoms this far out??” The replies demonstrated that long haulers developed new onset symptoms weeks or months after their first COVID-19 infection. For instance, one member who had suffered from post-COVID symptoms for eight months shared that she had developed new breathing issues, while another long hauler experienced fast heart rate and fatigue. Similarly, another person experienced new symptoms “all the time,” writing, “I’m starting to hate life. And no one believes that I have these symptoms.”

In addition to asking questions, COVID-19 long haulers sought advice regarding how to care for themselves to improve health conditions. For instance, one member returned to exercise after recovery from COVID-19 but experienced some lingering conditions such as shortness of breath and fatigue. “Did a few hikes this week, a mile minimum since I was starting to feel better. Had a few anxiety attacks, maybe working myself too much?” she asked. “Now the last few days have shortness of breath, fatigue and feeling lightheaded/faint. Anyone else experiencing this? Any tips? Thanks in advance!”

The replies offered health advice in the form of experiential knowledge. Most long haulers suggested that others not “push yourself too hard.” One member wrote, “Slow down and try not to push yourself so hard. I found I had that trouble when I first started to feel better. Just be kind to yourself and and try not to make up for lost time, so to speak. It is different to be a “long hauler” but recovery is in sight.” Another long hauler saw post-COVID recovery different from other types of illnesses and returning to exercise and active activity would be a slow process and required patience:

I found with this recovery it's two steps forward and either one, two or three steps back. It's definitely unlike any other illness or surgery or anything I've fought before. And the anxiety and/or depression make it 100x worse. I would say don't push yourself too hard. I think a lot of us need to take it SLOOOOOOW. Maybe start with 1/4 mile walk and see how you feel the next day?

Some group members also shared tips for managing their fatigue and nausea. One long hauler wrote that she ate a light fruit bar when she felt dizzy. Another recommended others lay down for an hour. Another member suggested that long haulers should not exercise unless they were nearly fully recovered. "Only exercise when you feel as close to good as you have been post covid. Don't push yourself," she wrote. "I used to run 2 miles, now I walk 2 miles and that is all I can do."

### ***Emotional Support***

The majority of posts were also categorized as giving and receiving encouragement, emotional support, and reassurance. As COVID-19 long haulers tried to make sense of their health problems, reassurance enhanced their knowledge and understanding of the lingering symptoms. When confronted with uncertainty, some long haulers sought reassurance from others. For example, one member asked, "Anyone else have pain in lower back like possibly the kidney area? I'm 2 months post covid. The pain seems to be getting worse."

The replies contained both similar experiences and reassuring messages. "Yes my kidneys hurt sooooo bad," replied one member. "I was sick with Covid in January this year. My kidneys were about to shut down during that time. Since then they have been hurting off and on but this past 2 weeks they have been getting worse." Some

long haulers shared treatment using, such as using heating pads and having steroid injections in the lower spine.

Another long hauler asked, “Anyone develop thrush with covid?” as a way to seek reassurance from others. Many replies showed that a number of long haulers experienced the same health condition. Comments included: “My lips are full of blisters”; “yes tongue was sore for a week”; and “similar, covid tongue can have white coating and ulcers. I also had a bit yes, but it cleared as I got better.” Some members stated that thrush was the side effects of antibiotics and/or steroid inhalers, and they shared their tips for healing thrush by using “a nystatin mouth rinse.” One member wrote, “A mix of my mouth wash a hydrogen peroxide to rinse my mouth out then would use a tongue brush to scrape the crap off.”

In addition to seeking reassurance, the majority of posts were categorized as giving and receiving encouragement. With encouraging messages shared in the group, long haulers were able to see that they were not alone in the situation. Some examples of encouragement messages were: “Everyone has bad days. Don’t give up. Pause. Rest. Reset. Restart. But, never quit. Always pick yourself up and keep going,” and “Give yourself some credit for the days you made it when you thought you couldn’t.”

It was also apparent that the sense of community helped mitigate the feelings of “loneliness” often reported by COVID-19 long haulers. One new member, for example, posted, “Thanks for the add. Nice to know I am not alone in this :)” The replies offered welcoming encouragement and support, saying “not alone for one moment,” and “you are never alone” as a way of providing a judgment-free space to members and helping others to manage their emotional distress. Similarly, another long hauler commented, “I agree! I’m thankful for finding this group and knowing I’m not alone.....or crazy! Had covid in Dec 2020. Still no taste or smell, except for

horrible phantom chemical smells that make me nauseous. The doctors only advice was to suck on hard candy.”

