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Sun, Wenxiu Zhou, Ying Chen, Wei-Ti et al.

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## ORIGINAL ARTICLE



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# Disclosure experience among COVID-19-confirmed patients in China: A qualitative study

Wenxiu Sun RN MSN, Research Nurse<sup>1</sup> | Ying Zhou RN MSN, Staff Nurse<sup>1</sup> | Wei-Ti Chen RN, FAAN, CNM PhD, Associate Professor<sup>2</sup> | Feifei Huang RN PhD, Associate Professor<sup>3</sup> | Meiyan Sun RN MSN, Research Nurse<sup>1</sup> | Lei Shen RN MSN, Staff Nurse<sup>1</sup> | Yan Gao RN MSn, Staff Nurse<sup>1</sup> | Qing Zhang RN MSN, Staff Nurse<sup>1</sup> | Siyue Ma RN MSN, Staff Nurse<sup>1</sup> | Chengshi Shiu MSW, GStat PhD, Assistant Professor<sup>4</sup> | Lin Zhang RN, MPH, MHA, Nursing Director<sup>1</sup> | Hongzhou Lu Professor MD, PhD, President<sup>1</sup>

# Correspondence

Wei-Ti Chen, School of Nursing, University of California, Los Angeles, Los Angeles, CA 90095, USA. Email: wchen@sonnet.ucla.edu

Hongzhou Lu, Shanghai Public Health Clinical Center, Fudan University Shanghai, China, CA 201500, USA. Email: luhongzhou@fudan.edu.cn

Lin Zhang, Shanghai Public Health Clinical Center, Fudan University Shanghai, China, CA 201500, USA. Email: zhanglin@shphc.org.cn

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# **Abstract**

Aim: To understand COVID patients' experiences of and perspectives on disclosure of their illness and to explore and describe the factors affecting disclosure decisions among COVID patients in China.

Background: Disease disclosure is a critical component of prevention and control of a virus outbreak, and this is especially true during the COVID-19 pandemic. Understanding COVID patients' experiences and perspectives on disclosure could play a vital role in COVID management.

**Design:** A qualitative study.

Methods: A semi-structured interview guide was used to conduct qualitative in-depth interviews from April to June 2020. All the interviews were audio-recorded and transcribed, and then, a thematic analysis was conducted. The Standards for Reporting Qualitative Research (SRQR) were applied to this study.

Results: A total of 26 COVID-confirmed patients were recruited for the in-depth interviews. Four themes emerged from the thematic analysis on disclosure: persons disclosed to, reasons for disclosure, reasons for nondisclosure and impact of disclosure. The participants disclosed their COVID diagnosis to different groups, including family, close friends, community members and workplace contacts. The main reasons for disclosure included the following: government policy, social responsibility, gaining support and fear of being blamed for nondisclosure. However, some participants decided not to disclose to some groups for fear of facing stigma and discrimination or to protect family members from discrimination. Despite the potential benefits of obtaining support after disclosure, many participants did experience stigma and discrimination, privacy exposure, psychological distress and social isolation.

Conclusions: An individual's decision as to whether to disclose their COVID-positive status is affected by many factors. To prevent the spread of COVID-19 and reduce the potential risks of disclosure, such as discrimination and privacy exposure, a balanced

<sup>&</sup>lt;sup>1</sup>Shanghai Public Health Clinical Center. Fudan University, Shanghai, China

<sup>&</sup>lt;sup>2</sup>School of Nursing, University of California Los Angeles, Los Angeles, CA, USA

<sup>&</sup>lt;sup>3</sup>School of Nursing, Fujian Medical University, Fuzhou, China

<sup>&</sup>lt;sup>4</sup>Department of Social Work, National Taiwan University, Taipei, Taiwan

intervention should be designed to protect COVID patients and to secure any contact tracing. Therefore, the chances of discrimination could be decreased and patients' confidentiality could be protected.

Relevance to Clinical Practice: As the number of COVID patients increases, disclosure of an individual's infectious status is encouraged by health departments. Despite the potential benefits of disclosure, discrimination and privacy exposure should not be ignored. A disclosure protocol is necessary to ensure patients' privacy regarding their COVID status.

KEYWORDS

China, COVID, disclosure, qualitative study

# 1 | INTRODUCTION

Since the first case was reported in Wuhan, China, the coronavirus disease 2019 (COVID-19) has profoundly affected lives all over the world (Huang et al., 2020; World Health Organization [WHO], 2020a) as it has spread to 216 countries (World Health Organization [WHO], 2020b); there are currently more than 2 million confirmed cases globally. To battle against and control this highly contagious disease, WHO and local governments have published a series of guidelines and policies for contact restrictions, guarantine and isolation. China was the first country to close all connections within the country and globally (air and land; WHO, 2020c; National Health Commission [NHC], 2020a) to contain the virus. As a result, this lockdown policy controlled the outbreak of COVID in China, and Chinese society is expected to gradually resume normal operations (NHC, 2020b). However, COVID-related issues, such as disclosure, stigma and discrimination, as well as psychological distress, affect all individuals' well-being (Yao et al., 2020).

