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Contents lists available at ScienceDirect

American Journal of Infection Control

journal homepage: www.ajicjournal.org

State of the Science Review

Psychological experience of COVID-19 patients: A systematic review and qualitative meta-synthesis

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Key Words:

COVID-19

Patient's experience

Psychological experience

Meta-synthesis

A B S T R A C T

Background: Coronavirus disease 2019 (COVID-19) has not only placed an unprecedented strain on health-care systems worldwide, but has also caused irreparable physical and psychological damage to those infected. It is essential to understand the disease process and psychological experience of patients with COVID-19, to provide them with efficacious psychological guidance and interventions. This qualitative systematic review sought to explore the experience of COVID-19 patients.

Methods: The meta-analysis methodology developed by the Joanna Briggs Institute guided this systematic review and qualitative meta-analysis. Seven databases were searched, with no language restrictions. This study was registered with PROSPERO under accession number CRD42021279266.

Results: A total of 3107 potentially eligible articles were identified through database and reference list searches, among which 23 studies (from 10 countries) were ultimately included in our analysis. Five interrelated themes emerged: the complex psychological course of COVID-19 patients; the impact of the disease on the body; the expectation of support and guidance from multiple sources; coping strategies; and post-traumatic growth.

Conclusions: Psychological distress among patients with COVID-19 was found to be widespread. Healthcare providers should pay attention to the psychological changes in patients, ensure continuity of care and provide professional support from hospital to home, and build patients' confidence so that they can return to their families and society. Long-term follow-up studies may provide deeper insight into the psychological needs of survivors.

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BACKGROUND

Coronavirus disease 2019 (COVID-19) is a highly contagious virus. On January 30, 2020, the World Health Organization (WHO) announced that the global outbreak of COVID-19 was an international public health emergency and subsequently classified it as a worldwide pandemic on March 11, 2020.¹ COVID-19 has not only placed healthcare system worldwide under tremendous pressure, but has also caused unpredictable losses in the domains of the

economy, politics, and culture. Thus, countries all over the world are facing unprecedented pressures.²

Most studies have focused on the physical symptoms of COVID-19, such as fever, cough, and difficulty breathing.³ However, the potential psychological and mental health effects of COVID-19 survivors should also be taken seriously.⁴ Unlike the modest spread of viruses such as Ebola and Middle East Respiratory Syndrome, COVID-19 is a novel disease characterized by a sudden, global-scale outbreak, where infected people experience fear and worry due to uncertainty and the physical symptoms of the disease. Even in the absence of somatic symptoms, or when the symptoms are only mild, patients may experience negative emotions such as loneliness, guilt and pain as a result of isolation, and the effects of such negative emotions can be long-lasting.⁵ Some survivors have reported

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Conflicts of interest: None to report.

experiencing varying degrees of anxiety and depression, even 6–12 months after discharge from the hospital.⁶ For patients, psychological distress can reach dangerous levels if not managed properly, affecting functional and mental health, undermining functioning and quality of life, and possibly even causing death. The psychological impacts and burden of major disasters on survivors are much more persistent and widespread than the physical damage.⁷

The number of confirmed COVID-19 cases in countries around the world is still increasing, and the psychological effects of the outbreak are being felt by millions of people. Many studies have reported the experience of patients with COVID-19. However, medical systems and culture differ among countries, as do the disease experience and emotional changes of infected persons. Thus, a single qualitative study cannot fully reflect the authentic disease experience of heterogeneous populations. Therefore, it is necessary to comprehensively investigate changes in the inner world of COVID-19 patients.

In this study, the published quantitative literature on COVID-19 patients was evaluated and integrated, to elucidate the psychological experiences and needs of COVID-19 patients. We aimed to obtain deep insight into the psychological and spiritual changes of confirmed COVID-19 patients, provide a reference point for the formulation of psychological interventions for patients, promote physical and mental recovery, and help patients return to society and family life.

METHODS

Design

The meta-analysis methodology developed by the Joanna Briggs Institute (JBI) guided this systematic review and qualitative meta-analysis.⁸ This approach is based on pragmatism and phenomenology, and was designed to aid the synthesis of qualitative research. We prospectively submitted the systematic review protocol for registration on PROSPERO (CRD42021279266).

Inclusion criteria

The Population, Indicators, Context and Study (PICoS) criteria were used as a framework when evaluating the literature, as shown in [Table 1](#).

Search strategy

The CNKI, Wanfang, SinoMed, Pubmed, Web of Science, Cochrane Library, and Embase databases were searched systematically, mainly for qualitative studies on the experience of COVID-19 patients. The retrieval period was January 2020–July 17, 2021. The search was carried out by combining subject words and free words. The whole search strategy is provided in [Appendix S1](#).

Table 1
Inclusion criteria for the literature studies

PICoS criteria	Eligibility criteria
Population / Participants	Adult patients diagnosed with COVID-19 by clinicians
Indicators/ phenomenon of interest	Patients' experiences of illness, mental state
Context	Any country, hospital, or place
Study design	Qualitative research, including phenomenological research, grounded theory, focus groups and other qualitative methods, as well as mixed methods with qualitative components
Exclusion criteria	Duplicate publication and incomplete information; full text no available; poor-quality methodology; topic of the article cannot be extracted

Quality assessment

The quality of the literature studies was evaluated using the Quality Research Evaluation Criteria of the Centre for Evidence-based Health Care, JBI, Australia.⁸ Grade A indicates that the quality standard is fully met, such that the possibility of bias is remote. Grade B indicates that the quality standard is partially met, such that the possibility of bias is moderate. Grade C indicates that the quality standard is not met at all, such that the possibility of bias is high. Grade C studies was excluded from this study. Two reviewers trained in qualitative research methods independently evaluated the studies, and a third reviewer arbitrated in the case of dissenting opinions. Literature quality assessment results in [Appendix S2](#).

