

BMJ Open Fighting COVID-19: a qualitative study into the lives of intensive care unit survivors in Wuhan, China

Dong Wu ,^{1,2,3} Hanyue Ding ,⁴ Jiaye Lin ,⁴ Meng Xiao ,^{2,5} Jing Xie ,^{2,6} Feng Xie ,^{7,8} Shuyang Zhang ,^{2,9}

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DW, HD and JL contributed equally.

DW, HD and JL are joint first authors.

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For numbered affiliations see end of article.

Correspondence to

Professor Feng Xie;
fengxie@mcmaster.ca and
Professor Shuyang Zhang;
shuyangzhang103@163.com

ABSTRACT

Objectives We aimed to provide an insight into the life of survivors of critical COVID-19 in China.

Methods We conducted an online survey and qualitative interviews among intensive care unit survivors of critical COVID-19 between November and December 2020 in Wuhan, China. Eligible participants were asked to complete the EQ-5D-5L and the Short Form 36-Item Survey, and invited to participate in a semistructured face-to-face interview. Descriptive analyses and phenomenological approach were adopted to analyse quantitative and qualitative data, respectively.

Results Of 10 survivors who completed the questionnaire, 8 participated in the interview. The mean scores±SD of EuroQol-5 Dimensions-5 Level utility and EuroQol-Visual Analogue Scale were 0.88 ± 0.15 and 80.9 ± 14.2 , respectively. The qualitative interview identified four themes, namely poor physical health, post-traumatic stress, social stigma and family support.

Conclusions COVID-19 survivors continue fighting physical and psychological impacts. Despite strong family support, these patients are struggling with social stigma. It is a long, challenging journey to recovery for patients and society.

INTRODUCTION

Since the outbreak of COVID-19 in Wuhan, China, in December 2019, the pandemic has debilitated global society for 2 years. As of 17 December 2021, WHO recorded over 272.0 million cases and more than 5.3 million deaths related to COVID-19 in 223 countries, areas or territories.¹

COVID-19 damages the respiratory system, causing symptoms, such as dry cough, difficulty breathing and shortness of breath. Several studies have reported the impact of COVID-19 infection after discharge, including lung function abnormalities, gastrointestinal symptoms, delirium, anxiety and depression.^{2–5} About 5% of the infected progressed to critical illness and required intensive care.^{6–8} Approximately 80% of patients on mechanical ventilation developed postintensive care syndrome and experienced severe physical and mental dysfunctions. Hosey

Strengths and limitations of this study

- This study reveals that COVID-19 survivors in China are struggling with social stigma despite strong family support.
- This study has only a small number of survivors participated in our survey and interview. Despite the care and effort made by one of the best medical teams in the country, only 20% of critical patients survived.
- It was challenging to conduct in-person survey during a pandemic.

and Needham emphasise the importance of rehabilitative care in the COVID-19 recovery period.⁹ However, to our best knowledge, little is known about the long-term impact of the COVID-19 infection among the survivors of intensive care unit (ICU).¹⁰

Therefore, this study aimed at providing an insight into the life of ICU survivors in Wuhan using quantitative and qualitative methods.

METHODS

Study design and participants

Survivors of critical COVID-19 infection in Wuhan, China were approached for an online survey and invited to participate in an interview between November and December 2020. All survivors were recruited from Wuhan Union Hospital where a national medical team from Peking Union Medical College Hospital (led by SZ, one of senior authors) was dispatched and provided care to critical patients. Survivors who met the following inclusion criteria were eligible: (1) diagnosed as critical COVID-19 with respiratory failure, shock, or multiorgan system dysfunction; and (2) survived and discharged from the hospital.

The Consolidated Criteria for Reporting Qualitative Research was followed.

Procedure

After obtaining an oral informed consent, each eligible patient was asked to complete an online questionnaire that consists of sociodemographic questions, the Short Form 36-Item Survey (SF-36), and the EuroQol-5 Dimensions-5 Level (EQ-5D-5L). After the survey, the patient was invited to participate in a semistructured face-to-face interview. After explaining the objectives and the process, we started the interview with a general question: 'Please tell me about your quality of life and rehabilitation experience after you were discharged from the hospital'. A few open-ended probing questions were asked to obtain as much information as possible (see the interview guide in online supplemental table 1). All interviews were audio recorded.

