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Article

Online information and support seeking during COVID-19 lockdown in Wuhan: implications for health promotion

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Summary

The lockdown that was deployed in Wuhan, China to combat the COVID-19 pandemic curbed the infection but also created great information challenges for people in social isolation. This resulted in surge in online health information seeking (OHIS) behaviors of the patients and their families. While the Internet has been widely used by Chinese public to access and search health information, there is relatively little research in the context of pandemic outbreaks, especially at the onset of a strong lockdown while many people were panicking. From a total of 10 908 '#COVID-19 Patient Seeking Help' posts on *Weibo* in a period of 20 days when the lockdown policy was first initiated, we identified 1496 unique patients living in or with family in Wuhan, China. Using textual analysis, we explored OHIS behaviors at the onset of the pandemic. Many faced increased difficulties accessing offline healthcare services and such turned to social media for help and information. In particular, the findings highlight the following themes: '*OHIS for medical treatment*', '*OHIS to manage self-quarantine*', '*OHIS for tangible support*' and '*OHIS to navigate information discrepancy*'. Overall, our findings provide important insights into health information seeking behaviors and the role of social media during a pandemic. Our findings also highlight the importance of considering people's information need and challenges created due to the lockdown policies in the future pandemic communication and preparedness.

Keywords: COVID-19, lockdown, information seeking, social media, Wuhan

INTRODUCTION

Existing research has shown that social media has the potential to enable new ways of health information seeking and sharing (Robinson and Robertson, 2010; Lagoe and Atkin, 2015; Lin *et al.*, 2016; Laugesen and Hassanein, 2017; Introne and Goggins, 2019; Yang and Wu, 2020) due to the increased access to a variety of health information (Cao *et al.*, 2016) and social support especially for stigmatized and marginalized individuals (Zhao and Basnyat, 2018). Further, social media has also seen a significant growth in use by hospital and healthcare professionals (Antheunis *et al.*, 2013). However, to harness the potential of social media for health information, an individual must be active and purposeful in their online health information seeking (OHIS). OHIS often arises from the need to fulfill specific health information gap (Basnyat *et al.* 2018). Wang *et al.*'s meta-analysis of 44 studies on OHIS found that trust of information source, as well as quality and usefulness of information rather than perceived risk and self-efficacy were more important factors that affect individual's OHIS behavior (Wang *et al.*, 2021). With the advancement of information and communication technologies, patients are expected to take an active role and responsibility for their health, increasing the need for information-related self-management (Introne and Goggins, 2019; Sun and Jiang, 2020; Yang and Wu, 2020). In China, the outbreak of severe acute respiratory syndrome (SARS) in 2003 marked the emergence of OHIS (Cao *et al.* 2016). With increased eHealth behavior (Robinson and Robertson, 2010; Laugesen and Hassanein, 2017; Introne and

Goggins, 2019), COVID-19 provides a unique opportunity to explore the ways in which OHIS occurs in China. In doing so, we can understand the implications for not only future pandemic communication but also promotion of health during a pandemic.

December 2019 saw the first emergence of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in Wuhan, the capital of Hubei province in China. On 30 January 2020, World Health Organization (WHO) declared the novel coronavirus (COVID-19) a public health emergency of international concern (PHEIC) (WHO, 2020). Within a month, mainland China had 79 394 confirmed cases and 2838 deaths from COVID-19, of which 48 557 cases and 2169 deaths occurred in Wuhan (Wu *et al.* 2020). To limit the spread of the virus, Chinese government enforced lockdown on Wuhan (Beijing News, 2020), and the unprecedented *cordon sanitaire* lasted for 76 days (Pan *et al.*, 2020b). All transport was prohibited in and out of Wuhan city, entertainment venues were closed, and public gatherings were banned (Tian *et al.*, 2020). Since then, lockdowns have been deployed in many parts of the globe as a social distance strategy to slow the rapid spreading of the disease (Pan *et al.*, 2020a; Van den Broucke, 2020). Lockdowns and travel restrictions instituted nationwide in China have been associated with a delay in the growth of the pandemic, which was marked by the reduction in the number of cases (Chinazzi *et al.*, 2020; Liu, 2020; Tian *et al.*, 2020). Nevertheless, debates over the lockdowns continue around whether the strategy acted as an institute of social control through surveillance of the public (Basnyat and Lee, 2015; Liu, 2020).