Data extraction and synthesis

The following data were extracted from the studies: author, location, qualitative research method, interesting phenomena, and qualitative analysis results (See [Appendix S3](#)). Using the standardized data extraction tool of JBI-QAR, the literature results were summarized and integrated using pooled integration method. The 2 reviewers extracted the theme of each study from the full text, reclassified the theme to derive a new category after discussion with the third reviewers, and then integrated the new theme.

RESULTS

Study screening

The research selection and inclusion processes are shown in [Figure 1](#).

A total of 23 studies were included (8 in China, 3 in the United States, 5 in Iran, and 7 countries including South Korea, India, Belgium, Turkey, Nigeria, Australia, and Denmark). Qualitative studies (n = 22) and mixed-method studies (n = 1) with qualitative data were included in the meta-synthesis.

Meta-synthesis of qualitative data

Eighty-seven topics were extracted from the 23 studies. The topics were then reclassified, summarized, and integrated into 20 categories and 5 themes [Table 2](#). lists the main themes and subthemes.

Theme 1: Complex psychological course of COVID-19 patients

COVID-19 perceived as a distant threat

Four studies showed that some people pay no attention to COVID-19 and have insufficient awareness of the disease; this can be referred to as “blind confidence.”^{9–12} They believe that the threat of the virus is remote and only infects people with low immunity, such as the elderly and children, while those who regularly exercise and are in good health will not be infected. Thus, they have low self-awareness of prevention measures like wearing masks and social distancing. When patients show early stage COVID-19 symptoms, they often believe that they are suffering from other conditions (such as the common cold, allergies, or digestive tract diseases). However, while waiting for the results of the COVID-19 tests, patients are often nervous and anxious, and hope that they will not test positive.^{13,14}

Panic caused to COVID-19 diagnosis

After receiving the news of a COVID-19 diagnosis, the psychological course of the patient is time-dependent. Three studies reported that the first thing the patients showed was shock, perceiving the result as a surreal event.^{9,14,15} Four other studies mentioned that patients first expressed denial.^{12,13,16,17} Infected individuals believing

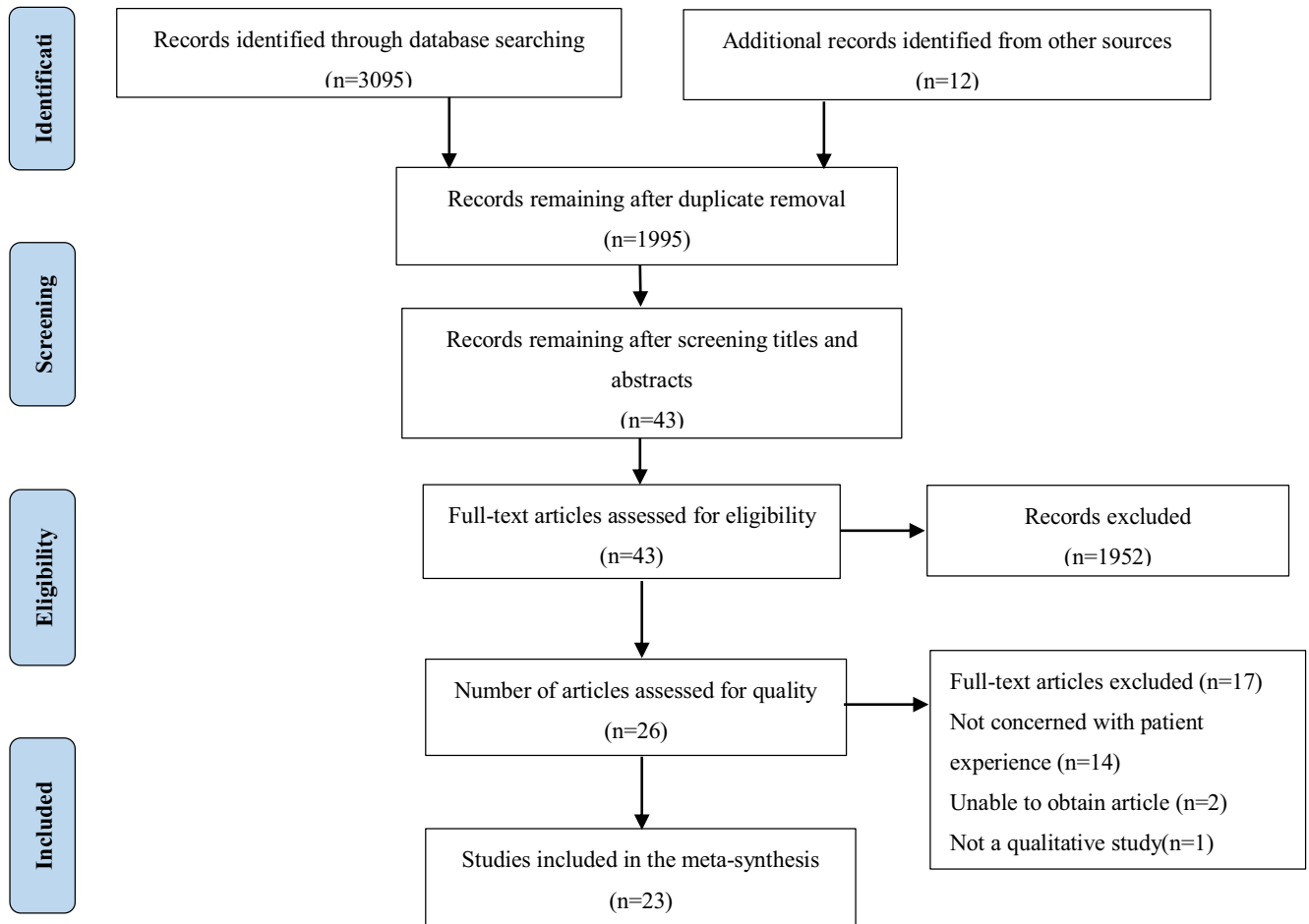


Fig 1. PRISMA flow diagram of the study selection and inclusion processes.