Data analysis

The SF-36 and EQ-5D-5L responses and utility scores calculated using the China value set were descriptively summarised.^{11 12} The interviews were transcribed verbatim by a transcription team and verified by the interviewer (DW) to ensure accuracy. Two authors (DH and LJ) used the phenomenological approach to independently analyse the transcripts, including reading the transcripts to familiarise materials, identifying and extracting significant statements, formulating meanings of statements, categorising meanings into themes, and developing a full and inclusive description. Disagreements were resolved by discussion to achieve a consensus among the team. All data collection and analysis were conducted in Chinese. For the manuscript writing, one author translated themes and quotations to English which were backwards translated to Chinese by another author. The information related to the patient's identity was removed before the data analysis.

Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Role of the funding source

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RESULTS

Between February and May 2020, the medical team from Peking Union Medical College Hospital admitted 109 critical patients with COVID-19 to ICU at Wuhan Union Hospital. By November 2020, 23 patients have survived with 13 still hospitalised. The 10 patients who were discharged were invited and completed the online questionnaire, and 8 participated in the interview. The characteristics of the patients are shown in table 1. The 10 patients were aged between 28 and 74 years. The mean±SD follow-up time after discharge was 5.8±0.6 months. The

Table 1 Characteristics and health-related quality of life of participants

ID	Time after discharge	Interviewed	Gender	Age	BMI	EQ-5D-5L					SF-36									
						MO	SC	UA	PD	AD	VAS	Utility	PF	RP	BP	GH	VT	SF	RE	MH
P1	6 months	Yes	Male	28	32	1	1	1	1	1	80	1.00	65	100	67.5	60	70	87.5	100	72
P2	5 months	Yes	Female	55	23.3	1	1	1	1	1	81	1.00	80	0	100	65	70	62.5	100	68
P3	5 months	Yes	Female	71	19.5	3	2	3	3	2	56	0.50	10	0	35	40	45	25	100	92
P4	6 months	Yes	Female	74	27.3	2	1	1	2	3	61	0.76	50	0	45	55	50	62.5	0	44
P5	6 months	Yes	Female	54	23.5	1	1	1	1	1	95	1.00	95	100	77.5	100	95	100	100	100
P6	7 months	Yes	Male	74	22	1	1	1	2	1	85	0.94	85	100	77.5	95	100	100	100	92
P7	5 months	Yes	Female	69	19.5	1	1	1	1	1	100	1.00	100	100	100	80	100	100	100	100
P8	6 months	Yes	Male	57	25.6	1	1	1	1	2	76	0.95	95	100	80	60	75	87.5	100	60
P9	6 months	No	Female	37	26.7	2	1	2	2	2	100	0.78	85	25	77.5	55	45	50	33.3	44
P10	6 months	No	Female	55	24.7	1	1	2	2	2	75	0.85	65	75	77.5	50	60	62.5	66.7	68

AD, anxiety/depression; BMI, body mass index; BP, bodily pain; GH, general health; MH, mental health; MO, mobility; PD, pain/discomfort; PF, physical functioning; RE, role emotional; RP, role physical; SC, self-care; SF, social functioning; UA, usual activities; VT, vitality.

Table 2 Clinical characteristics for patients interviewed

Characteristic	Interviewers (n=8)	Non-interviewers (n=2)
Age, year (SD)	62.50 (53.5, 72.25)	32, 73*
Male, No/total (%)	3/8 (37.5)	0/2 (0.0)
SIRS (%)	8 (100.0)	2 (100.0)
Shock (%)	2 (25.0)	0 (0.0)
Respiratory failure (%)	7 (87.5)	2 (100.0)
Renal failure (%)	2 (25)	0 (0.0)
APACHE II (SD)	12.50 (10.50, 14.50)	9, 14*
SOFA (SD)	4.50 (3.25, 5.75)	2, 4*
qSOFA (SD)	1.00 (1.00, 1.00)	1, 2*
CURB-65 (SD)	1.50 (1.00, 2.00)	1, 3*
Charlson index scores	2.50 (1.00, 5.00)	2, 3*
More than one organ failure (%)	3 (37.5)	0 (0.0)
Non-invasive ventilation (%)	8 (100)	2 (100.0)
Invasive ventilation (%)	7 (87.5)	1 (50.0)
Tracheotomy (%)	1 (12.5)	0 (0.0)
ICU days (SD)	18.50 (7.75, 23.25)	14, 25*
Length of hospital stay (SD)	51.50 (43.00, 71.50)	23, 56*

APACHE II, SOFA, qSOFA, CURB-65, and Charlson index scores were assessed within 24 hours from admission, while the rest information was evaluated at discharge.