The virtual group helped long haulers cope with stress and worries. One member, for example, shared that her health had improved because of the information and emotional support from the group. “You’ll see your symptoms in so many others and know you not alone,” she wrote. “After 6 months I’m finally improving and this group kept me going, hearing others success stories.” The sense of “togetherness” also appeared in the conversations. “Nice to have a place where we r all here together” and “We are all here for you and each other.”

As they were coping with the chronic illness, some COVID-19 long haulers shared their health improvements, the little victories that encouraged them to move forward. “Just cried into a bag of chips because I can tell they have a smokey flavor,” wrote one member. “My first flavor since October of 2020. Best fucking feeling ever.” The replies offered positive and encouraging messages and demonstrated emotional connection to the poster. “Loved seeing your post I am so happy for you!” one member replied. “I can taste salt and sweet but that is it. I have had no taste since January. I have been given soured milk twice and never knew it. I will cry also when I can taste in layers again and smell again.” Some other examples included, “Yay!!!! So excited for you still waiting for my taste and smell to come back” and “Omg yay ! I had it nov 7 haven’t smelled or tasted since.”

Some long haulers who were able to regain their health also shared their stories as a way to receive emotional support from others and at the same time motivate other long haulers. One woman wrote, for example: “So excited!It’s taken a month, but I finally broke the 750 mark! Also, I’m able to take longer deeper breaths. I’m on 2L oxygen but can go down to 1L for a little bit while resting! It’s a slow

process for many, but never give up!” The replies she received mostly offered emotional support to give her the strength to carry on and thrive. Positive, encouraging messages included: “Keep up the great work!!!”; “Hang tough, keep blowing and inhaling”; “Keep fighting the good fight! You got this”; and “Hell year!! Keep going, keep practicing and push yourself!”

While many long haulers in the Facebook group shared positive stories about their recovery and progress, others lost loved ones to the illness. Some members shared their tragic stories to the group as a way to express grief, while others reached out to the bereaved to express their sympathy. A widow and a solo mom of two children shared that she was suffering from post-COVID symptoms and recently lost her husband from COVID-19:

So glad to have found this page. I am approximately nine weeks out from being diagnosed. I lost my husband a month ago to it. He went to the hospital and I did home care. He was in the hospital a month, intubated for two weeks and passed on a ventilator. It’s a long tragic story and not the time to go into it. I thought I was going to die too, but for the sake of my two boys I didn’t want them losing both parents. I’ve hit the recovery with a strict anti inflammatory diet and all of the supplements and recommended treatments. I started doing vitamin IV with added glutathione push twice a week and hyperbaric oxygen therapy every weekday. None of it is covered by insurance but I’ve canceled everything I possibly could and am making it work. This has helped a lot with the fatigue and relapses. I’ve gone every weekday for almost three weeks now. I still require oxygen at night but am capable of now going for brisk walks and doing some housework. I’ve met dr’s and nurses in there getting treatments as well after they had it. Some of them are several months out. Giving yourself

the best fighting chance as soon as you can seems to be the most helpful. I'm sure the more time goes on the more we will learn what works and what doesn't. I know everyone is different and different things work for different people on different levels.

A number of long haulers experienced the same loss and grief during the pandemic and provided support to one another in the comment section. "As a widow my heart goes out to you. I pray God gives you strength and stamina for this," wrote one long hauler. "I am one year post Covid with my neuropathy coming and going. The fatigue hits off and on. There is hope. Keep going." Although the stories posted to this Facebook wall were personal, COVID-19 long haulers could feel connected and offer emotional support to others who needed help dealing with grief and loss during the pandemic. They gave each other sympathy and uplifting messages to overcome the grief. For example:

Comment 1: So sorry to hear what you and your family have been thru sounds like you've got it with your positive attitude, half the cure. Please take any help anyone offers and take care of yourself first. Hope you're 100% soon.

Comment 2: My deepest sympathy for your loss. My deepest admiration for your desire to live for you and your two boys. You have a big story to tell.

Comment 3: That's really sad for you sending you so much love and strength to carry on keep doing what you are doing you sound very determined.