that their disease experience is inconsistent with the clinical symptoms reported in the media may question the test results. Once infection is confirmed, fear may arise; this emotion was expressed by all

Table 2
Main themes and associated subthemes

Theme	Associated subtheme
Theme 1: Complex psychological course of COVID-19 patients	1. COVID-19 perceived as a distant threat 2. Panic caused by COVID-19 diagnosis 3. Feelings of loneliness and helplessness 4. Stigma and being labeled 5. Uncertainty and desire for respect
Theme 2: Impact of disease on the body	6. Painful physical manifestations 7. Powerlessness over the after-effects of the disease
Theme 3: Expectation of support and guidance from multiple sources	8. Inadequate information about the disease 9. Desire for communication and emotional support 10. Heavy financial burden 11. Desire for continuous medical support 12. Expectation of support from family, society and the state
Theme 4: Coping strategies	13. Active personal response 14. Support from family and friends 15. Reassurance from medical staff 16. Spiritual beliefs provide comfort
Theme 5: Post-traumatic growth	17. Rethinking the meaning of life 18. Enhancement of health literacy 19. Increased stress resistance 20. Gratitude to the country and healthcare providers

participants. Fear comes from 2 primary sources: uncertainty about the disease (concern regarding prognosis and the possibility of death), and the requirement to isolate. The unfamiliarity of the isolation ward, constant beeping of instruments, and proximity of medical staff in strange clothing create a sense of oppression. Also, negative events such as resuscitation and death of other patients can occur in the ward.

Twenty-three studies reported the presence of worry in patients, for various reasons. Some people expressed concern about their illness, fearing that they would not receive timely medical assistance, and that the disease would worsen resulting into complications or even death.^{11,14,18} Some people are afraid that they will infect their family and friends, and damage their health.^{9,12,13,19-26} Some patients play multiple roles, such as the family breadwinner and a leader at work. Infection forces them to play the patient role, possibly leading to role conflict and feelings of guilt due to failure to fulfill family responsibilities and work in a timely manner.^{17,19,23,27,28} Patients with children may think that being sent to the hospital by ambulance will cause psychological distress for their children.

Feelings of loneliness and helplessness

Eventually, patients tend to gradually accept their diagnosis and cooperate with the treatment. Because COVID-19 can be transmitted through droplets and aerosols, patients must be isolated. During the treatment period, patients are not allowed visitors, cannot communicate with others face to face, lack social contact and are thus socially disconnected. Patients may feel abandoned, such that their mental health is impaired. Patients are deprived of their freedoms and cut off

from the outside world, with phones being the only means of communication therewith. Eleven studies reported that patients felt lonely and missed their families.^{10,12–15,17,18,21,22,24,27} During isolation patients need to take care of themselves, due to their diminished health status, and cannot do many things by themselves.²⁸ One patient reported that it was difficult for him to drink a glass of water. The monotonous and tedious isolation days mean that patients eagerly look forward to the end of that period.⁹

Stigma and being labeled

Seven studies reported that patients felt ashamed; they thought that their failure to protect themselves caused more people to become infected, and their lack of opportunity to apologize to them, led to feelings of guilt.^{9,10,14,22,23,25,26–28,31} The feelings of shame were so persistent that some patients continued to feel it even after discharged from the hospital.¹⁴ Fear of being contagious was reported, along with feeling under pressure when hearing people talk about COVID-19, due to fear that the conversation will be about them.

With the spread of rumors, the public's attitude towards infected persons has deteriorated. Patients with COVID-19 reported being discriminated against and labeled by others. Epidemiological traceability is a component of disease investigations, and infected individuals are required to disclose their travel plans for outbreak prevention and control. However, some respondents stated that the survey process made them uncomfortable, as if they were being interrogated like criminals.²⁸ Some patients' privacy is compromised, and they became subjects of gossip, sometimes even suffering personal attacks and cyberbullying. Patients thus may feel angry and aggrieved, given that they are also victims of the virus.^{13,15,19,23,28}

Uncertainty and the desire for respected

In the late stages of treatment, patients may feel happy and excited on learning that a viral nucleic acid test is negative. After receiving the discharge notification, many patients show concern regarding the uncertainty of the disease course. Five studies reported that patients did not know if the virus was still present in their bodies, fearing that the illness would return, they felt like “ticking time bombs” and cut themselves off from other people.^{9,10,13,21,28} This persistent alienation had an impact on the participants' social and emotional functioning. The participants also feared being re-infected by others, and never wanted to go through that painful time again.

Ten studies showed that the public's alienation of COVID-19 patients can affect the relationships of the cured at home and work, where they are sometimes asked to work in separate offices or home-school their children.^{9,10,13,14,16,17,25,28,29,31} Others associate survivors with the virus. Recovered persons may always feel that others are talking about them behind their back, that people “avoid them like the plague”, and that they are seen as a “walking virus” that brings misfortune to others.¹³ Avoidance, rejection, and blaming of the healed person are more difficult to deal with than physical pain. Patients have an innate desire to be respected and understood. To address this situation, some people in recovery try to conceal their medical history from others.¹⁷

Theme 2: Impact of disease on the body

Painful physical manifestations

In ten studies, patients reported feeling miserable, and that the illness was an awful experience.^{9,11–14,18,21,26,28,29} Unlike ordinary pneumonia infections, COVID-19 is associated with an intense attack on bodily systems by a highly functioning immune system, in addition to compromised lung function. Patients may exhibit non-specific symptoms such as labored breathing, high fever, headache, loss of taste, diarrhea, and weakness, as well as inexplicable crying, emotional disorders, hallucinations, and recurrent nightmares. In some

patients, underlying illnesses are also aggravated by COVID-19, which can be a very severe mental test.²⁴ Every person who has recovered from the virus experiences pain that may be difficult for others to imagine.