*As there were only two subjects, we listed the specific values of their clinical information.

ICU, intensive care unit; APACHE II, acute physiology and chronic health evaluation II; qSOFA, quick sequential organ failure assessment; SIRS, systemic inflammatory response reaction; SOFA, sequential organ failure assessment.

proportions of patients reporting any problems in five dimensions of the EQ-5D-5L were 30% for mobility, 10% self-care, 30% usual activities, 50% pain/discomfort, and 50% anxiety/depression. The mean±SD EQ-5D-5L utility and EQ-VAS were 0.88±0.15 (range 0.5–1) and 80.9±14.2 (range 56–100), respectively. The mean±SD of SF-36 subscale was 73.0±25.8 for physical functioning, 60.0±45.0 role physical, 73.8±19.6 bodily pain, 66.0±18.5 general health, 71.0±20.5 vitality, 73.8±24.0 social functioning, 80.0±34.0 role emotional and 74.0±20.2 mental health (table 1). Clinical characteristics of the participants and non-participants are shown in table 2.

Four themes were identified from analysing the interview transcripts: poor physical health, post-traumatic stress, social stigma and family support.

Poor physical health

All eight interviewed described poor physical health in general. As a result, some of them lost their ability to work or, to some extent, perform activities of daily living. Participants mentioned the impairment on pulmonary function: ‘After exercise, especially going upstairs, I wheezed a bit. My blood oxygen is lower than normal, about 94%–95%...The pulmonary fibrosis does not get recovered, which affects my life.’ (P2) ‘[During the subsequent visit] doctor said my pulmonary fibrosis was quite severe...The recovery is quite slow.’ (P3) One patient said: ‘I had endotracheal intubation. Previously my voice

was not hoarse like this and my vocal capacity reduced... There are few pulmonary nodules in my left lung.’ (P5)

Post-traumatic stress

The psychological impact experienced by the patients is immense. The experience with COVID-19 in ICU is traumatic and has continued haunting the patients after discharge. All the participants reported the difficulty falling asleep at night. ‘I do not want to do anything. I cannot sleep at night and always have nightmares and wake up...I almost do not want to live...I cannot overcome the barrier in my mind. I know I should not, but I am not able to...I think I do not have psychological problems, but I am just sad and regretful...When I am at home now, the scene appears, and I cannot help thinking about it and I cannot forget.’ (P4) Another survivor who also worked in the hospital said ‘when I dreamed about the scene in hospital at night, I am still stressed in mind...I am a patient, but also the leader of our hospital. I did not take good care of our health workers. I feel very sad [sobbing].’ (P2)

A few patients who lost a family member or colleagues to COVID-19 were suffering severe traumatic stress. ‘My husband and I were ill at the same time. I am alive, but my husband passed away. I thank you all for saving me, but actually, it would be better if not. I feel very sad now [crying]. Only me at home, I always remember him...A sudden call from the hospital informed me about his

death. I could not accept [crying]... I cannot stop crying when I see my husband's belongings at home.' (P4) 'Our hospital was severely affected by COVID-19. A lot of health care workers were infected, and some died. I was very sad.' (P2). One participant was grieving about the death of a stranger: 'In the ICU, I saw a person of my age died beside me. I felt very sad.' (P6)

These patients were also worried about their poor health. 'I have been feared for recurrence after discharge... I heard that COVID-19 might affect reproduction. Although I have not gotten married, I am a bit worried about that.' (P1) 'I thought that I would never recover...I had a low mood after discharge mainly because I am unable to speak and wheezed. I feel very bad and think that I will never recover. There is no sense to live.' (P3) The stress also affects family members. 'I feel good now, but my parents have much heavier psychological stress than me. I know they come to my room at night when I am sleeping. They will be seriously worried if I feel a little sick. I have to call them every day, otherwise, they will be worried.' (P1)

Professional counselling helps patients with stress management. One patient mentioned her positive experience: '[In hospital] I thought I had muscular dystrophy and I would never walk again. I had anxiety and delirium at that time...I did not want to answer my daughter's call, and then she called for a psychological doctor...I had psychological counselling and attended the online course at night when I could not sleep, and the doctor made me feel that I could walk again.' (P5). However, the desire to seek counselling has been largely hindered by China's strict social norms and cultural beliefs regarding personal/family reputation. Most of the patients have not sought any professional counselling since discharge.

