

How Lived Experiences of COVID-19 Shape Mental Health: A Case Series of COVID-19 Patients from Wuhan, China

ABSTRACT

Coronavirus disease 2019 (COVID-19) severely impacts physical and mental health of COVID-19 patients. This study aimed to investigate COVID-19 patient narratives to reveal how their lived experiences of COVID-19 infection and quarantine shape their mental health. In-depth semi-structural interviews were conducted with 5 COVID-19 patients from Wuhan to elicit their lived experiences of COVID-19. The case reports showed that persons diagnosed with COVID-19 infection and admitted to the COVID ward developed the symptoms of anxiety, worry, low mood, frustration, irritability, stigma, distress, guilt, and loneliness. Lack of scientific information, long-term social isolation, and limited social support were the main risk factors leading to their mental health problems. The study suggests that timely diagnosis of patients' mental health problems and diverse psychological interventions are needed before, during, and after their hospitalization.

Keywords: Patient isolation, COVID-19, mental health, personal narrative

Introduction

The Coronavirus disease 2019 (COVID-19) pandemic has multiple consequences on the health and well-being of individuals.¹ A rapidly expanding body of work on COVID-19 and mental health reveals that the pandemic led to increased psychiatric disorders such as post-traumatic stress, depressive symptoms, anxiety disorders, and grief-related symptoms.¹⁻⁸ Numerous survey studies regarding the mental health of COVID-19 patients have indicated that patients with confirmed COVID-19 are very likely to experience mental health symptoms such as anxiety, depression, distress, insomnia, boredom, loneliness, and anger.⁹⁻¹³ For instance, a study of 62 354 COVID-19 patients from America showed that patients demonstrated a higher risk of psychiatric problems such as anxiety disorders and insomnia, as compared to the healthy controls.¹³ A survey of 3947 suspected COVID-19 patients from Vietnam found that they demonstrated higher depression scores and lower quality-of-life scores.¹² Post-traumatic stress disorder was reported as another salient mental health symptom among patients diagnosed with COVID-19, in particular among those who have a near-death experience, delirium, and ICU-related trauma.^{10,11} Notably, a survey of 714 stable patients infected with COVID-19 from Wuhan indicated that post-traumatic stress symptoms among patients were as high as 96.2%.⁹

Despite the large body of survey literature regarding COVID-19 patients' symptoms of mental disorder, it seems that little research has focused on the in-depth psychological status of individual patients diagnosed with COVID-19. To remedy this issue, examining patients' narratives of lived experiences of COVID-19 infection provides a new perspective on capturing the psychological status and mental health of patients during the pandemic.¹⁴⁻¹⁸ For instance, Sahoo et al¹⁶ reported the lived experiences of 3 hospitalized patients infected with COVID-19 in India and discovered mental health symptoms such as anxiety, fear, worry, and abnormal behaviors among the patients. In this sense, the mental health issues of COVID-19 patients should be evaluated regularly by healthcare professionals, to help patients tackle their psychological problems. Missel et al¹⁵ explored the lived experiences of



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Table 1. Demographic and Clinical Information of the Participants

Subject	Gender	Age	Marital status	Occupation	Time in hospital	Severity classification	Infection source
1	Female	38	Y	Housewife	22 days	Severe	Family cross-infection
2	Male	38	Y	Businessman	20 days	Moderate	Cake shop
3	Female	71	Y	Retired	40 days	Mild	Shopping center
4	Male	35	Y	Businessman	20 days	Moderate	Tourist attraction
5	Male	31	Y	Computer engineer	16 days	Mild	Business trip

Subject 1 and Subject 2 are a couple.

Y, yes.