Powerlessness over the after-effects of the disease

Although patients are discharged from hospital when cured, the devastating effect on the body of the illness remain. Recovered patients may think they are entirely free of the virus, and thus do not expect the sequelae thereof to be unbearable.^{16,28} Typical sequelae of SARS and COVID-19 in severely ill patients 1–3 years after discharge from the hospital include pulmonary fibrosis. Stroke and tinnitus may also be experienced while in recovery, and even simple movements (such as going up and down stairs or turning over in bed) can be a struggle. Thus, their battle with the virus is not over, they may in fact experience more torment after being cured. COVID-19 not only affects the body, but also weakens the will; the recovered person suffers the double blow of physical and psychological damage. The life of the recovered patient thus changes markedly.

Theme 3: Expectation of support and guidance from multiple sources

Inadequate information about the disease

As a novel infectious virus, the COVID-19 pandemic has also constituted an information crisis. There is a lack of public knowledge about the characteristics of COVID-19, as well as prevention and control measures in the early stages of the disease. Mass media (TV, radio), social media platforms (WeChat, Facebook), and online resources (web search) are essential channels through which the public can obtain information about diseases, but mixed messages from various sources makes it difficult for patients to distinguish the true from the false, leading to confusion and distrust of information.^{10,15,22} As a consequence, some people try to prevent the virus with obscure remedies, such as eating and performing nasal washes with salt water.^{9,28}

With the rising number of confirmed diagnoses and deaths reported in the media, patients may experience a substantial psychological burden. Some intentionally avoid exposure to news about COVID-19.²⁹ The confusion, vague predictions, and sense of impending doom associated with COVID-19 messaging has created uncertainty and confusion among patients. Some participants described the experience as like being caught between life and death.^{11,27}

The desire for communication and emotional support

In ten studies, patients reported desire for emotional support from family and medical care, especially during isolation.^{9,10,13,14,16,22,25–28} However, precautions to prevent viral transmission make it difficult for patients to interact and communicate with others. Some patients reported being unable to communicate with healthcare providers because of language barriers (eg, limited English proficiency, poor ability to communication in local languages), and their needs were not accurately communicated to healthcare providers.^{9,27} Isolating patients can only relieve their distress through phone screens and videos calls their families.

Heavy financial burden

Seven studies reported on the stress that financial burdens placed on patients.^{10,14,17,20,24,25,28} In particular, the sudden change of circumstances disrupted the financial plans of married people staying at home due to their illness. Many young and middle-aged patients stated that it was difficult to meet their regular financial commitments. Hospitalization disrupted the family's primary financial source in some cases, leading to the inability to repay loans and the need for home care even after discharge from the hospital, all of which put families under tremendous financial pressure.^{14,20,25}

Moreover, the uncertainty associated with the disease meant that some patients were unable to return to work in a timely manner, and some feared being fired by their bosses or replaced by others. For various reasons, it can be difficult for recovered patients to find jobs again even after they are discharged from the hospital.^{10,17,24,28}

Desire for continuous medical support

In the early stages of the pandemic, overcrowded hospitals and a large number of new patients prevented timely treatment. As they moved from hospital to hospital, patients became tired, experienced feelings of helplessness, and even became distrustful of hospitals and the government.^{14,19,26,29} Recovered patients returning to their families after discharge are not trained by medical staff. Hospitals may fail to provide continuous medical care, such that the families do not know anything about the physical and psychological problems of recovered patients; this causing considerable stress and tension within families.^{10,25}

Expectation of support from family, society, and the state

The power of individuals to overcome the disease or combat rumors is weak, and patients desire support from the family, society, and government.^{10,21} The government may implore the public to change their perceptions of COVID-19 survivors, help survivors resume work and productive activities, improve the tenuous economic status of patients, and enact relevant laws and regulations to protect the privacy and rights of patients and the interests of their families.

Theme 4: Coping strategies

Active personal response

After a bout of depression, patients tend to adjust their mindset to face treatment in a positive manner and comply with the requirements of healthcare provider. Six studies reported that patients improved their self-confidence by constantly encouraging themselves to overcome the disease through enhanced resilience.^{9,13,19,23,25,28} Most patients reduced their anxiety via cognitive adjustment and distraction. During isolation, many patients distracted themselves from their monotonous surroundings by reading, listening to music, and participating in religious activities.

Support from family and friends

During isolation, 11 studies reported that patients mentioned family support as the best source of motivation to overcome the disease.^{9,13,16–19,24,25,28–30} Patients experienced love from, and recognized the value of their families. Three studies reported the importance of the comfort and support from friends during treatment, who helped patients through difficult times by providing money and food.^{9,28,29} A special kind of friendship is also established among friends who have overcome the virus together. In such a shared environment, patients develop empathy for each other, and build deep friendships by sharing information, and listening to and encouraging each other.