Although these control measures were considered effective in halting and reversing the rise in incidence, patients and their families were expected to deal with uncertainties and fears, and manage the challenges of information deficit (Liu, 2020; Pan *et al.*, 2020a; Van den Broucke, 2020; Atehortua and Patino, 2021). Self-management of information as self-care in the eHealth context (Robinson and Robertson, 2010; Laugesen and Hassanein, 2017; Sun and Jiang, 2020; Abel and McQueen, 2021) became essential, especially at the start of the pandemic. Information deficit was also coupled with scarcity of hospital beds and the increased risk of fatality (Liu, 2020). In China, infected patients walked on average 2.67 km (1.65 miles) to the nearest clinic to seek medical care due to traffic ban (Zhao *et al.*, 2020). Furthermore, in China, family and community transmission was also prevalent due to multigenerational home quarantine (Lin, 2020).

Timely access to quality healthcare information during outbreaks of infectious diseases can be effective to curtail the spread of disease and feelings of anxiety (Holmes, 2008; Tausczik *et al.*, 2012; Généreux *et al.*, 2021; Atehortua and Patino, 2021). While the effectiveness of lockdowns and social distancing measures in preventing the spread of infection have been extensively studied (Flaxman *et al.*, 2020; Liu, 2020; Tian *et al.*, 2020), rarely have the studies explored OHIS behaviors of infected patients and their families for mitigating frustration and uncertainty and managing their health information needs.

In view of the information crisis associated with COVID-19, scholars have extended a call to act and contribute to the understanding of citizens' information behaviors during lockdowns (Pan *et al.*, 2020a; Xie *et al.*, 2020; Généreux *et al.*, 2021). While previous studies explored the use of social media to mitigate the threat of COVID-19 in China (Zhong *et al.*, 2020), their analysis focused on the general public rather than the COVID-19 patients and their families. The social media platform Weibo, often referred to as the 'Chinese Twitter', was also excluded from their analysis. According to the Weibo User Development Report published in 2021, by September 2020, Weibo saw 511 million monthly active users regularly accessing the platform (Sina Weibo, 2021). Weibo is one of the largest and the most important social network platforms for information and opinion sharing in China (Medaglia and Zhu, 2017). Additionally, there are also hundreds of thousands of Weibo accounts established by government agencies at the local, regional and central levels in recent years to communicate with the public (Zheng and Zheng, 2014). Considering the role Weibo has played in connecting patients with related information and local government departments (Chinanews, 2020), it is necessary to examine the ways in which patients and their families were using Weibo to seek health information and support at the onset of the COVID-19 pandemic. Therefore, in this study we examine the ways in which coronavirus patients and their families in Wuhan, China sought health information on the social medial platform Weibo, specifically during the lockdown. Particularly, a textual analysis of Weibo posts was conducted to explore the kinds of health information patients and their families in Wuhan were seeking, and how OHIS was related to the functioning of the regular healthcare services and institutions offline. The findings show that the lockdown policy created difficulties in accessing offline healthcare and cutoff interpersonal ties that could provide support. A lack of coordination between different health institutions further caused information inconsistency and increased anxiety among patients and their family members. These conditions created a need to seek health information to make subsequent decisions. Overall, the social media platform Weibo played a vital role in OHIS and support seeking during the pandemic.