# 2 | BACKGROUND

Disclosure of an infectious disease is a stressful and anxious process because the information is shared with individuals who may be unaccepting and misunderstanding of the condition and the disclosure may lead to a stigmatising reaction (Evangeli & Wroe, 2017). People carefully choose whom they disclose to and weigh the benefits and risks of disclosure. Studies have shown that people living with HIV were willing to disclose their condition to spouses and family members but were less likely to disclose to friends and co-workers (Zang et al., 2015). People choose to disclose or not based on the closeness of their relationships and on who might potentially provide support after disclosure (Maman et al., 2014; Zang et al., 2015). One study indicated that people living with HIV who disclosed to intimate networks of people could obtain more support, instead of discrimination, if the relationships were positive (Green et al., 2018).

# What does this paper contribute to the wider global community?

- The study provides insights into COVID patients' experiences regarding disclosure of their infection and describes the factors affecting their disclosure decisions.
- The study identified facilitators of COVID disclosure that could be considered in future studies.
- Given the importance of confidentiality to and the potential discrimination against individuals in the process of COVID disclosure, it is important for future studies to establish disclosure protocols to ensure patients' privacy.

Disease disclosure is a complex issue, especially when involving ailments such as mental illnesses or sexually transmitted diseases, such as HIV. Many researchers have found that ill individuals were unwilling to reveal the status to other persons (Adeoye-Agboola et al., 2016; Brohan et al., 2012); however, disclosing an infectious disease has important implications for both patients and the general population. From a public health perspective, disclosure has been advocated due to its vital role in reducing transmission of disease (O'Connell et al., 2015). Additionally, people who disclose their disease status are more likely to gain social support, reduce self-stigma and adopt positive coping strategies to address the disease (Ekama et al., 2012; Mao et al., 2018; Yonah et al., 2014). Despite these potential positive outcomes, disclosure can also carry several risks, such as stigma and discrimination, violence, social marginalisation or loss of employment (Kennedy et al., 2015; Nachega et al., 2012; Siu et al., 2012; Syed et al., 2015). These negative outcomes not only take a toll on social relationships and adversely affect quality of life but also discourage further disease disclosure (Adeoye-Agboola et al., 2016).

The outbreak of the COVID pandemic has brought anxiety, depression, worries and stress to the general population (Dong & Bouey, 2020; Fegert et al., 2020). People have tended to take

TABLE 1 Interview questions

Number	Questions
1	How do you know that you have COVID-19?
2	Please tell me what do you know about COVID-19?
3	When you knew you had COVID-19, what was the first thing that came to mind?
4	What are your concerns and worries before and after the diagnosis?
5	Who did you tell about your COVID-19 diagnosis? Why or why not?
6	After people know about that you have COVID-19, what did they do? Can you share one or two reactions with us?

self-protective actions, such as avoiding contact with individuals with respiratory symptoms. People have mainly discriminated against those whom they perceive as bringing COVID to the public, such as Asians (Eaton & Kalichman, 2020; Logie, 2020). In China, since Wuhan was where the first cases were reported, people who came from Wuhan were highly stigmatized (End coronavirus stigma now, 2020; Huang, 2020). After the province lockdown, people held hostile attitudes and displayed aggressive behaviours towards people from Wuhan and its vicinities (End coronavirus stigma now, 2020; WHO et al., 2020). In addition, people who have recovered from COVID-19 or been released from home isolation or quarantine also face stigma (Centers for Disease Control, National Center for Immunization, and Respiratory Diseases (NCIRD), 2020).

These kinds of attitudes may have an impact on COVID disclosure among patients; however, patients' perceptions and views on disclosure are still unclear. Although the use of quantitative studies exploring disclosure has predominated in recent literature, such studies are seriously limited in regard to capturing patients' experiences and perceptions in relation to disclosure (Geary et al., 2014; Vu et al., 2012). Since the experiences of and responses to disclosure are complex, attaining a detailed understanding of COVID-19 patients' views on disclosure necessitates a qualitative study method. Therefore, in this study, we aimed to explore COVID patients' experiences and perspectives on disclosure, and to explore and describe the factors affecting disclosure decisions among COVID patients in Shanghai, China. With this data, healthcare providers can develop appropriate interventions to assist individuals who are willing to disclose, as well as protect their personal privacy during the process of disclosure.

# 3 | METHODS

# 3.1 | Aim

The aim of this study was to explore COVID-confirmed patients' perceptions of disclosure and describe the factors affecting decisions to disclose among COVID patients in China.

# 3.2 | Study design and settings

This qualitative study used a phenomenology approach (Merleau-Ponty, 2002), which allowed us to obtain and analyse first-person experiences and perspectives regarding COVID disclosure. We conducted 26 in-depth interviews with COVID-confirmed patients who received care at a designated hospital for COVID-suspected and confirmed cases in Shanghai. As of this writing, more than 1000 COVID-confirmed patients were cared for by this hospital. Guidelines for good reporting of a qualitative study (Standards for Reporting Qualitative Research [SRQR]; O'Brien et al., 2014) were used in this paper (see File S1).

## 3.3 | Participants

The purposive sampling method was used to invite individuals to participate in the study. The inclusion criteria were (a) confirmed as having COVID-19, (b) 18 years of age or older and (c) received care at the COVID-designated hospital in Shanghai. Since participants came from different cities in China and there were traffic blockages during the pandemic, in-depth interviews were carried out by Zoom or WeChat (a cell phone application). Seventy-three COVID patients were contacted, of whom 26 were recruited after securing their informed consent (36% acceptance rate). The recruitment was carried out and semi-structured in-depth interviews were conducted from April to June 2020. After interviewing 26 participants, a saturation point was reached, that is no new information was obtained (Guest et al., 2006). Study participants received a small reimbursement for their participation.