15 COVID-19 patients in Denmark through telephone interviews. The results showed that the COVID-19 infection posed a threat to patients' existence, bodily perception, and social relationships. Noteworthy is that they experienced stigma thinking that the people around them might act with excitement and curiosity. Thus, follow-up and rehabilitation for patients during and after COVID-19 infection are essential for their recovery. Sun et al¹⁷ conducted semi-structured interviews with 16 COVID-19 patients from China. The results revealed 3 stages of emotional potency among patients. At the beginning of infection, patients experienced denial, shame, and fear; in the second stage, they gradually accepted and faced the medical treatment; in the third state, they were uneasy with the coronavirus on the one hand, but they expected a positive test result on the other. Through a small-scale qualitative study, Wu et al¹⁸ identified 8 intertwined dimensions impacting the hospitalized COVID-19 survivors' well-being: physical symptoms, anxiety, trauma, economic loss, place-based identity, self-stigma, health self-interventions, and changing lifestyles. Deng et al¹⁴ interviewed 6 re-positive patients to investigate their lived experiences of recurrent COVID-19 infections. The results showed that the SARS-CoV-2 nucleic test re-positive patients demonstrated psychological problems such as anxiety, depression, irritation, stress, mistrust, insomnia, suicidal tendency, grief, panic, and worry. Long quarantine duration, restricted isolation space, fear of virus transmission to others, limited family support, worry about delayed work, and negative news in mass media coverage were the main risk factors leading to their mental health issues.

Taken together, although Wuhan was the most seriously affected city in China at the outbreak of the COVID-19 pandemic, the lived experience about the psychological status of COVID-19 patients in Wuhan were somehow neglected, in that the narrative studies on the mental health of COVID-19 patients in China mainly concerned participants from Henan province,¹⁷ Guangxi province,¹⁸ and Chongqing city.¹⁴ This study investigated how a group of 5 COVID-19 patients from Wuhan communicated about their lived experiences of COVID-19 through

MAIN POINTS

- Five cases of COVID-19 patient narratives were reported, to reveal how their lived experiences of COVID-19 infection and quarantine shape their mental health.
- COVID-19 patients developed the symptoms of anxiety, worry, low mood, frustration, irritability, stigma, distress, guilt, and loneliness.
- Lack of scientific information, long-term social isolation, and limited social support were the main risk factors.
- Timely diagnosis of COVID-19 patients' mental health problems and diverse psychological interventions are needed before, during, and after their hospitalization.

in-depth semi-structured interviews on the phone. It aims to explore COVID-19 patients' mental health issues before, during, and after hospitalization, and offer insights to psychological interventions for COVID-19 patients at different stages.

Methods

Design

The narrative data in this study emerged from a larger qualitative project "Lived-Experience Narratives and Mental Health of People in Wuhan During the COVID-19 Pandemic." This project used semi-structured interviews on the phone to collect lived experiences of 27 participants from Wuhan, including COVID-19 patients, frontline healthcare professionals, social workers, teachers, businessmen, and college students. Regarding COVID-19 patients, the criterion was set to be those who had been hospitalized for at least 14 days and were required to quarantine at home or hotel for another 14 days after being discharged. Due to the ongoing lockdown, isolation, and prevention policies, telephone interviews were employed to ensure the personal safety of the interviewer and interviewees.¹⁸ The term "lived experiences" designates the phenomenological tradition regarding experiences of the everyday lifeworld. Such lived experiences are prereflective and less available to our awareness.¹⁵ Thus, the lived experience narratives can capture COVID-19 patients' psychological status that cannot be explored by survey method. The lived experience narratives in the present study involved multiple dimensions of the COVID-19 patients' of quality of life, such as physical, mental, and social factors.

Participants

Five COVID-19 patients infected in Wuhan were randomly selected to attend the semi-structural interview by cellphone, as paid volunteers. They were contacted through a recruitment advertisement online. Table 1 shows the participants' demographic and clinical information. The participants were contacted by phone to obtain verbal informed consent. They provided additional written informed consent before the interview. Subjects 1-3 were interviewed between June 2020 and July 2020, and Subjects 4-5 were interviewed in October 2020 by a single researcher specializing in psycholinguistics.