### **Group Gave Me Perspective**

As expressed through posts, COVID-19 long haulers faced similar challenges and uncertainty as they were embarking on the post-COVID journey. Without a clear solution or effective treatment, they struggled to cope with a range of symptoms and emotional trauma associated with the infection. COVID-19, however, gave a number of members hope as well as a new perspective on life.



## *Hope*

Many members shared their personal success stories in the group to give hope to others, including hope for a full recovery, to be better, and to be normal. One long hauler who experienced depression and suicidal thoughts, for example, shared how her physical and mental symptoms improved after she received the COVID vaccine. She said:

I just want to give some hope. I had off and on HIDEOUS depression, filled with suicidal thoughts. I couldn't smell anything. I had severe tinnitus. I got my second Moderna on Saturday about 2:30pm. Yep, the next 36 hours are best forgotten! BUT AT ABOUT THE 48 HOUR MARK, SOMETHING CHANGED.....The only way to explain it is, imagine being zipped up in a clothes bag. Then it is unzipped and you step into a lightness of nearly everything: my mental state was the first and most notable. It was like stepping out of Pigpen's cloud into a citrusy clean meadow. I'm sorry if this sounds flowery or what not...but that was it. And I knew then, and know now, it is real—the lifting of the dark despair. My sense of smell soon followed. I must have sniffed every candle in the house. The tinnitus is better, it may stay a low grade hum. I can live with that. I'm cautiously optimistic but the key is OPTIMISTIC. My emotions are mine and not being led by some virus. If it changes I will certainly post. But I wanted hope in my worst moments and now I want to pass that hope on. God bless you all.

In reply, a number of group members expressed their emotional distress as they struggled to recover and stated that this message gave them hope when they needed it most. For example, one said, "This makes me cry I'm just filled with darkness and nobody understands." Another wrote that "this is good to hear and hope is so

important to have. I wish the same wonderful results for everyone else suffering with this horrible illness.” Still another said, “I’m desperately hoping, wishing, praying and willing that it will cure me.”

Hope allowed some COVID-19 long haulers to achieve a sense of peace amidst the uncertainty. Cultivating a grateful attitude and a positive outlook, such as simply feeling grateful for being “alive,” as one long hauler said, provided others with hope and perspective on living a normal life with the illness. One group member said:

GOOD NEWS! After 7 months of long COVID and SARS Cov2 pneumonia, my follow-up CT scan of my lungs is 80% better and the pulmonologist expects it to completely clear in the next 3-4 months with no permanent damage or scarring of the lungs!!! Sure I still have some other crazy symptoms but they are less than they were and I am alive!! This has given me hope not just for me but for all of us who suffer as long haulers.

This type of message provided other long haulers with hope that recovery was possible and they, too, could be healed and survived. “What awesome news! Very happy for you and thanks for sharing. It gives me hope!” and “Wonderful news! Thank you for giving me hope!” were some of the replies to illustrate that the story provided them with a new perspective on life and recovery journey.

Some people who faced ongoing symptoms and struggled to return to normal life routines also shared their problems in the group, asking for advice and emotional support as they were losing hope. One member asked, “Just wondered if any of you were eventually able to jog/run again w/out major heart racing issues? I am a long hauler. Covid gifted me w/ anemia, an enlarged heart and now asthma (nothing before covid)! Wanted to know if there’s any hope?” Many long haulers, though facing the same challenge, shared messages of hope, love, and faith to others. For example:

There is hope! I have stuck to a low inflammation/ antihistamine diet, studied holistic ways to heal myself whether it be herbs, supplements, or little ways to relieve stress. I've taken to cold water therapy which has tremendously helped with lowering my heart rate. I'm an avid hiker and I started off flat and I'm back to doing moderate inclines on the trail. I know this sounds easy to say but I decided I was not going to accept this as my "new normal" and I truly believe that headspace has provided a lot of healing. Good luck! You'll get better!

While some uplifting messages such as "Never give up" or "Never lose hope" appeared in several wall posts and comments to inspire others to focus on the positive perspective of life, some long haulers expressed feelings that they were losing hope. One member expressed her concern if she would ever recover again and perhaps "dying is the better bet," she said:

I'm trying my hardest to believe that one day I'll be better. Some days I have more hope and faith than others. Some days I wonder if I'm slowly dying. It's very frustrating, I don't think people realize that I'm in as much pain as I am. I have four children so I tried to put on a brave face. The brain fog and what feels like dementia is really scary, I find myself forgetting simple words or meshing two words together. At this point I'm not sure if living like this or dying is the better bet. Good luck to all of you and I wish everyone wellness.