# 3.4 | Qualitative data collection

All the in-depth interviews were audio-recorded and conducted by two research nurses who had provided care for COVID-confirmed patients, a fact which gave them confidence to interview the participants. Before they conducted interviews, these two research nurses were trained on in-depth interview skills and role-played exercises to ensure consistency between their research skills. Then, each research nurse interviewed the same two study participants so as to further compare the consistency of their interview skills. The interview guide focused on the participants' perceptions of their experiences regarding disease disclosure and their mental status before and after the COVID-19 diagnosis. Sample questions were as follows: "Please tell me how you know about your COVID diagnosis." "Who do you talk to about your diagnosis? Why or why not?" and "What are the impacts of COVID-19 infection after disclosure?" The details of the in-depth interviews are presented in Table 1. The average interview took 40–60 min.

# 3.5 | Ethical considerations

The study was approved by the relevant institutional review boards of the involved university (IRB#20-000832) and the hospital (YZ-2020-S037-01). Potential participants were provided the study consent forms, were informed about the study and told they had the right to withdraw from the study at any time without consequences if they were to participate. Interviews were conducted after securing the signed informed consent forms. Participants were assigned a study ID before the in-depth interviews to ensure their anonymity and confidentiality. The linked name and study ID were kept in an encrypted computer and only accessed by the study PI.

# 3.6 | Analysis

The data were analysed with Giorgi's analysis approach (Giorgi, 2009) using NVivo 12 software (QRS International). All interviews were transcribed verbatim. The study team then analysed these qualitative data. Initially, each case was read several times to get a sense of the content. The study team then developed the preliminary codebook, specifically gearing it to COVID disclosure. Two of the research staff separately coded two transcripts and then compared their results. For discrepancies between researchers' coding, they discussed the differences and achieved consensus for the final coding. After confirming the coding reliability, the research staff started coding all the transcripts. The research team then examined the codes and themes to formulate the sub-themes and final themes. Last, researchers finalised the qualitative analysis and translated the selected quotes into English for publication.

# 3.7 | Enhancing trustworthiness

Lincoln and Guba's (1985) criteria for trustworthiness of qualitative research were adopted in this study to ensure its quality. First, the heterogeneity of the investigators, such as research experience and length of employment, was considered to enhance the credibility of the study. Before the interviewing, all investigators were trained

with the interview guide and pilot interviews were conducted. Second, to guarantee confirmability and dependability, the analysis was performed using researcher triangulation (Elo et al., 2014). Then, all investigators met to discuss discrepancies in the coded data and eventually achieved consensus on the final coding. To enhance transferability, the context of the research, such as study sample, method and results, is described in detail below.

## 4 | RESULTS

# 4.1 | Participant characteristics

Twenty-six participants were recruited; they had a mean age of 34 years (SD = 9.3), ranging from 19 to 56 years of age, and 12 were male (46%) and 14 were female (54%). Eighteen participants (69%) came from Shanghai, two from nearby Zhejiang province (8%), one from Fujian province (4%), one from Guangdong province (4%) and four from Hubei province (15%). A total of 20 study participants (80%) had an educational level above a college diploma. Most were employed (n = 19; 73%). Nearly half of the participants were married; the majority were living with family members (n = 19; 73%). Some of the participants' family members were also infected with COVID (n = 5; 19%). The detailed demographic characteristics of participants are shown in Table 2.

## 4.2 | Thematic results

Four themes emerged from the analysis: persons disclosed to, reasons to disclose, reasons for nondisclosure and the impact of disclosure. We present the themes and sub-themes in Table 3.

# 4.2.1 | Theme 1: Persons disclosed to

All participants disclosed their COVID diagnosis to others. We examined whether their disclosures were to family members, close friends, community members, workplace colleagues or others. All the participants had disclosed to their family members (100%, n = 26), many disclosed to community members (57.7%, n = 15) and workplace colleagues (50.0%, n = 13), and just under half disclosed to close friends (46.2%, n = 12).

A 24-year-old female stated:

When I received the COVID diagnosis from the CDC, the first thing I did was inform my manager because I could not continue to work. Then I told my parents and boyfriend who was living with us. I also informed some of my colleagues with whom I had close contact.

Very few disclosed to their children's schools (7.7%, n = 2). Some parents were disinclined to report their COVID status to their

TABLE 2 Demographic characteristics (N = 26)

Characteristics N  Gender (%)  Male 12	Mean (SD) or %
Male 12	
· · · · · · ·	46.2
Female 14	53.8
Education (%)	
Above college diploma 20	76.9
Employment (%)	
Employed 19	73.1
Unemployed 7	26.9
Residence (%)	
Shanghai 18	69.2
Zhejiang province 2	7.7
Hubei province 4	15.4
Fujian province 1	3.8
Guangdong province 1	3.8
Marital status (%)	
Unmarried 11	42.3
Married 15	57.7
Living with family members (%)	
Yes 19	73.1
No 7	26.9
Family members infected with COVID	
Yes 5	19.2
No 21	80.8
Age (years, mean)	
Years old	34 (9.3)
Age range	19-56

children's school. One mother said that she did not want to let her children's classmates know her COVID status because she was afraid that her children would be marginalised by others.