Interview Procedures

Prior to the interview, the interviewer made an appointment with each participant to ascertain that the condition of the participants was suitable for the interview. During the interview, the conversation started with some general warm-up questions. To obtain the lived experience of going through the COVID-19 infection, a narrative approach was used for data collection during individual interviews.¹⁵ The participants were encouraged to narrate their lived experiences and feelings concerning COVID-19 infection in an open-ended

fashion. The interview questions included multiple dimensions of their experience, such as “How were you infected by COVID-19?”; “How did you feel when your infection was confirmed?”; “What did you do before, during, and after hospitalization?”; “How did you feel in the pandemic hospital?”; “How did healthcare professionals help you in the hospital?”; “How were your work and daily life affected by the infection?”; “What gave you comfort when you felt frustrated?”; “What changes in perceptions of life and death do you have?”; and “How did you deal with social relationship after discharge?”. Each interview lasted about 60 minutes, depending on the condition of the patient. If the patient felt reluctant or unwilling to continue the interview, the interview was terminated immediately. The interviews were recorded and transcribed verbatim by the individual interviewer for case reports.

Case Presentation

Case 1: “I drafted a will, stating how to distribute my property after death.”

The 38-year-old woman (Subject 1) was hospitalized after being tested positive for COVID-19. Three out of five members in her family were infected, namely herself, her husband, and her mother-in-law. According to her narration, she was infected by her husband. This irritated her and she was “filled with anger that no words can express.” When she had to leave her 5-year-old daughter and set off for the hospital, she was anguished as if “her flesh was cut off.” On the first day of hospitalization, she was tranquil in a single ward because her physical symptoms were mild. She was confident that she could recover soon with the help of the medical staff. On the second day, however, she started to feel anxious when she was moved to the same ward with her husband. Her husband’s severe symptoms “cracked her confidence” and “drove her to anxiety.” On the third day, her ward was changed again and she stayed in the same room with her husband and mother-in-law. The pain regarding COVID-19 and frequent change of wards made her crazy and mad. Loneliness and confusion ruined her emotion although she stayed with her family in the same ward. A few days later, her symptoms were aggravated with fatigue and emesis. She felt extremely fearful of COVID-19, and “drafted a will, stating how to distribute her personal property after death.” For one thing, she worried about her daughter, in case her husband married another woman who might maltreat her daughter. For another, she was extraordinarily afraid of death. She kept searching the internet for the symptoms and reports of the fatalities. On the 20th day of her admission, the doctor informed her that her husband and mother-in-law had been cured and discharged from the hospital. However, she still had to stay in the hospital as she had not yet reached the standard for discharge. She was severely stricken, crying and shouting in the ward for a whole day. During the hospitalization, she felt like “being caged and fed in a prison.” She did not trust the medical staff, considering that “she was a laboratory mouse in experiments.” She lost confidence in the treatment. When she felt anxious, frightened and depressed, she had a video chat with her daughter or looked at the pictures of her daughter to ease the psychological trauma. Leaving her daughter brought her “a deep sense of guilt,” so she bought her daughter toys and stationery online. After being cured and discharged from the hospital, she was reluctant to share her COVID-19 experiences with others, in the fear that “friends or neighbors might isolate her, criticize her family, or discriminate against her daughter.”

Case 2: “I am blamed for infecting my family members.”

