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Survivor's Experiences of Psychological Challenges in COVID-19 Patients: An Internet-based Phenomenological Study

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Abstract

Background: Confirmed and suspected patients with SARS-CoV-2 may fear contagion to others and the severe consequences of the disease. Therefore, they may feel loneliness, denial, anxiety, depression, insomnia, and hopelessness, reducing treatment adherence.
Objectives: This study aimed to discuss the psychological challenges of survivors' experiences in SARS-CoV-2 infection.
Methods: This descriptive phenomenological study explored survivors' experiences of COVID-19 infection. Validated websites' stories and notes were used to collect data. The stories were transcribed and analyzed by Colaizzi's phenomenological analysis method. The authors screened the transcribed texts, extracted and summarized meaningful statements, and reported the themes independently. In addition, six criteria of authority, accuracy, objectivity, currency, coverage, and appearance were considered for evaluating web page quality. The data were analyzed using MAXQDA 10 software.
Results: A total of 45 patients' stories with COVID-19 were analyzed. Four general themes and 11 sub-themes were extracted via reading stories and extracting themes, including stigma (the sub-themes of embarrassment, defame, and Hopelessness), horror (sub-themes of denial, not professional experience, and toward death), different lifestyles (the sub-themes of change, unfriended, and sleeplessness), and freedom (two sub-themes of calmness and Rescue).
Conclusions: Based on the studies, the participants reported high rates of symptoms of fear, change, insomnia, and horror. Supporting COVID-19 patients in these critical conditions is one of the essential components of acute care measures. Specific interventions to promote mental health in exposed patients should be applied immediately and require special attention.

Keywords: COVID-19, Experience, Recovery, Survivors

1. Background

The first cases of pneumonia caused by a novel enveloped RNA beta-coronavirus were identified worldwide in December 2019 (1). The World Health Organization (WHO) announced the official name of the disease as acute respiratory syndrome coronavirus 2 (SARS CoV-2) and 2019 coronavirus disease (COVID-19). Since the disease outbreak in Wuhan, China, the infection has rapidly spread across the countries (2). The number of confirmed patients was reported as 608,328,548 on September 16, 2022, 6:53 pm CEST (3). The COVID-19 pandemic severely affects the physical health and lives of people worldwide with various psychological, mental, and behavioral issues, such as panic disorder, anxiety, and depression (4). Apart from physical symptoms, people with or suspected of having COVID-19 often suffer from severe mental pressure and other health problems (5). Suspected and confirmed people for COVID-19 may experience fear related to severe disease and its complication and contagion (6). Denial, loneliness, anxiety, depression, insomnia, and hopelessness may reduce adherence to treatment. This condition can increase the risk of aggressive behaviors and suicide. Suspects who were isolated showed obsessive-compulsive symptoms such as frequent body temperature testing, sterilization, and quarantine due to a lack of accurate information about their health status and prognosis.

In addition, strict quarantine and mandatory contact tracing policies by health authorities can cause community isolation, financial and economic harm, discrimination between people, and stigma (5). The general public may also experience boredom, frustration, and irritability under isolation intervention (7).

The National Health Commission of China has released "Psychological Adjustment Guidelines for Coping with the New Coronavirus Pneumonia" for children, adolescents, pregnant women, and health professionals. Mental health

workers in Wuhan have developed an expert association to respond to mental health problems and uploaded psychological training videos to the public via WeChat and other social media. Psychological interventions recommended three critical points in crises: recognizing mental health status in affected populations, identifying people at risk of suicide and violence, and providing psychological interventions tailored to people's needs (6). People's attitudes are essential factors for the presentation of better care plans in COVID-19 outbreaks. In a study in China, most participants were optimistic about the COVID-19 pandemic 90.8% believed that COVID-19 would eventually be successfully controlled, and 97.1% had confidence that China could win the fight against COVID-19 (8). COVID-19 patients may express negative emotions in the early stages of the disease, revealing a mix of positive and negative emotions (9). The patients who experienced COVID-19 infection and were hospitalized have a valuable experience for us to provide better care plans and give them the best psychological support based on evidence.

2. Objectives

This study aimed to explore survivors' experiences of COVID-19 infection.

3. Methods

This phenomenological study qualitatively aimed to understand phenomena experienced by different people (10). This study used a descriptive phenomenological approach to explore Survivor's experiences of COVID-19 infection.

The data was collected using the website's validated story and notes, such as John Hopkins Hospital, Centers for Disease Control and Prevention (CDC), and New York Times.