# 4.2.2 | Theme 2: Reasons to disclose

#### Policy

Government policy was the most mentioned reason as to why participants disclosed their COVID status in this study. One participant (a 40-year-old male) said that the community he lived in posted notifications of the special situations of all residents, such as home quarantines and medical observations, with his housing number highlighted due to his COVID diagnosis.

A 41-year-old female said:

I was informed that I needed to disclose my status to my workplace so the company can protect other workers' safety. Therefore, I called my boss, as well as my colleagues in the office.

TABLE 3 Themes and sub-themes

Themes	Sub-themes
Disclosure to whom	Family
	Intimate friends
	Community
	Workplace
	Children's school
Reasons to disclose	Policy
	Responsibility for protecting others
	Gain social support
	Fear of being blamed for nondisclosure
Reasons for nondisclosure	Fear of stigma and discrimination
	Protecting family members
Impact of disclosure	Social support
	Stigma and discrimination
	Psychological distress
	Self-isolation
	Privacy exposure

# Responsibility for protecting others

Some of the participants felt that they were responsible for disclosing to people with whom they had close contact, such as family members and friends. The general thinking was that as the whole society was combating COVID, everyone needed to protect others' safety. One male participant (28 years old) said:

Once diagnosed with COVID, the first thing I did was to disclose. If you hide it, it is irresponsible to others... I have an obligation to remind others. I contacted my friends and reminded them to make sure they were safe.

## Gain social support

Gaining social support was an important reason for disclosure, as all of the participants were quarantined during hospitalisation and could not see others. As one 31-year-old male described:

After being diagnosed with COVID, I was placed in this designated hospital, where I could not see my family. I needed someone to help my wife and children to do a medical visit. I could only ask my manager for help, so I needed to disclose my status.

#### Fear of being blamed for nondisclosure

The potential of being blamed for spreading the COVID virus was an important contributing factor to disclosure. Some participants were afraid that if they did not disclose, people who found out later would have negative attitudes towards them. One 41-year-old male stated:

If I don't tell them and something happened, I would be complained about more and treated badly.

## 4.2.3 | Theme 3: Reasons for nondisclosure

#### Fear of stigma and discrimination

One of the most important reasons for participants to favour nondisclosure was the fear of being stigmatised and discriminated against due to the COVID infection. They believed that they would be treated differently as soon as others knew about their COVID diagnosis. As one 35-year-old female said:

I was afraid to tell others that I had COVID... I can imagine that I would be rejected when others knew my status... To avoid people looking at me with strange eyes, I would not proactively disclose.

#### Protecting family members

A few participants feared that disclosure could socially marginalise their children, spouses or other family members. They kept their COVID status to themselves as a way to protect their family. One mother (35 years old) expressed her worries as:

As I went back to Wuhan (from hospitalization in Shanghai), I avoided letting others know that I had been infected with COVID. I didn't want to let my children's classmates, their parents and neighbors in our community know about this because the rumors could influence how people react, especially children and their parents. My child would be marginalized and stigmatized by others, which would cause harm to him. I hid my diagnosis to protect my children.

# 4.2.4 | Theme 4: Impact of disclosure

#### Social support

To get social support from others, participants had to disclose their COVID status. A number of participants who disclosed to others reported that they received support from families, employers and community members. This support included emotional support from families and friends, as well as practical support from colleagues and neighbours during the quarantine period. One 24-year-old female study participant stated:

When I got a call from CDC that I was confirmed with COVID infection, I cried and couldn't accept the truth. I told my parents, employer, and colleagues this bad news. After they knew it, they comforted me. Then I gradually began to accept it and felt that I needed to cheer up.

## Stigma and discrimination

The majority of COVID patients in this study shared their experiences of stigma and discrimination in the workplace, community and society. They experienced being marginalised by the public, refused services, driven out by their landlord and forced to resign. A female (30 years old) said that her supervisor told her to resign after knowing her diagnosis. A 56-year-old male stated:

People felt so sacred when they contacted me. At a high school reunion, I was told that I couldn't attend because they were scared. I was also told that I couldn't return to work and should go back to my hometown. I felt I was discriminated against by the public.

## Psychological distress

The COVID diagnosis was stressful for many participants. They were considered virus carriers even after recovering and being discharged from the hospital. A number of patients said that they felt stress and anxiety contacting others who knew their status. One 31-year-old male stated:

I have worked at home for two months. I did not know how to face my colleagues in the company. It made me stress out.

# Self-isolation

To avoid stigma and discrimination, most of the participants reduced their social activities and kept a distance from others. One 40-year-old female said:

After discharge from the hospital... I did not contact anyone. I am so afraid that my network cannot accept me.

## Privacy exposure

Contact tracing is a critical way to prevent and control the spread of COVID; therefore, disclosure can result in personal privacy exposure. One 41-year-old male relayed the following:

When I was diagnosed with COVID, my wife reported the situation to my children's school, which was the school policy. When I found out that my personal information, my children's names, and level of the class were posted on the parents' notification board, I was so angry. Later, my personal information was posted on the internet.