The 38-year-old man, who was the husband of Subject 1, was admitted to the same hospital after he tested positive for COVID-19. He was a businessman in Wuhan. As reported by him, his wife and mother were probably infected by him. After returning from Wuhan to his hometown in Xiangyang city, he showed the symptoms of fever but still stayed home with his family. Five days later, 3 out of 5 family members were detected positive for COVID-19, which made him feel “heavy-laden” and “extremely guilty.” He worried that his daughter might be infected by COVID-19, and her future would be negatively impacted. When the medical staff took them to the hospital, “his anger was rising up” and he yelled at the staff, considering that “it was the departure for death.” He insisted that “the infection of his family members should be blamed on his quarantine at home.” In sum, he received 20 days of treatment in the hospital. Compared with his wife, he did not cooperate with the nurse for the admission procedures, given his state of furiousness and anger. Worried about infecting his friends, he kept calling those he had met as soon as he was hospitalized. During his hospitalization, the worry of losing his family and business troubled him. He felt immensely anxious that his daughter might be deserted if his wife and himself died of COVID-19. He was also worried that the pandemic had severely impacted his business. His sleep was light, despite the fact that that autonomous sensory meridian response (e.g., sounds of chewing, rubbing hands, pulling ears) was used to promote sleep. Furthermore, he suffered from loss of appetite, showing the symptom of emesis. When he was discharged from the hospital and quarantined in the hotel, he was still in a state of anger and irritability. He even regarded those who came to help him as “monsters and demons.” He was dominated by anger throughout the hospitalization and the hotel quarantine. These psychological symptoms were confirmed by the DSM-5 scale of anger and anxiety, which showed a high level of anger (18/25) and a medium level of anxiety (13/40). He speculated that “those who had been infected with COVID-19 like him would be isolated from others psychologically until the pandemic is completely under control and the vaccine is developed.”

Case 3: “Why 2 elder patients in the same ward were discharged before me?”

The 71-year-old woman was infected when she was shopping in Hankou, Wuhan. At the beginning of her hospitalization, she was tranquil and open-minded, despite the helplessness and confusion she felt about COVID-19. She searched for information on the internet and shared it with 2 fellow patients who had no smartphone. After a few days of treatment, however, she felt impatient and anxious because patients in her ward were discharged one after another except herself. She kept doubting why 2 elder patients in the same ward had been discharged before her, and why she could not reach the criteria for discharge. When she stayed in the hospital for 40 days, she was tested with high blood pressure. In addition, she had difficulty in sleeping due to the light in the corridor and the sound of the ventilator. Hypnotics was used to aid sleep.

Before being infected by COVID-19, she was active in organizing activities such as singing in the university, traveling around China, and holding parties. However, she was reluctant to contact her friends after discharge, in the sense that “her friends may isolate her.” She seldom went outside except for practicing sport in the park by

herself every morning. Despite the anxiety, depression, and impatience that she had experienced, she generally seemed peaceful and optimistic about COVID-19.

To confirm the accuracy of her memory and narration, we interviewed her 44-year-old daughter. As far the daughter recollected, her mother always stayed with the oxygen concentrator during home quarantine, showing a strong desire for survival and a fear of COVID-19. During the 40-day hospitalization, the failure to reach the criteria for patient discharge made her mother depressed, anxious, and irritated. She emphasized that her mother become self-contemptuous, considering that “she was a COVID-19 patient who would be detested.” Moreover, her mother turned highly defensive as she regarded herself as a trouble for the family. She behaved evasively, by isolating herself in the bedroom and returning to her hometown alone. The third-person narratives reflected the concealed side of her mother’s psychological status, suggesting that Subject 3 felt embarrassed to mention her negative psychological experiences and her intention to isolate herself from others.

Case 4: “My brain kept thinking about the infection of COVID-19 without control.”

The 35-year-old man (Subject 4) was tested positive for COVID-19 when he went to the hospital with a fever. During his hospitalization, he suffered from insomnia, with the spirit “broken down.” He was scared by the rumor about COVID-19, in that “his hair was standing on end.” Within 2 or 3 days, 10 persons in his extended family were infected, which “increased the heavy load of his heart.”