Reassurance from medical staff

Doctors and nurses had the most contact with patients during isolation, and provided a sense of security during hospitalization. Patients in 7 studies reported that the healthcare providers not only saved their lives but also boosted their morale and helped to manage negative emotions.^{10,12–14,17,29,31} Equal respect and love were felt by everyone; discrimination against patients who had the virus was not experienced. According to 1 study, the medical team also gave small gifts and sang songs for patients who had birthdays during hospitalization, and this humanistic care brought patients psychological comfort.³¹

Spiritual beliefs provide comfort

Although countries vary in terms of culture and ethnicity, spiritual beliefs have helped patients in many nations deal with the difficulties caused by the pandemic. Some patients believe in and rely on God, and that faith will help them through difficult times. During illness, some religious people try to find spiritual comfort. Charitable acts and oaths can bring inner peace and strengthen their faith. Such people believe in divine destiny and are satisfied with the future planned for them by God. Many participants reported that their relationship with God improved after experiencing difficult and exhausting situations associated with the pandemic.^{9,10,14,18,23,25}

Theme 5: Post-traumatic growth

Rethinking the meaning of life

Patients in 8 studies viewed their illness as a significant turning point in their lives.^{12,13,19–21,24,26,30} Some participants reported experiencing a physical and spiritual cleansing, and feelings of rejuvenation. The pandemic slowed down their fast-paced lives, and patients had time to reflect on and re-prioritize their lives. Some patients states that they would be more respectful of life and appreciate how hard health is to come by. They also said that they intended to cherish every day, spend more time with their families, exercise more, and approach life with an optimistic attitude.¹³

Enhancement of health literacy

Cured patients in 3 studies stated that COVID-19 improved their health literacy.^{9,12,26} These patients reflected on their previously unhealthy lifestyles and reported that they would improve their personal hygiene and pay more attention to diet, nutrition, and protection measured; they intended to wash their hands more frequently, wear masks, and maintain social distancing. However, some patients reported extreme, compulsive behaviors such as washing their hands all the time and completely shutting themselves off from others.

Increased stress resistance

The pandemic has caused not only negative emotions and effects, but also many positive ones, such as courage, personal growth, and increased mental toughness. In particular, some survivors of COVID-19 thanked the virus for giving them the courage to face life,^{21,26} and other described the experience as “touching the devil’s nose and coming back.”¹³ Some of those who recovered from the disease stated that they are not afraid to face difficulties in the future.

Gratitude to the country and healthcare providers

Medical staff had to wear heavy protective clothing, risked infection, and worked tirelessly to provide medical support to patients, resulting in a significant change in patients’ attitudes toward medical staff and increased awareness of their importance for disease recovery. During the pandemic, the citizens of many countries experienced a sense of social responsibility, solidarity and warmth toward society.^{12–14,26,28} The Chinese government covered the treatment costs of diagnosed patients, deployed human and material resources at the national level, and implemented various measures to protect people’s livelihoods. Patients felt the strength and vigor of their motherland, and a sense of well-being.^{19–21} The selflessness of many community service workers, volunteers, and police officers deeply affected some patients. Many of them also developed a sense of purpose, and hope to give back to society after discharged and recovery. One respondent stated that “Others saved me, and now I want to give back to the community.”²¹

DISCUSSION

This meta-synthesis included 23 qualitative studies pertaining to the inner world of confirmed COVID-19 patients. These studies covered more than 10 countries, including China, the USA, and Iran, allowing comprehensive analysis and interpretation of the experience, inner feelings and, psychological needs of infected persons. Five themes emerged: the complex psychological journey of patients with COVID-19, the physical impact of the disease, the expectation of multifaceted support and guidance, coping strategies, and post-traumatic growth. Our findings should help the public and healthcare professionals gain insight into the inner world of patients and could inform tailored care.

COVID-19 is a novel disease, such that patients have gone through the process of diagnosis, treatment, and recovery with limited information about their condition. Their healthcare experiences and the psychological journeys have been complex and dynamic; most interviewees experienced unpleasant physical, psychological, and social effect of their illness, and many developed post-traumatic stress reactions. Infected patients feel threatened by the unpredictability of the disease and may have a constant fear of death, as an instinctive reaction to unknown circumstances. The Centers for Disease Control and Prevention showed that patients in the acute phase of disease fear death due to clinical deterioration. Patients who are quarantined may not be aware of the possible psychological challenges after crisis ends. A qualitative study by Brooks³² revealed that isolation leads to negative emotional states such as irritability, insomnia, decreased concentration, and even anxiety and depression, which may all worsen over time. Similar conclusions were reached with respect to survivors of SARS, Ebola, and H1N1.^{33–35} Park found that 42.9% of survivors experienced post-traumatic stress disorder, and 27.0% reported depression 1 year after Middle East Respiratory Syndrome.³⁶ If negative emotions are not alleviated promptly, patients may exhibit unpredictable behaviors, such as concealing their disease, avoiding screening, and resistance to routine vaccination. Therefore, it is necessary to provide timely psychological treatment and counseling for patients. There are differences in the emotional responses among patients with different characteristics. For example, older infected patients with chronic diseases tend to be more anxious and pessimistic about their condition, while younger people are more positive. Also, female patients are more likely to express their feelings and show anxiety, while men tend to suppress their emotions and show anger.³⁷ Therefore, psychological interventions should be individualized according to the patient's different characteristics.

The emotional reactions of patients differ by disease stages. Therefore, stage-specific psychological interventions should be developed for patients. In the early stage, patients are guided and encouraged to use the Internet to actively communicate their inner thoughts to family, friends, and medical personnel.³⁸ In the middle stage, medical personnel impart disease knowledge to patients, and explain treatments and medications so that patients can understand their condition; they may also introduce patients to others who have been cured and discharged from hospital, to enhance patients' confidence about overcoming the disease. Positive encouragement and guidance can promote inner resilience, which is important because the disease can put the individual under psychological pressure. Patients are subsequently informed about home care and self-examination and -testing, and are encouraged to reintegrate with society and family life.