Some members replied that they could relate to her post, yet providing her with emotional support and hope. One man who had lived with COVID symptoms for eight months, for example, said, "I am at 8 months and have felt the exact same way. The fog is much better and the depression has waned quite a bit.. still having bad

breathing days and fatigue but not nearly as bad as they were a few months ago...

Keep your chin up, we will get better!!!”

### *Journey*

To many members of the Facebook group, long-haul COVID-19 is a journey of growth and life transformation. Though there was no explanation why people experienced a wide array of symptoms, and there was no known cure at the moment, some COVID-19 long haulers looked on the bright side of life, stating that COVID-19 had given life lessons and they acknowledged and accepted that their lives had changed. According to one member:

My husband took me out to dinner tonight to celebrate my first full week in the office. It was tough, and I was beyond exhausted after each day, but I did it. Thankful I don't have to go back for 8 more weeks, however!! I thought I might be ready to work from the office full time, but, after this week, I know I'm not there yet. If I have learned anything since my positive COVID test in March, is that I need to listen to my body and to be patient. It's the small hurdles and goals that I meet that gives me hope to a full recovery. This isn't my life, it is just my life right now. COVID took many things from me, and has taught me many lessons.

Similarly, another long hauler who had lived with the illness for almost one year shared her COVID-19 journey to inspire others. It was a long and winding road; however, she accepted the situation and learned to love her new self:

On November 15 it will be 1 year since I started my Covid journey. 4 weeks in the hospital—not on a vent thank the Lord. I was on the high flow, forced air, humidified oxygen at 100%. Was able to finally get home on 5 liters of oxygen, but physically depleted. Did 8 weeks of physical therapy, breathing

exercises and daily homework from PT. Covid pneumonia has left my lungs scarred. I still use oxygen at night and now that I'm starting to exercise again, I find I need oxygen to do that too. With exertion my heart goes into irregular rhythms and I'm short of breath. I already have asthma, diabetes, high blood pressure and immune deficiency, so what's one more issue to deal with. I started a new injectable biologic for my asthma back in July and that is helping along with breathing treatments I do twice a day. I'm still scared to be around large crowds. I've had my third Covid shot, my flu shot and a booster pneumonia shot. I'm tired all the time and I still have days when brain fog hits me, but I do ok most of the time. My husband and 2 teenage boys have to slow down for me these days, but I try not to be a burden. It took me to March 2021 to get back to work on full time oxygen then. I had to change my job after 27 years. At least I could stay with my employer. I tell you all of this for this point...Tonight I had a good cry...mourning the me of last year. I compare everything to last year. I've struggled, I've been angry, I've been depressed and I've cried... a lot. I'll never be me of last year again. This is my new me now. So much medication, so many supplements, so many concessions I didn't think I'd have to make at 49 years old. Life goes on...I'm not the same, but I've had to learn to love the me of today and that's hard. I go slower, working and moving with purpose and just having to figure out my new normal. I have a great support system, a wonderful family, a job that has done all they can to keep me working and lots of friends that have prayed for me, called me and who I am more than grateful for...especially hearing all of your stories and knowing that I'm not alone in this long hauler journey. So, keep

fighting, keep asking questions, keep supporting each other and keep loving your new you.

The replies demonstrated that other long haulers were also on the same journey, stating: “I feel like I’m looking in a mirror, same exact situation for me!!” Despite the distress, they were grateful to be alive. One group member commented:

You and I are on a very similar path my sweet friend. I am NOT yet back to work because i am still on oxygen full time. I'm a nurse ....I worked the Covid unit and got covid doing what I love in Full PPE. The fatigue, the damage to my lungs, having my whole world turned upside down has been a very angry filled ride this past year. I’ve got a WHOLE New respect for lab rats!!!!!!

Thank you to each and every single member of this group. I am a pretty strong person. But igotta tell you, with out your comfort, wisdom, and ears, this journey would have been a lot harder!! I am forever grateful to you all and to God for keeping me alive. Again I am gonna straighten my crown and fight. I am my fathers daughter!!!!