Social stigma

In China, some people may think that patients with severe COVID-19 infection, even recovered, are still contagious, and therefore are afraid of having any contact with them. The youngest survivor interviewed said that 'My girlfriend broke up with me because I was ill...The landlord kicked me out last month and he said he would even not allow me to rent the house if he knew I was infected before.' (P1) This stigma could also come from friends. 'After discharge, both friends and other people I know are afraid of me and fear for getting infected ...They do not visit me anymore...Relatives only contact me by phone and do not allow me to go back to my hometown.' (P8) Social stigma could lead to feeling of shame. 'I go out much less, and do not go far.' (P3). 'I do not want to see my relatives...I am struggled, as I do not want to stay at home alone, but I am also afraid of going out and meeting others.' (P4) 'My relatives and friends knew, but my neighbourhood did not, because we found ill people were discriminated against.' (P6) 'I feel not good when going out. I do not want to talk with others, and I am afraid of others' fear.' (P7) People with medical knowledge are less likely to discriminate against COVID-19 patients. 'We did not tell

neighbours, or anyone, [about my illness] in the community. They were afraid of it, as they did not have medical knowledge...Also, my friends and colleagues invited me to their home or to have a meal. My relatives and friends are extremely nice to me. We can eat and sing together. The illness does not estrange them from me; perhaps this is due to the fact that many of them have medical knowledge.' (P5) 'Most of my relatives, friends, and colleagues are health workers, and they are all kind and do not discriminate against me.' (P2)

Family support

After discharged from hospital, patients with COVID-19 started a long journey to recovery. Due to the lack of professional rehabilitation services, family members become an important source of support, both physical and psychological. 'I remembered the first time after discharge when having a meal with my parents. I felt alive again and felt good to be alive at that moment... My family and relatives are kind and do not discriminate against me.' (P1) 'I thought that I have a family, and my daughter has not graduated, and my husband was good to me. I must try my best to recover.' (P2) 'I persist in exercising because I do not want poor health. My son and daughter are great, and I made a concerted effort to be alive. I must try my best to take exercise for recovery.' (P6) 'I almost get normal now. I always have a good appetite. My parents made a lot of nutrition-dense meals for fear of my poor nutrition state. I ate a lot these days and even gained weight.' (P1)

DISCUSSION

The patients who participated in our study are among few ICU survivors during the first wave of COVID-19 in Wuhan. However, surviving COVID-19 does not end with the hospital discharge. Six months into the recovery, all the survivors have been battling physical and psychological impacts while facing social stigma. It is fortunate that they have strong family support in their journey to recovery.

The physical and psychological impacts experienced by COVID-19 survivors are massive. Symptoms like fatigue, muscle weakness, insomnia, sadness, depression and fear were consistent with the previous studies, as well as the QoL scores.^{4 5 13-15} Huang *et al* conducted a cohort study and use ED-5D-5L to follow-up survivors 6 months after discharge, which indicated the pain/discomfort and anxiety/depression dimensions had more problems and showed VAS (0.80) of survivors at 6 months after critical infection.⁴ These findings highlight the paramount importance of post-COVID rehabilitative care. Patients may recover or cope well with physical impairments, for example, through physical exercises.¹⁶⁻¹⁹ It is more challenging to recover psychologically. Research has suggested that the COVID-19 rehabilitation programme should consider individual needs according to their condition and progress.^{16 18 19} Therefore, we suggest an effective

and routine examination and rehabilitation programme during recovery, which could be conducted at the group setting in the community.²⁰ The uptake of rehabilitation care is low in China due to a few factors. First, the rehabilitation care facility is limited in China. In a pandemic, access to this service becomes even more difficult. Second, the awareness and acceptance of psychological impairment remain low due to the misunderstanding and negative stereotype of psychological problems in the Chinese culture. As a result, patients may refuse to seek professional psychological support. Therefore, it is imperative for China to improve its rehabilitation care system and, in the meantime, enhance the awareness of psychological disorders and care.