To alleviate negative emotions among the public and patients during the COVID-19 pandemic. China implemented a series of interventions, including the provision of mental health manuals and video education pertaining to disease prevention and control.³⁹ Italy formed a multidisciplinary mental health team to provide services to

inpatients and outpatients.⁴⁰ The Korean Neuropsychiatric Association issued targeted psychological guidance for various groups⁴¹ (eg, the general public, parents of young children, healthcare providers, etc.). Countries such as the USA⁴² and UK⁴³ have taken similar measures. Isolated patients should be provided with adequate spaces in which they can walk around freely, while isolation wards with windows allow patients to observe and maintain contact with the outside world. Finally, clocks on walls enable patients to keep track of time. Given the contagious nature of COVID-19, online therapy is recommended, via video conferencing with telephone follow-ups, to reduce the chance of viral transmission. It is recommended that hospitals establish psychological clinics so that survivors and their families can receive psychotherapy to reduce the adverse effects of the pandemic.

Notably, the survivors mentioned social stigma many times. Social stigma has long been closely associated with disease, with some labeling the sick unfavorably, creating stereotypes, and stigmatizing and othering the sick.⁴⁴ An example of this is the 18th century "Typhoid Mary" phenomenon in the UK.⁴⁵ Outbreaks of COVID-19 result in social stigmatization of the infected and discrimination by others. Social stigma spreads much faster than diseases themselves and can have long-lasting psychosocial consequences for cured patients. It is therefore vital to communicate with patients and the public about COVID-19, and to prevent the stigmatization of patients. Stigmatization is irresponsible. Everyone should be treated equally during a pandemic, and survivors should not be isolated and viewed with suspicion. Negative stereotypes and misconceptions deny patients, who have already experienced physical suffering, their human rights. Social stigma exists among people and races, as well as cities and countries (eg, the label of the "Chinese virus").⁴⁶ No country is innocent in an outbreak; the worldwide community should unite to overcome pandemics. In the case of COVID-19, final victory will only be achieved when the last patient with the disease is discharged from hospital.

Some studies have reported factors promoting disease recovery, where the cultural milieu can significantly influence patient's psychological adjustment and adaptation. Traditional Chinese culture is collectivist, emphasizing collective. After the COVID-19 outbreak, the Chinese government fought the pandemic while under tremendous pressure, isolating Wuhan and surrounding cities to contain the spread of the virus. The solidarity among family members during the crisis was profoundly inspiring for patients. Medical and nursing staff always adhere to their code of professional ethics. Their fearlessness while fighting the pandemic conveyed a strong sense of support and security to patients. Religiosity also played an essential role with belief in God, prayer, and meditation creating inner peace for patients by promoting a positive attitude.⁴⁷

In the current study, most survivors articulated multiple unmet needs, including a lack of employment, health literacy, and sanitation. According to the International Labor Organization report, the global unemployment rate is projected to rise from 4.936% to 5.644% pre- vs post-pandemic, equating to 24.7 million lost jobs.⁴⁸ As the outbreak stabilizes, the state should actively encourage enterprises to resume work and production, and provide financial assistance to people with damaged livelihoods and economic difficulties, to foster economic development of cities and create more jobs. In addition, many patients expressed concerns about relapse after discharge, recovery of physical and mental status, and disease complications. High-risk (ie, psychologically impaired) groups should receive more psychological support. In the context of the current pandemic, survivors should be allowed to actively participate in prevention and control efforts, such as community-based disease awareness activities and anti-discrimination campaigns, and could also provide peer support for those having the same experience.⁴⁹ For patients with sequelae, healthcare providers need to provide professional guidance and education;

ongoing follow-up is needed after discharge, and home planning and hands-on rehabilitation are needed for patients and caregivers.

The initial phase of the COVID-19 outbreak exposed the inadequacy of public health event management, and individual countries should learn from their experience.⁵⁰ A new system for epidemic prevention and control, and a new consultation process, should be implemented, along with public education pertaining to major public health emergencies. Also, healthcare departments should provide patients with relevant information on epidemic prevention and control, and address misconceptions. Governmental administrators should disseminate health and disease information through the Internet, media, and official channels. If necessary, celebrities could be employed to increase public confidence in a timely, open, and transparent manner.⁵¹ Adequate medical resources, and up-to-date and accurate health information, can reduce panic among the public.

Pandemic prevention and control measures can create medical ethical issues due to invasion of patient's privacy (eg, the disclosure of patients' residential addresses, workplaces, and movements and disclosure of information about patients' families). Patients may feel angry and powerless in this context, which promotes distrust of the government. Therefore, public health departments must safeguard patients' privacy, while carrying out prevention and control work. Confidential and practical information must be disseminated rapidly and accurately.

Countries around the world are implementing strictly measures to check for and control the spread of the virus. Overall, the COVID-19 global pandemic has been well controlled, and such that we are now in the so-called post-epidemic era that is an era in which the virus has not completely disappeared, fluctuates seasonally, and may break out on a small scale at any time. In the post-epidemic era, people are slowly adapting to the "new normal", and how to coexist with the virus merits deeper investigation. Reconstructing the inner world of COVID-19 survivors is an important long-term goal. The improvement in the pandemic situation and optimistic data made many people less vigilant; some even expressed the opinion that "this disease is not difficult to cure and many people recover", and "even if you get infected, it can be cured anyway." However, everyone who has experienced infection will likely agree that it is painful, with many unknowns. Only when the pandemic is completely over will patients' lives return to normal.

Meta-synthesis involves reinterpretation of study findings others and has many strengths and limitations. The strict inclusion criteria of this study ensured the reliability of the included articles, and the lack of publication language restriction ensured an adequate number of papers and national data sources. However, this study did have some limitations; gray literature may have been missed, and the data were mainly from COVID-19 survivors rather than family members and healthcare providers. Also, we were concerned only with the recent psychological experience of survivors; the long-term effects of COVID-19 on patients need to be further explored in the future. Long-term follow-up studies are needed to gain a deeper understanding of how the psychological needs of survivors evolve over time.