There were 45 cases who had written their stories on the internet. The inclusion criteria were writing stories on the internet, and the web pages were validated.

3.1. Data Interpretation

The stories were transcribed and analyzed by Colaizzi's phenomenological analysis method. The two authors (RJ and MJ) carefully screened the stories several times and independently to understand and be informed of the participants' experiences based on Colaizzi's seven steps. These steps included familiarization, identifying significant statements, formulating meanings, clustering themes, developing a detailed description, producing the fundamental structure, and seeking verification of the primary system (11). All steps were followed strictly.

The conflict in content and extracted themes was resolved through a group discussion, including a master of nursing, a doctor of nursing, and a master of epidemiology. The data were interpreted using MAXQDA 10 software. Guba criteria for qualitative analyses were used for the study's trustworthiness (12).

Seven tips were used to determine the study's validity and evaluate Web Resources considered (13). To this end, this study focused on seven recommendations: (1) Start with Sites You Know. (2) Check the Date, (3) Check Credentials, (4) Check the Top Level Domain (TLD) and Domain, (5) Digging Deeper, (6) Check Your Local Library, and (7) Don't Trust Your First Source (13). In addition, six criteria for evaluating the webpage quality were considered. These criteria included authority, accuracy, objectivity, currency, coverage, and appearance (14). Extracted codes and texts were confirmed by qualified experts.

4. Results

A total of 45 stories of patients with COVID-19 were analyzed in the study. After screening the stories, four general themes and 11 sub-themes were extracted (Table 1).

Themes include stigma (the sub-themes of embarrassment, defame, and hopelessness), horror (the sub-themes of denial, not experienced experience, and toward death), different lifestyles (the sub-themes of change, unfriended, and sleeplessness), and freedom (two sub-themes of calmness and rescue).

Horror theme was one of the main themes, and the study participants had a severe fear due to their illness and described it as not experiencing experience and thinking about death.

"I have never experienced anything like it ...".

They expressed their fear of dying. One told (story number 5), " ...I was thinking that might be my last time where I can write something in my life," and another told (story number 9), "I thought I was dying Wednesday last week when I couldn't take a breath and was losing consciousness."

Another important theme was a different lifestyle, which included three sub-themes: change, unfriended, and sleeplessness. The participants often regarded the illness as a change in their lives and roles and considered the disease unfriended.

In this regard, one participant (story number 4) said, "The big one is preparing for her bac (end of secondary school exam), and I see her cry when she can't manage, and I can't hold her in my arms, console her, help her."

Table 1. Codes and Categories Extracted from the Stories of COVID-19 Survivors

Themes	Subtheme	Codes
Freedom	Calmness	Calm
		Faith
	Rescue	Hopefulness
Different lifestyle	Change	Change in parenting
		Change in attitude
	Unfriended	Quarantine
		Loneliness
	Sleeplessness	Sleepless
		Night terrors
Horror	Denial	Refusal
		Unbelievable
	Not experienced experience	Shocked
		Horrifying situation
	Toward death	Suffocation
		Dying notion
		Fear
Stigma	Embarrassment	Shame
		Secrecy
	Defame	Signed
	Hopelessness	Incurable

"I think the biggest change for me is that my way of looking at things is different now."

A group of participants (stories number 8, 11, 16, 32, 41, 42) reported this disease and the unpleasant experience of sleeplessness. "I could not sleep at all," or "The hardest part was the nights, alone with his fears."

Another central theme extracted from this study was a stigma. Participants were anxious about their disease and sometimes lost hope.

Story number 10: "…I have seen a negative stigma for those who admit to being positive. But this sickness doesn't discriminate, many people are afraid of testing. Some also don't exhibit the common symptoms and assume they have something else." Or story number 12: "My moral is rock bottom. I can't stop crying…."

They blamed themselves for possible transmission of infection or received a threat from others.

Story number 5: "How many people did I infect? Did I infect somebody? Will I cause somebody to die?"

Story number 7: "People started calling my family the Corona family, and I even got an anonymous call saying that they would come to the hospital to kill me."

Another patient said: "Other people told me that there was a group planning to stone me to death at the beach."

Another central theme was freedom; the participants said they were lucky and felt calm after recovering from the disease.

story number 3: "I feel calm about everything, really calm… I went to the gate of hell and came back. I saw with my eyes that others failed to recover and died, which has greatly impacted me."

Story number 1: "I feel fortunate that I didn't die or infect anyone else," or "I was fighting for every single breath; I was fighting for mine and my baby's life."