The pandemic of COVID-19 has not just strained health systems but also scarred society. The global scale of the crisis has already reoriented our relationship with each other. It is heartening to see strong family support among the survivors. This reflects that family is a core value element deeply rooted in the Chinese culture. However, social stigma faced by survivors is one of the biggest barriers to their recovery. In China, many, when facing social stigma, may develop a strong feeling of shame that further prevents them from seeking help and re-entering to the community.²¹ Indian researchers also reported high levels of enacted and perceived externalised stigma among COVID-19 survivors.²² Enacted stigma refers to the experience of discrimination, prejudice and social isolation by others, while perceived stigma can be identified as the individual's belief against the attitudes of others. In our study, we found that enacted and perceived stigma decreased significantly with a higher level of education. Patients experience less stigma if their family and friends have medical expertise and knowledge. In the era of social media, it is important to ensure citizens to have access to true information and minimise the impact of misinformation and disinformation to eliminate stigma. This could be an effective way to recovery not just for patients but also for the society as a whole.

Using predeveloped instruments is a widely used method to assess the quality of life of patients. The scores of EQ-5D-5L or SF-36 among the survivors are slightly lower than the general population norms of these instruments in China.^{23 24} There are some discrepancies between quantitative and qualitative results. For example, participant #4 reported moderate problems on the EQ-5D-5L anxiety/depression dimension, but she was deeply depressed and sobbed several times during the interview. Furthermore, the participants #6 and #7 reported full scores on the SF-36's social function dimension, but in the interview, they emphasised the discrimination that affects their social life. These discrepancies highlight the importance of analysing both qualitative and quantitative data in order to understand the true impact of COVID-19 on the daily lives of patients.

There are a few limitations in this study. Some of the struggles experienced by the patients should be interpreted in the context of Chinese culture and with

caution. They may not be generalisable to other countries. Even if survivors have such strong family support, they are struggling with social stigma. We have only a small number of survivors participated in our survey and interview. Despite the care and effort made by one of the best medical teams in the country, only 20% of critical patients survived. Furthermore, it was challenging to conduct in-person survey during a pandemic where some level of control measures was still in place in Wuhan and across the country. The interpretation of the qualitative data was not based on information saturation and therefore may not include all important impacts experienced by COVID-19 survivors.

CONCLUSION

COVID-19 survivors continue fighting physical and psychological impacts after discharge. Despite strong family support, these patients are struggling with social stigma. It is a long, challenging journey to recovery for patients and society.

Author affiliations

¹Department of Gastroenterology, Peking Union Medical College Hospital, Beijing, China

²State Key Laboratory of Complex Severe and Rare Diseases, Peking Union Medical College Hospital, Beijing, China

³Clinical Epidemiology Unit, International Clinical Epidemiology Network, Beijing, China

⁴JC School of Public Health and Primary Care, The Chinese University of Hong Kong Faculty of Medicine, Hong Kong, Hong Kong

⁵Department of Clinical Laboratory, Peking Union Medical College Hospital, Beijing, China

⁶Department of Infectious Diseases, Peking Union Medical College Hospital, Beijing, China

⁷Department of Health Research Methods, McMaster University, Hamilton, Ontario, Canada

⁸Centre for Health Economics and Policy Analysis, McMaster University, Hamilton, Ontario, Canada

⁹Department of Cardiology, Peking Union Medical College Hospital, Beijing, China

Twitter Feng Xie @fengxie_mac

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Contributors DW, HD and JL contributed equally. Concept and design: DW, HD, JL and FX. Acquisition, analysis, or interpretation of data: DW, HD and JL. Drafting of the manuscript: DW, HD, JL, and FX. Critical revision of the manuscript for important intellectual content: MX, JX, FX and SZ. Obtained funding: SZ. Supervision: SZ. Guarantor: SZ.

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Please contact Dr. Dong Wu (ORCID: 0000-0001-9430-9874) for the access requests. The final decision will be made after the authors discussion.

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ORCID iDs

Dong Wu <http://orcid.org/0000-0001-9430-9874>

Hanyue Ding <http://orcid.org/0000-0001-9977-0985>

Jiaye Lin <http://orcid.org/0000-0001-8858-620X>

Meng Xiao <http://orcid.org/0000-0003-2103-7008>

Jing Xie <http://orcid.org/0000-0002-9115-8895>

Feng Xie <http://orcid.org/0000-0003-3454-6266>

Shuyang Zhang <http://orcid.org/0000-0002-1532-0029>

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