Some long haulers found this life-changing journey an inspiration for them to move forward and get back to life, though it was not easy to do. “You inspire. We are almost the same,” commented one member. “Got it the week of November 2020. Still on oxy at night, lungs permnently scarred at 68% functionality. I have yet to accept the new me.” Some others, however, tried to maintain a positive outlook on life, saying, “Covid has changed my life as well. I too have many of your remaining issues, but your positive attitude is inspiring!”

Some long haulers shared their personal stories of pain and perseverance and strength and survival to motivate others to fight against post-COVID symptoms. This

narrative allowed others to see the poster and themselves as “survivors” and “warriors” who never gave up the shared fight:

I have been seeing so many stories of those who have survived Covid in general and thought I'd share mine in hopes of giving some the hope they need knowing you can beat this! I'm coming up on my one-year Covid-ersary, and I think about it A LOT! When my siblings and I tested positive back in November of 2020, we did not know at the time that Covid would pretty much turn our lives upside down (we also were already planning to get vaccinated, but they were not available to the general public yet) My mom had just started chemo in October so Covid was just the little extra push we needed to make it worse! We had already been following guidelines, social distancing, etc. because I previously had Kidney Failure and my twin sister was coming up on her one-year Kidney Transplant-ersary so we were very careful... but we unfortunately caught it (I'm thinking maybe from a clinic I was at for my regular doctor appointments!). My siblings all had very mild symptoms, but I ended up with the worst side of things and ended up with Covid Pneumonia... by November 19th, I was rushed to the hospital after passing out at home, in the ICU by about the 21st, and finally, after talking with doctors and family, on the vent by the 27th of November because my body was basically giving up. I was finally taken off the meds that were keeping me in a coma and started being aware of my surroundings by Christmas! I had lots of complications because of the Pneumonia, added to the fact that I had Kidney Failure... I had been trached (twice - we were positive that everything was good when we took it out the first time, but I ended up going into respiratory arrest again so it was placed back again for about another two weeks - biggest issues

were my vocal cords being paralyzed)... I even shaved my head bald because with thick, polynesian, curly hair and not being able to wash it for weeks, it was completely matted. I spent about 2 1/2 months in the ICU before finally being transferred to a rehab center for Physical and Occupational therapy for about 2 weeks. I spent 3 months away from home and away from my family! There are no words to explain the depressing thoughts I felt when I got home... I had to use a walker (at 34, very depressing for myself), a commode, I had to have someone sleep in my room because breathing wasn't great yet and to help me to the restroom, I spent an entire month in my room because I couldn't even walk or go to our kitchen and eat meals with my family! I had nurses, PT & OT at my house a few times every week for about 2 months to help me regain my strength. I've had many hospital visits since, including Pneumonia again in July, subglottic-stenosis which results in a bronchoscopy and dilation of my airway (back in May and again yesterday), and just a lot of brain fog, fatigue, etc. Not to mention the mental aspect of this entire thing! TODAY, I feel like I am at 85%! My family, who have been such a huge, huge support to me during this recovery, just keep talking about how they didn't think I would be where I am at today! We had so many close calls where they wanted my family to sign a DNR while on the vent, and they kept refusing! I haven't used a walker or commode since about May and can now go on walks of more than 30-45 minutes and my o2 doesn't go below 97-99 I still have a bit of fatigue, some brain fog, and I'm still dealing with PTSD (this will take time) but overall, I keep pushing myself a little every single day to get back to where I want to be! We hear so many horror stories and hopelessness in this all so I hope that you all keep on fighting the good fight



because when you come out at the end, the feeling is beautiful! The little wins, whether it's doing a lap or two around your living room every hour, or standing and cooking - even if it's just a simple pot of ramen, are so important and help!

The replies showed how much others were being inspired. Some comments called the poster "warrior" and encouraged all COVID-19 long haulers, saying "Oh My Gosh YOUR STORY GIRL but WE ARE SURVIVORS!" Another member found this post uplifting and in return, "sending all the positive vibes your way," she commented. Other long haulers praised the poster's strength and resilience that gave the drive and motivation for others to survive. "THANK YOU for sharing your story," commented one member. "I am so glad you overcame this and have taken control back of your life! You are phenomenally strong!!!!!!!"