Later, he was transferred to a higher-level hospital. He felt that “his mind had lost the direction” and insisted that “he became a laboratory article in experiments.” Frequent nighttime awakenings bothered him and he “lost the ability to control his brain.” According to his report, the sound of the handcart by the nurse terrified him awkwardly. Worse still, his son was infected by him and was sustained by nutrient solutions because he could not eat properly. His worry about the well-being of his son increased his helplessness. Being reluctant to answer any calls, he sat by the window in a trance. After several consecutive positive results of the nucleic acid test, he felt that “he lost all consciousness and senses and only wanted to lie in bed.” He endeavored to distract his attention from the infection, but “his brain kept reflecting on the infection of COVID-19 beyond control.” The locked doors in the hospital increased his sadness and fear. He considered himself to be “locked in prison.” Fortunately, the healthcare professionals unlocked the door after a two-way communication. This relieved his mood to a large extent. Furthermore, encouragement from the healthcare professionals consoled him deeply. When he was sent to a hotel for quarantine after recovery, he felt that he “successfully escaped from the disaster” and requested the driver to speed up.

Generally, the adverse impact of COVID-19 on him lasted for a long time. The memory of a patient whose limbs turned stiff lingered in his mind. His business was affected by the pandemic and he had to sell his flat due to the economic loss. It was his family that sustained his spirit of living. Nevertheless, discriminatory words such as “the man with the virus came back” by his neighbors haunted him when he was quarantined at home.

Case 5: “I felt guilty to infect my family members.”

The 31-year-old man (Subject 5) was hospitalized after he tested positive for COVID-19. At the beginning of his hospitalization, he was extremely anxious and frightened due to his visit with about 50 family members of his extended family before he was diagnosed with COVID-19. Worse still, the fact that 4 family members, including his young niece, were infected by him increased his guilt and frustration. His niece was forced to be quarantined because her parents were also infected by him (Subject 5). Worrying about his family members, he kept in touch with them frequently. He tested negative on the second day of his hospitalization but retested positive on the third day. Developing fever and being isolated from his family, he suffered from loneliness and depression. Furthermore, dissatisfaction with the food in the hospital and extreme worry about his career “drove him crazy.” Noteworthy is that he was petrified of death in the sense that “he was in his prosperous age with a happy family and a successful career.”

Fortunately, the understanding from his family encouraged him a lot. His family members believed that “he was also a victim who did not spread the virus on purpose.” Moreover, the healthcare professionals in the hospital took good care of him, which brought him the belief that he could “undoubtedly defeat the monster of COVID-19 successfully.” After a few days of treatment, he turned optimistic, as his symptoms of fever were alleviated. He started to work on the phone, and this changed his mood and left him with profound memory. According to his narration, “parents are the wall against death, and he would not worry about death as long as his parents are still alive.”

After being released from the hospital, however, discrimination and complaints such as “he is a plague that afflicts us deliberately” bothered him deeply. After the experience of the COVID-19 infection, he realized that family was his most precious treasure, and he regretted treating other people too harshly before.

Discussion

In our case reports, the 5 patients diagnosed with COVID-19 demonstrated various psychological problems such as anxiety, excessive worry, irritability, low mood, frustration, stigma, distress, guilt, and loneliness.¹⁶

Previous studies have shown that lack of information and ambiguous knowledge of COVID-19 can lead to mental health problems.^{14,19,20} According to the narratives of our interviewees, their severe stress, worry, irritability, and mental agony were largely attributed to the lack of scientific information about COVID-19. This is consistent with Muruganandam et al.’s²⁰ interview study in which most patients diagnosed with severe mental illness had little knowledge about COVID-19. In the absence of knowledge of COVID-19, social media is the most common source for the general public to obtain information and deal with psychological stress.^{2,21} As our case series revealed, the unknown COVID-19 destroyed patients’ confidence in treatment. For instance, Subject 1 considered herself as a laboratory mouse in the COVID-19 treatment. Subject 2 claimed that infected people constantly face social isolation before the vaccine is developed. Subject 3 stayed with the oxygen concentrator all the time. Subject 4 considered himself as a laboratory article when he was sent to a different hospital, and the information about COVID-19 terrified him so much that he was afraid of his phone. In this respect,

ensuring the accuracy of the information and extending “wider mass media” is essential to reduce the fear, worry, and anxiety related to COVID-19.²² To relieve patients’ mental illness, the medical staff should promptly explain the scientific information, treatment plans, progress reports, and health status updates to the patients.²³ It appears that the prescription of appropriate treatment and regular communication with the patients about COVID-19 are equally important.