5. Discussion

The study showed that the survivors of COVID-19 had experienced stigma, horror, different lifestyle, and freedom. The patients who recovered from COVID-19 perceived extreme fear and discomfort caused by the coronavirus infection, intensive care unit ward hospitalization, and fear of death, which was agreed with nurses' experiences during the MERS-CoV pandemic (15-17) and among Chinese people in the COVID-19 outbreak (4). As shown in this study and previous research, emotional distress is common in life-threatening situations such as disease outbreaks such as COVID-19 and unknown conditions (17, 18). Patients' stress and fear can be reduced by acknowledging their existence and helping them normalize them. Patients should be empowered to recognize distress symptoms, including worry, fear, sleeplessness, difficulty concentrating, interpersonal problems, avoidance of certain situations in daily life, unexplained physical symptoms, and recognition of signs and symptoms of horror. As a result, they can better understand their mental health status and resolve their distress before the management becomes too severe. Coping styles, cognitive evaluation, and social support have been reported to be stress moderators. Previous studies have shown that psychological adjustment and social support play an important role in psychological rehabilitation in conditions of stress outbreak. It has been demonstrated that all coping actions during pandemic conditions can reduce stress and promote psychological health (19).

The patients had concerned about infecting others and blamed themselves because of the transmitting infection. In a study in China, about 75.2% of respondents were very concerned or somewhat worried about other family members getting COVID-19 (20). Stigmatization and rejection by neighbors, colleagues, friends, and even family members can appear as abnormal behaviors, suspicion, and fear in the infected person and cause them to avoid free time, work, or other activities. The experiences are rejected and faced with derogatory comments. When quarantined individuals are members of an ethnic or religious group, the

stigma can be exacerbated (5, 7). However, stigma from the population is a central theme throughout many studies; this highlights the need for health authorities to provide clear and effective messages to the affected population to promote an accurate understanding of the situation (21-23).

Most people who have experienced quarantine report it as an unpleasant situation. Separation from loved ones, loss of freedom, the uncertainty of disease status, the uncertainty of prognosis, and boredom can sometimes have many effects. Studies have reported that previous outbreaks resulted in suicides, anger, and lawsuits (24, 25). When a quarantine is essential, officials should take every function to ensure that this experience is as tolerable for patients as possible. This can be provided by telling patients what is happening and why, explaining how long it will continue, providing clear communication, and reinforcing the sense of altruism that people should feel (25-27).

The results showed that positive emotions such as rescue, calmness, relaxation, and hopefulness appeared gradually or with other negative emotions in patients. In contrast, past studies have only shown many negative feelings during the pandemic (6, 16).

However, other studies have reported similar findings, especially during the MERS pandemic (16). Therefore, it is necessary to provide social support to fight against the outbreak of COVID-19. The calmness and comfort of the patients in the current study can be related to the gradual adaptation of the patients to their condition, acceptance, positive response, and personal growth of the patient (28, 29). Studies have shown that positive emotions are essential in promoting and adjusting psychological trauma (30).

5.1. Limitations

Based on the entity of the study, we could not have a face-to-face interview and ask follow-up questions. Hence we could not clarify some quotations from participants. Contact and personal information were not allowed to be collected because of ethical codes regarding confidentiality.

5.2. Conclusions

The patients who recovered from COVID-19 reported high fear, change, insomnia, and horror rates. Supporting patients in this critical situation is essential for acute measures during the COVID-19 pandemic. Professional and evidence-based interventions to promote mental health in patients with COVID-19 should be implemented by health systems immediately. An experienced team comprising mental health personnel is a basic tenet in dealing with emotional distress and other mental disorders caused by pandemics and other public health emergencies.

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Footnotes

Authors' Contribution: LM and RJ contributed to the design. MJ, and RJ contributed to the analysis and participated in most of the study steps. LM and RJ prepared the manuscript. LM and MJ assisted in designing the study and helped in the interpretation of the study. All authors have read and approved the content of the manuscript.

Conflict of Interests: The authors declare that they have no known competing financial or personal interests to declare. All of the authors are employed by the Kermanshah University of Medical Sciences. This study has no relation with any company and is a review study. There are no patents related to this study. None of the authors have a family relationship and are only academic colleagues. Overall the authors declare that there is no conflict of interest.

Data Reproducibility: All of the data are available on request from the corresponding author.

Ethical Approval: The study was approved by the Kermanshah University of Medical Sciences with registry ID: 990272. The ethical ID for this study is IR.KUMS.REC.1399.350; link: ethics.research.ac.ir/EthicsProposalView.php?id=137558

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