## **CHAPTER V**

### **DISCUSSION**

In this qualitative study, I explored the contents of a Facebook group established for COVID-19 long haulers. My objective was to understand how COVID-19 long haulers exchange social support with one another and make sense of their illness uncertainty. Three themes emerged from my analysis of the group: group gave me voice, group gave me community, and group gave me perspective. Generally, the findings demonstrated that COVID-19 long haulers have been facing lingering symptoms and distressing emotions stemming from unpredictable and uncontrollable conditions. Without a clear path to recovery, COVID-19 long haulers have struggled to make sense of their health situation and thereby seek support as they cope with their illness. The Facebook group allows them to connect with other long haulers, share their stories, and learn from other people's experiences to comfort themselves, make sense of their own problems, and regain their sense of self. This is in line with Hyden's (1997) explanation about narrative as a powerful tool for patients to make sense of their illness and co-construct a new meaning of self. The ill are creators and narrators of their own stories (Morris, 1998), and stories are a "medium for connection" (Baruch & Springs, 2018, p. 216).

Theme 1: Group Gave Me Voice shows how the virtual support group allows COVID-19 long haulers' voices to be heard. After being infected with the virus, a number of COVID-19 long haulers have experienced a wide range of new and recurring symptoms such as body aches, exhaustion, loss of smell and taste, sleep disorder, depression, blurry vision, and many more. There is no clear explanation why and how people experience long-haul COVID, and there is no known standardized treatment at the moment. The lingering physical, neurological, and mental symptoms

of the long-haul COVID varied in intensity and duration. COVID-19 long haulers' narratives, therefore, appear to revolve around many of the illness uncertainty associated with a wide range of symptoms. Additionally, they share negative experiences with doctors and other medical professionals as they struggle to find definitive answers to their illness problems. As COVID-19 long haulers share their stories of experiences with symptoms and their negative feelings toward the uncertainty, while also receiving a number of reactions and comments showing understanding and empathy from others, they feel that their voices are heard. They exist. And they are not perceived as "crazy" as mentioned frequently in the posts. The virtual group is regarded as a safe place where COVID-19 long haulers feel free to vent out their frustrations and share their negative emotions without judgment.

Long-haul COVID is a subjective experience because the severity of symptoms cannot be measured with a tool or a scale. This is in line with Hyden's (1997) view that "the symptoms and consequences of illness, such as the loss of functionality, are not purely objective phenomena, but rather are phenomena that take on meaning for each individual," (p. 56). By sharing stories and receiving comments and answers from other experienced group members, COVID-19 long haulers are able to make sense of their illness and transform the symptoms into meaningful events for themselves. It shows that "shared narratives of sufferings can hold healing powers" (Morris, 1998, p. 201), and within this group, long haulers can share their stories, learn from other people's stories, and regain their sense of self.

As shown in Theme 2: Group Gave Me Community, the Facebook group serves as a social support community for members to ask questions about symptoms, ask for advice about treatment, and share their emotional support with one another. As COVID-19 long haulers battle with long-term symptoms and struggle to return to

normal self, they ask for guidance about treatment options and lifestyle changes, with attempts to regain control over their health and wellbeing. Reassurance also provides validation for those who share common issues and fears or have been through similar experiences. More importantly, the virtual support community helps COVID-19 long haulers combat the isolation and reduce loneliness. In the findings, a number of long haulers expressed their gratitude towards group members as they were in this situation together.

Social media has become an important platform for patient engagement, especially Facebook, which offers the ability for two-way communication. Under physical distancing measures during the pandemic, people turned to online communities where they could exchange experiences and support one another from afar. The member-driven nature of this Facebook group may have a potential to attract more members who would like to interact with COVID-19 long haulers who are dealing with similar difficult circumstances.

The results from the current study also showed that, in times of crisis, people provide encouragement and emotional support to one another as they cope with fear and stress. Encouraging messages such as “Never give up,” “Keep up the good work,” “Hang tough,” or “Keep fighting” provide long haulers with emotional comfort that keeps them engaged and inspires them to take a more active role in managing their condition. This finding supports Ji and colleagues’ (2019) statement about the role of emotional engagement in shaping individual’s behaviors.

While many long haulers in the Facebook group shared their positive stories about their recovery and progress, some lost their loved ones from the illness. Sharing their grief with others who have experienced similar losses might help them cope with the situation. People who write comments or provide reactions to the emotional posts

can be called “emotional rubbernecks” (DeGroot, 2014, p. 79). This term refers to those who engage in the Facebook group to “cope with their grief-related feelings” (p. 82). By reading emotional messages, members can regulate their own emotional states and create emotional experiences with others (Ji et al., 2019). This is also in line with the finding from Horstman and colleagues (2016) that, through interactional sensemaking, individuals engage, collaborate, and share stories together to make sense of their common situations.