Mental health problems can be caused by the quarantine, given that social disconnectedness and perceptions of social isolation are inducers of anxiety, depression, anger, boredom, and loneliness.^{14,23-25} Our case reports are consistent with the literature in that quarantine led to anxiety and depression. During hospital quarantine, Subject 1 felt caged in prison, and she experienced loneliness and confusion although she stayed with her family in the same ward. Subject 2 felt extremely anxious about his daughter and his business while in hospital. Subject 3 doubted “why 2 elder patients in the same ward were discharged before her” after 40-day hospital quarantine. The feeling of melancholy and anxiety descended on Subject 4 when he found that the door in the hospital was locked for virus control. He felt “locked in prison.” Subject 5 was dominated by depression and loneliness due to the isolation from his family.

Mutual influence among COVID-19 patients in the same ward should not be neglected in identifying risk factors for mental health issue.¹⁴ In our case reports, Subject 1 fell apart when her husband and mother-in-law were discharged from the hospital except her. Subject 3 became impatient and anxious when her fellow patients were discharged before her. Eight months after the release from quarantine, Subject 4 was still impacted by the bad memory of the severe symptoms of the fellow patient. This suggests that while the discharge of a patient in a ward might bring hope to the rest of the patients, it might increase the risk of anxiety and depression for others, in particular for those who repeatedly fail to meet the discharge criteria for a long time.

Enhancing the social support system (family, friends, and colleagues) and eliminating the stigma concerning the COVID-19 pandemic plays a significant role in reducing patients’ psychological pressure.^{2,25} The 5 patients in our study showed a similar degree of reluctance to mention their experiences of COVID-19, in the fear that others might isolate them, criticize them, and discriminate against them. The abnormal behavior was captured in the elderly patient (Subject 3) who became self-contemptuous and was unwilling to meet friends after discharge. Similarly, Subject 1 felt extremely sad when she heard words such as “I’m so scared that the person in our company who has been infected by COVID-19 comes back to work now.” Subject 2 assumed that COVID-19 patients would encounter long-term psychological isolation in the society. Discriminatory words and complaints such as “the man with the virus was back” and “he is a plague that afflicts us deliberately” also increased the grief of Subject 4 and Subject 5. Moreover, all the subjects in our study emphasized the importance of the understanding, support, and consolation from their family members in relieving their anxiety, depression, and loneliness. These findings suggest that COVID-19 patients need social support, not only from their family members and relatives, but also from medical staff, friends, neighbors, and colleagues.

So far, the mental problems of most COVID-19 patients have not been treated properly due to the failure to promptly diagnose their

mental health.⁴ The limitation of the current psychological interventions for COVID patients is that the treatments are confined to the recovery stage in the hospital. Interventions should be based on a comprehensive assessment of risk factors leading to mental problems in different stages. Thus, a diachronic diagnosis of the mental health problems and the diverse psychological interventions in different contexts are urgently needed.^{4,23} Given that COVID-19 patients’ symptoms of mental health problems may change before, during, and after hospitalization, follow-up psychological education and intervention are essential after hospital discharge.¹⁵ These might include offering both online and offline psychological counseling, providing scientific knowledge on COVID-19, as well as executing a transparent policy on eliminating discrimination. Even for the post-COVID-19 period, the psychological treatment and psychosocial support for individuals infected with COVID-19 require the preparation of new methods in the field of psychiatry.²⁶

This study has some limitations. First, we only interviewed 5 discharged COVID-19 patients from Wuhan by convenience sampling. Interviews with more participants, including hospitalized patients, would be needed to reveal their mental health conditions at the outbreak of COVID-19 pandemic. Second, factors such as individual backgrounds and hospital settings may impact the similarity in their responses. This poses a potential future research direction in narrative studies regarding mental health of COVID-19 patients.

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