# 5 | DISCUSSION

Disclosure is a critical component of prevention and treatment of infectious diseases (O'Connell et al., 2015). Whether to disclose a

positive COVID status is a complex decision that can carry the risk of stigma and privacy exposure and reduce potential support from others. In this qualitative in-depth interview with COVID patients, we explored COVID-confirmed patients' experiences of disclosure in China and described the factors affecting their disclosure decisions. To the best of our knowledge, this is one of the first projects exploring the impact of disclosure on COVID patients. This study provides a basic understanding of patients' viewpoints and perceptions regarding disclosure, which could direct the development of future interventions to assist in COVID disclosure and facilitate disclosure when needed.

Our findings indicate that Chinese policy and culture impact patients' decisions concerning COVID disclosure. In this study, policy requirements were one of the main reasons for disclosure. At the beginning of the COVID-19 outbreak, the Chinese government implemented a series of rigorous control strategies to halt the spread of the virus, such as community-based "grid-closed management," health codes, and student group management (Liu et al., 2020; Mozur et al., 2020). Within these prevention and control measures, COVID status disclosure has been highlighted and advocated widely, which encourages people within networks to pay attention to any symptoms they might have and potential infection (McCullough et al., 2020). These policies advocating disclosure, as well as the implementation of practical strategies, proved to be effective in controlling the pandemic.

Apart from policies, Chinese culture also played a vital role in participants' disclosure of their COVID status. On the one hand, it is a traditional context within China that the general public is required to follow the government's orders without question (Wang & Wang, 2020). As a result, the COVID disclosure policy was well executed by the public. On the other hand, because of the long-term moral and ideological education in China, a sense of social responsibility has taken root in the Chinese population (Zhang & Fagan, 2016). Since COVID is a highly transmittable disease, and individuals who present with symptoms need to be under medical observation to better protect others, infection disclosure is essential, which is the main reason for disclosure to family members, friends, colleagues and the communities (NHC, ). However, confidentiality was not discussed in the governmental policy.

Similar to having other infectious disease diagnoses, whether to disclose or not disclose a COVID diagnosis is a complex issue (Adeoye-Agboola et al., 2016; Brohan et al., 2012). Although there are many factors facilitating COVID disclosure—policy requirements, social responsibility, gaining social support and fear of being blamed for the spread of infection—COVID patients still hesitate to disclose. Studies have shown that as with other infectious disease disclosure (e.g., of HIV), stigma and discrimination remain the primary reasons for nondisclosure (Earnshaw et al., 2013; French et al., 2015). In this study, the expectation that an individual would be stigmatised when disclosing was more discussed, as most of the disclosures happened during hospitalisation. In addition, public stigma not only targets COVID patients, but also impacts patients' family members, especially their children, which concerns the COVID patients the most.

Protecting family members from public stigma is another factor for nondisclosure. Therefore, a decrease in public stigma is urgently needed so that people are more willing to alert the public regarding COVID exposure.

Disclosure of COVID status can impact social, emotional and practical support from others. A COVID diagnosis can be a shocking and stressful event, and, most likely, patients present with certain symptoms (e.g., flu-like symptoms, fever) and, therefore, cannot hide their serostatus, unlike those living with other infectious diseases who do not have symptoms (Sanga et al., 2019). Also, people infected with COVID have been required to be quarantined and possibly removed from societies, especially in China (NHC, 2020d; WHO, 2020c). During the course of the disease, support from family members and friends becomes critical for a positive adjustment (Fegert et al., 2020). Also, for severe COVID cases, when patients are in an intensive care unit and then a follow-up with self-quarantine, they need to suspend their daily activities and rely on assistance from friends and family. As such, practical support from their social networks plays a vital role in combating the effects of COVID. These study findings highlight the importance of social support in improving the well-being of people infected with COVID-19.

Disclosing one's COVID status not only potentially provides support for individual patients, but also creates a potential crisis for patients' circle of social networks. As shown in this study, people infected with COVID experienced stigma, discrimination and privacy exposure. And the perceived possibility of these negative experiences caused psychological distress and self-isolation, and led to some choosing not to disclose.

As disclosure is important to prevent and control COVID transmission, mandated disclosure should be followed by a thoughtful process, so as to protect patients' personal privacy (Kuhn, 2020). After patients are discharged from healthcare facilities, they should be considered noncontagious and should not be seen as patients. Also, during the period of hospitalisation, patients with COVID should be evaluated regarding psychological distress and concerns about diagnosis disclosure. Stigma and misconceptions of COVID transmission should be discussed before patients are discharged. In addition, updated knowledge regarding COVID prevention and transmission among the public is urgently needed because this can create a safer and supportive environment for all people.

# 5.1 | Limitations

There are some limitations to this study. First, due to the small sample size of this qualitative research, the study participants may not be representative of all COVID-infected patients in China or globally. Shanghai is one of the metropolitan areas in China that usually provides more resources than other cities in the country. Also, Chinese governmental COVID policies might not apply to other countries. Second, there may be potential bias due to the interviewers' abilities, coding and analysis of the data. However, we trained the researchers so as to increase the inter-rater reliability.

Third, the relatively young study participants (19–56 years old) also bring potential bias to this study. Thus, future research should replicate this study by using a larger sample and wider age range to explore the factors affecting COVID disclosure. Last, although the use of Zoom and Wechat is convenient and cost-effective, compared to face-to-face interviews, issues associated with using Zoom and Wechat included dropped calls and frozen conversations when internet connections were not stable. Also, poor video/audio recordings impacted the quality of the transcriptions of the in-depth interviews.