METHODS

Data collection

During the COVID-19 outbreak, in view of the increasing number of patients, the government set up a hashtag named #*COVID-19 Patient Seeking Help* (‘*Feiyan Huanzhe Qiuzhu Chaohua*’) on Weibo to connect the patients and their families to healthcare service people.[1] They were asked to leave their information under the hashtag, including [Name], [Age], [City], [Neighborhood], [Address], [Time of sickness], [Health condition], [Additional description] and [Contact information] (Sina News, 2020). The relevant government agencies would verify the information and provide information and support. Posts using the hashtag #*COVID-19 Patient Seeking Help* following the inclusion of all required information (as noted above) between 29 January 2020, when the hashtag was first created, and 17 February 2020 were extracted from Weibo. This period of 20 days was chosen because, by the end of this period, the number of patients’ posting with this hashtag fell to zero (People’s Government of Wuhan, 2020). Thus, our sample included all the patients seeking information on Weibo using the hashtag during those 20 days. In total, 10 908 Weibo posts were collected. For each post, in addition to the structured patient information required by Weibo, we further extracted the following items: *the date and time of posting*, *user ID*, *gender* and *URL of the thread* (to ensure the posts were from patients and families in Wuhan). We excluded retweets and general comments about the outbreak. After this step, we obtained 4983 posts using the hashtag #*COVID-19 Patient Seeking Help*. Of those, data consolidation was further carried out by patient name and residential address, which resulted in 1496 unique patients living in or with family in Wuhan, China.

Data analysis

To explore OHIS using the hashtag #*COVID-19 Patient Seeking Help*, we began with open coding. The first author fluent in Chinese read each entry, highlighting salient phrases and words (Corbin and Strauss, 2014). More than 200 open codes were generated during this process, such as queuing for test; called every hospital for bed; no foreseeable treatment; staying overnight for injection; the hospital is full of patients; waiting for confirmatory testing result; rushing between different hospitals; hundreds of people in the waiting list; reported to the neighborhood committee with no response and have to find solutions ourselves. Next, in the axial coding step, guided by the meaning condensation approach (Corbin and Strauss, 2014), relationships among the open codes were identified. Similar codes were conceptually clustered into broad categories. These codes were conceptually clustered into more than 20 different groupings through discussions between the authors. Some codes, although not many, fit into and thus were included under more than one groupings temporarily. We also maintained some codes that did not specifically answer the research question but were important data that illuminated the context of the study. We used ‘miscellaneous’ codes to manage them at this point (Braun and Clarke, 2006). After that, the authors reviewed the coded data extracts for each code to consider whether they appeared to form a coherent pattern. A set of themes were further devised to guarantee that the data within themes cohere together meaningfully and at the same time there was a clear and identifiable distinction between themes (Braun and Clarke, 2006). As a result, data were reduced into a more manageable set of significant themes in which process some codes were deleted if they substantially overlapped with other codes. Through additional discussion and data refinement the authors agreed on the following themes during the selective coding stage: ‘OHIS for medical treatment’, ‘OHIS to manage self-quarantine’, ‘OHIS for tangible support’ and ‘OHIS to navigate information discrepancy’. Table 1 illustrates some examples of the coding process.

Ethical consideration

The study was approved by the ethical review board of the first author’s home institution. Although the data used for this study were publicly available, and the research did not include interventions with the subjects, which makes it qualified for IRB exempt status (Hudson and Bruckman, 2004), IRB approval was obtained. In addition, to ensure confidentiality, the identity of each patient and other sensitive personal information were removed in the paper.