As outlined in Theme 3: Group Gave Me Perspective, a number of COVID-19 long haulers look for a positive side of COVID-19 and share their success stories or small wins to give other members a glimpse of hope that they, too, can recover and live a normal life. As they call themselves survivors or fighters, narratives can empower members by making them heroes in their own stories (Morris, 1998). Illness narratives can take several forms, but it is apparent that quest stories occur frequently in the group as COVID-19 long haulers are striving to accept the situation, living with the long-haul symptoms, and seeing COVID-19 experience as a life transformation. This finding supports studies by Whitehead (2005) and Horstman and colleagues (2016) that, through narratives, patients can develop control over the event and reconstruct their own self. By interacting with one another through posts, reactions, and comments, COVID-19 long haulers make sense of unexpected events and gain new perspectives on illness and life by confirming each other’s ideas and emotions and “incorporating the other’s experiences into their own stories” (Hortsman et al., 2016, pp.4–5).

### **Limitations and Suggestions for Future Research**

Although this research provides new insights into the lived experiences of COVID-19 long haulers, the study comes with limitations. A major limitation of this

research is that I examined one particular COVID-19 long hauler Facebook group. Though it is the largest virtual support group available on Facebook, not all COVID-19 long haulers may face the same challenges, and the posts and the views expressed in the group might not represent views and concerns of the whole COVID-19 long hauler population. Because I collected the five most popular posts per month for 13 months, I may have missed other aspects of support that the members sought and provided. Therefore, to explore the issues associated with COVID-19 long haulers, future research may study more diverse virtual support groups from other social media platforms.

Additionally, COVID-19 information obtained from the group was from the members' subjective experiences. Hence, it is not possible to verify their information accuracy related to long-haul COVID symptoms and treatments exchanged within the group. Furthermore, I collected data from the existing posts and comments without interacting with members. Not being able to interview any member limited my access to their thoughts, experiences, and explanations. Although I paid close attention to the details, it might be possible that some of the original contents may have been misinterpreted without additional data from follow-up interviews. Also, social media posts always have spelling mistakes, grammar errors, emoticons, and abbreviations, which made the content analysis challenging.

Despite the limitations, this qualitative study allowed me to access a rich source of data of long-haul COVID directly from COVID-19 long haulers who have been living with chronic conditions for days, weeks, months, or years. In summary, the results from this study provide long-haul COVID findings that contribute to the growing literature on how patients make sense of their illness uncertainty through narratives and how social media can serve as a virtual social support community from

patients to patients where members can support each other, informationally and emotionally. Although all the narratives shared within the group are personal, they are valuable for other members to make sense of their illness, manage their physical and emotional symptoms, and deal with stressful conditions.

As a COVID-19 long hauler, I have suffered from some lingering symptoms for eight months, especially loss of smell. I believe I have only regained about 50 percent of the smell perception I had prior to being infected with COVID-19. By reading and analyzing the posts in this Facebook group, I have felt that I am not alone in the situation, and the narratives shared in the group allow me to make sense of my own situation. Long-haul COVID is real. Though there is no known cure, it is manageable, and it is okay to take time to heal.

Looking forward, it is important to recognize the value of social media as a virtual supportive platform for patients who share illness narratives. Healthcare providers should understand the strengths and limitations of this type of online community. Policymakers should also consider using social media in their health communication efforts in order to communicate accurate information on post-COVID conditions and correct any misinformation that may occur. Since long-haul COVID is still a mystery and the COVID-19 pandemic is not over yet, I hope that these findings can address the COVID-19 situation and contribute to advances in public health research.

## **Conclusion**

As I write this thesis, long-haul COVID remains an unknown mystery of coronavirus that leaves COVID-19 long haulers suffering with new and recurring symptoms for a long period of time after their initial infection. This study has shed light on the illness narratives of COVID-19 long haulers and the use of virtual

communities for people facing similar challenges to seek and provide social support to one another, make sense of their health conditions, and cope with distress and concerns related to the illness. Findings from this study can advance theoretical development in the area of health communication and contribute to improving public health. Looking forward, it is important for healthcare providers and policymakers to understand the value of illness narratives and the popularity of Facebook group features to better design effective health communication strategies and campaigns for people in other situations or those who might need social support.



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