## 6 | CONCLUSION

This study explored COVID-confirmed patients' experiences in Shanghai, China, of disclosure their illness and described the factors affecting their disclosure decisions. To control the COVID pandemic, disclosure of an individual's infectious status is encouraged by health departments; therefore, concern regarding disclosure of COVID infection was high in our study participants. In this study, participants disclosed their confirmed status due to governmental requirements to disclose, a sense of social responsibility, fear of being blamed if the infection spread and the desire for social support. Others were concerned with the possible social stigma and discrimination after disclosure. After disclosure, COVID patients could obtain support to assist in coping with the disease. Despite this potential benefit, many patients experienced stigma, discrimination and privacy exposure. These can all cause psychological distress and self-isolation. As the pandemic might persist for a significant period of time, interventions should be designed to decrease public stigma and to establish a disclosure protocol to ensure patients' privacy regarding their COVID status.

# 7 | RELEVANCE TO CLINICAL PRACTICE

The present study provides in-depth insights into the experiences and perceptions of COVID patients regarding disclosure. Many factors were identified in this study as affecting COVID patients' disclosure decision. As disclosure is important to prevent and control COVID transmission, disclosure is encouraged by health departments; however, mandated disclosure should be followed by a thoughtful process that weighs the manifold impacts of disclosure on patients. Thus, an appropriate intervention that is balanced to protect confidentiality of patients with COVID as well as provide the ability to trace for potential contact cases should be designed.

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#### **CONFLICTS OF INTEREST**

The authors have no conflicts of interest to report.

#### **AUTHOR CONTRIBUTIONS**

This collaboration, Wei-Ti Chen, Hongzhou Lu and Lin Zhang are the correspondence authors of this study, responsible for designing, guiding, organising and planning this study. Wenxiu Sun is responsible for qualitative data analysis and manuscript writing. Feifei Huang and Chengshi Shiu are responsible for designing and guiding this study. Meiyan Sun, Lei Shen, Yan Gao and Qing Zhang are responsible for quantitative data collection and data analysis.

#### ETHICAL APPROVAL

This research was approved by the relevant institutional review boards of UCLA (IRB#20-000832) and Shanghai Public Health Clinical Center (YZ-2020-S037-01).

#### DATA AVAILABILITY STATEMENT

Data available on request from the authors.

#### ORCID

Wenxiu Sun https://orcid.org/0000-0002-3653-6443 Wei-Ti Chen https://orcid.org/0000-0002-2342-045X

#### REFERENCES

- Adeoye-Agboola, D. I., Evans, H., Hewson, D., & Pappas, Y. (2016). Factors influencing HIV disclosure among people living with HIV/ AIDS in Nigeria: A systematic review using narrative synthesis and meta-analysis. *Public Health*, 136, 13–28. https://doi.org/10.1016/j. puhe.2016.02.021
- Brohan, E., Henderson, C., Wheat, K., Malcolm, E., Clement, S., Barley, E. A., Slade, M., & Thornicroft, G. (2012). Systematic review of beliefs, behaviours and influencing factors associated with disclosure of a mental health problem in the workplace. *BMC Psychiatry*, 12, 11. https://doi.org/10.1186/1471-244X-12-11
- Centers for Disease Control and Prevention (CDC), National Center for Immunization and Respiratory Diseases (NCIRD). (2020, June 11). Reducing stigma. Retrieved from https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/reducing-stigma.html
- Dong, L., & Bouey, J. (2020). Public mental health crisis during COVID-19 pandemic, China. *Emerging Infectious Diseases*, 26(7), 1616–1618. https://doi.org/10.3201/eid2607.200407
- Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: A test of the HIV stigma framework. AIDS and Behavior, 17(5), 1785–1795. https://doi.org/10.1007/s10461-013-0437-9
- Eaton, L. A., & Kalichman, S. C. (2020). Social and behavioral health responses to COVID-19: Lessons learned from four decades of an HIV pandemic. *Journal of Behavioral Medicine*, 43(3), 341–345. https://doi.org/10.1007/s10865-020-00157-y
- Ekama, S. O., Herbertson, E. C., Addeh, E. J., Gab-Okafor, C. V., Onwujekwe, D. I., Tayo, F., & Ezechi, O. C. (2012). Pattern and determinants of antiretroviral drug adherence among Nigerian pregnant women. *Journal of Pregnancy*, 2012, 851810. https://doi. org/10.1155/2012/851810.
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, 4, 1–10. https://doi.org/10.1177/2158244014522633.
- End coronavirus stigma now. (2020). *Nature*, 580(7802), 165. https://doi.org/10.1038/d41586-020-01009-0
- Evangeli, M., & Wroe, A. L. (2017). HIV disclosure anxiety: A systematic review and theoretical synthesis. *AIDS and Behavior*, 21(1), 1–11. https://doi.org/10.1007/s10461-016-1453-3