CONCLUSIONS

This systematic qualitative review examined the experiences of COVID-19 infected individuals worldwide. Five themes emerged highlighting the commonalities and characteristics of patients. We conclude that all patients experience difficulty adjusting to the role change between healthy person and patient, and that the psychological distress caused by COVID-19 to survivors is widespread and persistent. Promoting the return of survivors to society and family life is important for healthcare providers. Survivors should have access to more support in the battle against COVID-19. Future long-term

follow-up studies are required to gain a deeper understanding of how the psychological needs of survivors evolve over time. (Appendix S1, Appendix S2, Appendix S3)

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Appendix S1

Article retrieval strategy

- #1 "COVID-19" [MeSH Terms]
- #2 Coronavirus [Title/Abstract] OR COVID-19[Title/Abstract] OR 2019-ncov [Title/Abstract] OR SARS-cov-2[Title/Abstract]
- #3 #1 OR #2
- #4 "qualitative" [MeSH Terms]
- #5 qualitative*[Title/Abstract] OR phenomenology [Title/Abstract] OR grounded theory [Title/Abstract]
- #6 #4 OR #5
- #7 "Patient" [MeSH Terms]
- #8 Patient*[Title/Abstract] OR Client*[Title/Abstract] OR survivor*[Title/Abstract] OR Infected person [Title/Abstract]
- #9 #7 OR #8
- #10 #3 AND #6 AND #9

Appendix S2

Literature quality evaluation

	Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Grade
1	Shaban, R. Z. et al.	Y	Y	Y	Y	Y	N	N	Y	Y	Y	A
2	Guo, Q. et al.	U	Y	Y	U	Y	N	N	Y	Y	Y	B
3	Sun, W. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
4	Jing Yuan Wang et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
5	Fang Li, Li et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
6	Kong Shuzhen et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
7	Yu Feng et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
8	Moradi, Y. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
9	Jesmi, A. A. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
10	Sahoo, S. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
11	Mukhtar, N. B. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
12	Berends, K. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
13	Sun, N. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
14	Wu, C. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
15	Missel, M. et al.	Y	Y	Y	Y	Y	N	N	Y	Y	Y	A
16	Akbarbegloo, M. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
17	Norouzadeh, R. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
18	Jamili, S. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
19	Aliyu, S. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
20	Cervantes, L. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
21	Santiago-Rodriguez, E. I. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
22	Kürtüncü, M. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B
23	Son, H. M. et al.	U	Y	Y	Y	Y	N	N	Y	Y	Y	B

Q1. Is there congruity between the stated philosophical perspective and the research methodology? Q2. Is there congruity between the stated philosophical perspective and the research methodology? Q3. Is there congruity between the research methodology and the methods used to collect data? Q4. Is there congruity between the research methodology and the representation and analysis of data? Q5. Is there congruity between the research methodology and the interpretation of results? Q6. Is there a statement locating the researcher culturally or theoretically? Q7. Is the influence of the researcher on the research, and vice-versa, addressed? Q8. Are participant, and their voices, adequately represented? Q9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? Q10. Do the conclusions drawn in the research report flow from the analysis or interpretation, of the data?

Y, Yes; N, NO; U, Unclear; Grade A: the quality standard is fully met, such that the possibility of bias is remote; Grade B: the quality standard is partially met, such that the possibility of bias is moderate.