- Fegert, J. M., Vitiello, B., Plener, P. L., & Clemens, V. (2020). Challenges and burden of the coronavirus 2019 (COVID-19) pandemic for child and adolescent mental health: A narrative review to highlight clinical and research needs in the acute phase and the long return to normality. Child and Adolescent Psychiatry and Mental Health, 14, 20. https://doi.org/10.1186/s13034-020-00329-3
- French, H., Greeff, M., Watson, M. J., & Doak, C. M. (2015). HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting. *AIDS Care*, 27(8), 1042–1046. https://doi.org/10.1080/09540121.2015.1020747
- Geary, C., Parker, W., Rogers, S., Haney, E., Njihia, C., Haile, A., & Walakira, E. (2014). Gender differences in HIV disclosure, stigma, and perceptions of health. *AIDS Care*, 26(11), 1419–1425. https://doi.org/10.1080/09540121.2014.921278
- Giorgi, A. (2009). The descriptive phenomenological method in psychology: A modified Husserlian approach. Duquesne University.
- Green, H. D., Weeks, M. R., Berman, M., Mosher, H. I., Abbott, M., & Garcia, N. (2018). Managing the risk of intimacy: Accounts of disclosure and responsiveness among people with HIV and intimate partners of people with HIV. Culture, Health & Sexuality, 20(10), 1117–1129. https://doi.org/10.1080/13691058.2018.1479535
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough?: An experiment with data saturation and variability. Field Methods, 18(1), 59–82. https://doi.org/10.1177/1525822X05 279903
- Huang, C., Wang, Y., Li, X., Ren, L., Zhao, J., Hu, Y. I., Zhang, L. I., Fan, G., Xu, J., Gu, X., Cheng, Z., Yu, T., Xia, J., Wei, Y., Wu, W., Xie, X., Yin, W., Li, H., Liu, M., ... Cao, B. (2020). Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *Lancet (London, England)*, 395(10223), 497–506. https://doi.org/10.1016/S0140-6736(20)30183-5
- Huang, J. (2020, May 13). With coronavirus lockdown over, Wuhan residents wrangle with being stigmatized. Retrieved from https://www.voanews.com/science-health/coronavirus-outbreak/coronavirus-lockdown-over-wuhan-residents-wrangle-being
- Kennedy, C. E., Haberlen, S., Amin, A., Baggaley, R., & Narasimhan, M. (2015). Safer disclosure of HIV serostatus for women living with HIV who experience or fear violence: A systematic review. *Journal of the International AIDS Society*, 18(Suppl 5), 20292. https://doi.org/10.7448/IAS.18.6.20292
- Kuhn, A. (2020, May 2). South Korea's tracking of COVID-19 patients raises privacy concerns. Retrieved from https://www.npr.org/2020/05/02/849535944/south-koreas-tracking-of-covid-19-patients-raises-privacy-concerns
- Lincoln, Y. S., Guba, E. G., & Pilotta, J. J. (1985). *Naturalistic inquiry*, Beverly Hills, CA: Sage.
- Liu, W., Yue, X. G., & Tchounwou, P. B. (2020). Response to the COVID-19 epidemic: The Chinese experience and implications for other countries. *International Journal of Environmental Research and Public Health*, 17(7), 2304. https://doi.org/10.3390/ijerph17072304
- Logie, C. H. (2020). Lessons learned from HIV can inform our approach to COVID-19 stigma. *Journal of the International AIDS Society*, 23(5), e25504. https://doi.org/10.1002/jia2.25504
- Maman, S., van Rooyen, H., & Groves, A. K. (2014). HIV status disclosure to families for social support in South Africa (NIMH Project Accept/HPTN 043). AIDS Care, 26(2), 226–232. https://doi.org/10.1080/09540121.2013.819400
- Mao, Y., Li, X., Qiao, S., Zhao, Q., Zhou, Y., & Shen, Z. (2018). Social support, stigma, and HIV disclosure among parents living with HIV in Guangxi, China. AIDS Care, 30(2), 168–172. https://doi. org/10.1080/09540121.2017.1387639
- McCullough, P. A., Eidt, J., Rangaswami, J., Lerma, E., Tumlin, J., Wheelan, K., Katz, N., Lepor, N. E., Vijay, K., Soman, S., Singh, B., McCullough, S. P., McCullough, H. B., Palazzuoli, A., Ruocco, G. M., & Ronco, C. (2020). Urgent need for individual mobile phone and institutional reporting of at home, hospitalized, and intensive care unit cases