Appendix S3
Included in the literature

number	Author	Year	Country	Methods	Sample	Interesting phenomena	Location	Theme
1	Shaban, R. Z. et al.	2020	Australia	Semistructured interview by telephone	11	Explore the lived experience and perceptions of patients in isolation with COVID-19	Hospital isolation ward	5 themes: 1. Knowing about COVID-19, 2. Planning for and responding to COVID-19, 3. Being infected, 4. Life in the isolation and room, 5. Post-discharge life
2	Guo, Q. et al.	2020	China	Mixed-methods	5	Explore the mental status of patients with COVID-19	Hospital isolation ward	3 themes: 1. Negative emotions, 2. Stigma, 3. Uncertainty regarding the virus
3	Sun, W. et al.	2020	China	Semistructured interview	26	Understand COVID patients' experiences of and perspectives on disclosure of their illness, and explore and describe the factors affecting disclosure decisions	Hospital isolation ward	4 themes: 1. Person disclosed to, 2. Reasons for disclosure, 3. Reasons for nondisclosure, 4. Impact of disclosure
4	Jing Yuan Wang et al.	2020	China	Semistructured interview	15	Explore the experiences and feelings of patients with novel coronavirus pneumonia during the disease process	Hospital isolation ward	3 themes: 1. Negative psychological experience, 2. Positive psychological experience, 3. Gratitude
5	Fang Li, Li et al.	2020	China	Semistructured interview by video clip	13	Investigating the psychological experience of patients with COVID-19 during their illness	Hospital isolation ward	3 themes: 1. Presence of varying degrees of anxiety in patients with novel coronavirus, 2. Acute stress in patients with novel coronavirus, 3. Post-traumatic growth in patients with novel coronavirus
6	Kong Shuzhen et al.	2020	China	Semistructured interview	11	Understanding the physical and mental experiences of patients with COVID-19 who have experienced infection	Hospital isolation ward	3 themes: 1. Effects of illness on the body, 2. The emotional experience of illness, 3. Feelings and thoughts post illness
7	Yu Feng et al.	2020	China	Semistructured interview	18	Explore factors influencing anxiety and depression in patients with COVID-19	Hospital isolation ward	3 themes: 1. Personal factors, 2. Family factors, 3. Environmental factors
8	Moradi, Y. et al.	2020	Iran	Semistructured interview by telephone	14	Explore psychological disturbances in COVID-19 survivors throughout the pandemic	Hospital isolation ward	3 themes: 1. Living in limbo, 2. Psychological distress behind the wall, 3. Psychological burden of being a carrier
9	Jesmi, A. A. et al.	2020	Iran	Semistructured interview by telephone and face to face	14	Describe experiences of patients with COVID-19 infection	Hospital isolation ward	3 themes: 1. Mental strain, 2. Physical manifestations, 3. Coping mechanisms
10	Sahoo, S. et al.	2020	India	Narrativ	3	Discuss the experience of 3 persons diagnosed with COVID-19 infection admitted to a COVID ward	Hospital isolation ward	3 themes: 1. Dilemma of being a leader, 2. The troubled family, 3. The computer savvy boy
11	Mukhtar, N. B. et al.	2020	Nigeria	Semistructured interview by telephone	11	Patients' experiences and perspectives about COVID-19 and its treatment.	Patient's home	4 themes: 1. Community and secondary transmission, 2. Beliefs and precautionary measures against COVID-19, 3. Experiences of patients during COVID-19 hospitalization, 4. Suggestions for improvement of care and post-hospitalization experience
12	Berends, K. et al.	2021	Belgium	Semistructured interview	19	Understanding the experience of patients admitted to hospital for COVID-19	Hospital isolation ward	4 themes: 1. Experience, 2. Coping, 3. Integrating experience into life, 4. The importance of support systems
13	Sun, N. et al.	2021	China	Semistructured interview by telephone and face to face	16	Explore the psychology of COVID-19 patients during hospitalization	Hospital isolation ward and Patient's home	5 themes: 1. Attitude towards the disease, 2. Stressors, 3. Body and mind reactions, 4. Factors promoting epidemic prevention, 5. Psychological growth and outlook
14	Wu, C. et al.	2021	China	Semistructured interview by telephone	16	Explore the daily life and HRQoL of hospitalized COVID-19 survivors 3 months after being discharged	Patient's home	8 themes: 1. Physical symptoms, 2. Anxiety, 3. Trauma, 4. Economic losses, 5. Place-based identity, 6. Self-stigma, 7. Health self-interventions, 8. Changing lifestyle
15	Missel, M. et al.	2021	Denmark	Semistructured interview by telephone	15	Explore the lived experiences of people infected with COVID-19 in Denmark during the first phase of the pandemic	Hospital isolation ward and Patient's home	3 themes: 1. COVID-19 as a threat to the body, 2. Interference of COVID-19 with Ordinary social relationships
16	Akbarbegloo, M. et al.	2021	Iran	Semistructured interview	30	Examine the psychosocial experiences of patients with COVID-19 after passing the crisis stage.	Hospital isolation ward	3 themes: 1. Social rejection, 2. Lack of support, 3. Efforts to gain mental tranquility

(continued on next page)

Appendix S3 (Continued)

number	Author	Year	Country	Methods	Sample	Interesting phenomena	Location	Theme
17	Norouzadeh, R. et al.	2021	Iran	Semistructured interview by telephone and face to face	16	Describe the experiences of patients with COVID-19 admitted to the intensive care units	Hospital isolation ward	3 themes: 1. Captured by a challenging incident with subcategories, 2. Flourishing of life, 3. Counting one's blessings (all with subcategories)
18	Jamili, S. et al.	2021	Iran	Semistructured interview by telephone	17	Understand the lived experience of inpatients hospitalized with COVID-19	Hospital isolation ward	4 themes: 1. Denial of the disease, 2. Negative emotions upon arrival, 3. Perception of social and psychological supports, 4. Post-discharge concerns and problems
19	Aliyu, S. et al.	2021	The United State	Semistructured interview	15	Explore the lived experience of being diagnosed with COVID-19 of black patients	Hospital isolation ward	3 themes: 1. Panic due to a COVID-19 diagnosis, 2. The repercussion of the diagnosis, 3 Personal assessment of risks in one's environment
20	Cervantes, L. et al.	2021	The United State	Semistructured interview	60	Describe the experiences of Latinx individuals who were hospitalized with and survived COVID-19.	Patient's home	5 themes: 1. COVID-19 as a distant and secondary threat, 2. COVID-19 as a compounder of disadvantage, 3. Reluctance to seek medical care, 4. Healthcare system interactions, 5. Faith and community resiliency
21	Santiago-Rodriguez, E. I. et al.	2021	The United State	Semistructured interview	24	Characterize the variability in the COVID-19 experience and recovery process	Patient's home	3 themes: 1. Infection with COVID-19 was associated with psychological distress, 2. The illness experience was characterized by uncertainty in terms of managing symptoms and recovery, 3. Health information-seeking behavior facilitated by access to medical care, and uncertainty regarding the course of the illness and recovery
22	Kürtüncü, M. et al.	2021	Turkey	Semistructured interview by telephone	18	To explore the lived experience of being diagnosed with COVID-19 as a black patient	Hospital isolation ward	3 themes: 1. Panic due to COVID-19 diagnosis, 2. The repercussions of the diagnosis, 3. Personal assessment of risks in one's environment
23	Son, H. M. et al.	2021	South Korea	Semistructured interview	16	Provide an in-depth understanding and description of the disease experiences of COVID-19 patients	Hospital isolation ward	6 themes: 1. Desperate and uncertain times during COVID-19 diagnosis and treatment, 2. Shock and complaints related to the disinfection process, 3 Social stigma: my "scarlet letter", 4. Mind and body deprived by COVID-19, 5. Rediscovering relationships through hardship