- of SARS-CoV-2 (COVID-19) infection. Reviews in Cardiovascular Medicine, 21(1), 1–7. https://doi.org/10.31083/j.rcm.2020.01.42
- Merleau-Ponty, M. (2002). Phenomenology of perception, London: Routledge.
- Mozur, P., Zhong, R., & Krolik, A. (2020, March 1). In coronavirus fight, China gives citizens a color code, with red flags. *New York Times*. Retrieved from https://www.nytimes.com/2020/03/01/business/china-coronavirus-surveillance.html
- Nachega, J. B., Morroni, C., Zuniga, J. M., Sherer, R., Beyrer, C., Solomon, S., Schechter, M., & Rockstroh, J. (2012). HIV-related stigma, isolation, discrimination, and serostatus disclosure: A global survey of 2035 HIV-infected adults. *Journal of the International Association of Physicians in AIDS Care*, 11(3), 172–178. https://doi.org/10.1177/1545109712436723
- National Health Commission of the People's Republic of China. (2020a, March 4). New coronavirus pneumonia diagnosis and treatment plan (Trial 7th edition). Retrieved from http://www.nhc.gov.cn/yzygj/s7652m/202003/a31191442e29474b98bfed5579d5af 95.shtml
- National Health Commission of the People's Republic of China (NHC). (2020b). Notice of the General Office of the National Health Commission on further strengthening the supervision of the prevention and control of infectious diseases in schools.
- National Health Commission of the People's Republic of China (NHC). (2020c). Notice of the General Office of the National Health Commission on strengthening guidance on epidemic prevention and control during resumption of work and production of enterprises. Retrieved from http://www.nhc.gov.cn/zyjks/s7786/20200 3/0bb76f6f44eb4cfd9260218527b80198.shtml
- National Health Commission of the People's Republic of China (NHC). (2020d). Notice on strengthening community prevention and control of pneumonia epidemic caused by new coronavirus infection. Retrieved from , http://www.nhc.gov.cn/jkj/s3577/202001/dd1e5 02534004a8d88b6a10f329a3369.shtmlhttp://www.nhc.gov.cn/zhjcj/s7892/202006/b81135ae3b784a9f9cb3ca669d0270 0f.shtml
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, 89(9), 1245–1251. https://doi.org/10.1097/ACM.000000000000388
- O'Connell, A. A., Reed, S. J., & Serovich, J. A. (2015). The efficacy of serostatus disclosure for HIV transmission risk reduction. *AIDS and Behavior*, 19(2), 283–290. https://doi.org/10.1007/s1046 1-014-0848-2
- Sanga, E. S., Mukumbang, F. C., Mushi, A. K., Lerebo, W., & Zarowsky, C. (2019). Understanding factors influencing linkage to HIV care in a rural setting, Mbeya, Tanzania: Qualitative findings of a mixed methods study. BMC Public Health, 19(1), 383. https://doi.org/10.1186/s12889-019-6691-7
- Siu, G. E., Bakeera-Kitaka, S., Kennedy, C. E., Dhabangi, A., & Kambugu, A. (2012). HIV serostatus disclosure and lived experiences of adolescents at the transition clinic of the infectious diseases clinic in Kampala, Uganda: A qualitative study. AIDS Care, 24(5), 606–611. https://doi.org/10.1080/09540121.2011.630346
- Syed, I. A., Syed Sulaiman, S. A., Hassali, M. A., Thiruchelvum, K., & Lee, C. K. (2015). A qualitative insight of HIV/AIDS patients' perspective on disease and disclosure. *Health Expectations*, 18(6), 2841–2852. https://doi.org/10.1111/hex.12268
- Vu, L., Andrinopoulos, K., Mathews, C., Chopra, M., Kendall, C., & Eisele, T. P. (2012). Disclosure of HIV status to sex partners among HIV-infected men and women in Cape Town, South Africa. AIDS and Behavior, 16(1), 132–138. https://doi.org/10.1007/s1046 1-010-9873-y
- Wang, J., & Wang, Z. (2020). Strengths, weaknesses, opportunities and threats (SWOT) analysis of China's prevention and control strategy for the COVID-19 epidemic. *International Journal of Environmental*

- Research and Public Health, 17(7), 2235. https://doi.org/10.3390/ ijerph17072235
- World Health Organization (WHO). (2020a). Considerations for quarantine of individuals in the context of containment for coronavirus disease (COVID-19). : World Health Organization. Retrieved from https://www.who.int/publications/i/item/considerationsfor-quarantine-of-individuals-in-the-context-of-containment-for-coronavirus-disease-(covid-19)
- World Health Organization (WHO). (2020b).Coronavirus disease (COVID-19) pandemic. Retrieved from https://www.who.int/emergencies/diseases/novel-coronavirus-2019
- World Health Organization (WHO). (2020c). Naming the coronavirus disease (COVID-19) and the virus that causes it. Retrieved from https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-(covid -2019)-and-the-virus-that-causes-it
- World Health Organization, International Federation of Red Cross and Red Crescent Societies, United Nations Children's Fund. (2020). Social Stigma associated with COVID-19.: World Health Organization. Retrieved from https://www.who.int/docs/default-source/coron aviruse/covid19-stigma-guide.pdf?sfvrsn=226180f4\_2
- Yao, H., Chen, J. H., & Xu, Y. F. (2020). Patients with mental health disorders in the COVID-19 epidemic. *The Lancet Psychiatry*, 7(4), e21. https://doi.org/10.1016/S2215-0366(20)30090-0
- Yonah, G., Fredrick, F., & Leyna, G. (2014). HIV serostatus disclosure among people living with HIV/AIDS in Mwanza, Tanzania. *AIDS Research and Therapy*, 11(1), 5. https://doi.org/10.1186/1742-6405-11-5

- Zang, C., He, X., & Liu, H. (2015). Selective disclosure of HIV status in egocentric support networks of people living with HIV/AIDS. *AIDS and Behavior*, 19(1), 72–80. https://doi.org/10.1007/s1046 1-014-0840-x
- Zhang, C., & Fagan, C. (2016). Examining the role of ideological and political education on university students' civic perceptions and civic participation in Mainland China: Some hints from contemporary citizenship theory. Citizenship, Social and Economics Education, 15(2), 117–142. https://doi.org/10.1177/2047173416681170

## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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