FINDINGS

OHIS for medical treatment

Many patients and their families expressed urgent needs for information about access to healthcare, medical treatment, hospital beds and testing. OHIS was initiated by patients encountering rejection by the hospital for admission due to the severe shortage of hospital beds. as explained in this post:

> My mom has to get up at 4 am every day to register in the hospital. The hospital is overflowed with pneumonia patients. It has been 8 days since my mom was confirmed, but the doctors still refuse to

[1] https://china.huanqiu.com/article/9CaKrnKpc7K

Table 1: Shortened illustrations of the coding process

Open coding	Axial coding	Themes
• Contacted many hospitals only being told that **there is no vacant bed** • The neighborhood committee only **makes us queue every day**. I am afraid it would be too late for my mother to get treatment • **Rushing between hospitals every day** but cannot get confirmatory testing • Queued up until very late but still **failed to get confirmatory test** • You could **by no means get treatment** even if you get confirmation result • However, if it is not **arranged by the organization**, he still cannot be admitted • The ambulance took us to **several hospitals which were all full** • Please tell us **a place that can admit**	Information need about access to healthcare resources Information need about access to confirmed test Navigation of centralized healthcare allocation Information about designated hospitals	OHIS for medical treatment
• The neighborhood committee has repeatedly **advised not to go to the hospital without providing other measures**, only saying that the hospital is more dangerous • The neighborhood committee has always **recommended isolation at home**, and did not arrange for medical confirmation or treatment • Is there any way to urge the neighborhood to **provide professional and effective quarantine**? • The **condition for self-quarantine is very poor**. He can only take some normal medicine with no treatment effect • After 7 days of self-quarantine, my **condition only gets worse**, although I keep taking medicine every day • Now my wife, my granddaughter and I **are all infected** • My mother has been taking care of her grandfather all day long, and now she is **suspected of being infected** • We **lack food** at home. Cannot supplement nutrition to her • There was **no medicine at home and food** was in short supply	Self-quarantine deterring patients from using hospital resources Information needed for strategic decisions about self-treatment Infection among family members Lack of daily necessities	OHIS to manage self-quarantine
• My father is almost giving up. **There is no family with him**, and my father is emotionally broken down • All my family members are now in quarantine, and **no one can send her food.** She can only eat biscuits every day • Is there any volunteer in Wuhan can **look after my baby?** • The child is only four years old and **has nowhere to go**. It is especially dangerous • Now my old father has lived alone for 2 days with **no one to take care of him.** It is unknown whether he is still alive • Now the old man's condition continues to deteriorate, and he is **isolated at home without anyone to take care of him** • My aged grandparents have to **walk an hour home** on this cold day • He **walked for 1 hour every day to the hospital** for injection because the **public transportation is suspended**, and driving is not allowed • My grandparents, both over 80 years old, had no choice but to **ride a tricycle back home** • We contacted the neighborhood committee for a car, only being told to **go by ourselves**. They do not send patients with a fever • Both my parents are sick at home, but I **could not go back** to my parents at this time. I am almost going crazy • All family members are **isolated in other districts** and traffic is completely blocked	Cutoff of social support network Childcare needs Daily nursing needs for the elderly Long distance to hospitals Transportation needs Families isolated in different areas	OHIS for tangible support

Table 1. Continued

Open coding	Axial coding	Themes
• I have contacted the neighborhood committee for transfer, but **there is no response**. Have called the **mayor's hotline too, still with no response** • They just **kept ignoring us** • Yesterday the hospital informed us **over the phone** that the infection was confirmed. But the neighborhood committee **insists on a paper report** or **short message** for hospitalization arrangement • The neighborhood committee informed us that there **was a bed available** for my mother, so we went to the hospital. But after arriving there, we found there was **no beds at all**. And there were **hundreds of patients waiting** • He was **transferred** by the neighborhood committee to the mobile carbin hospital but was **later returned**, on the grounds that critically ill patients over age *65* **cannot be admitted** • My mother **was arranged to the mobile carbin hospital** by the neighborhood committee. But the hospital **refused to admit** because she was short of breath. She was just sent back after *5* hours in the car • The neighborhood committee was just **dealing with the provincial command** rather than really helping • My parents are now being **dragged to death** by the government's policy • We tried to communicate with the hospital leaders, only being **replied with some high-sounding words** • The doctor on duty who was enthusiastic and helpful at that time **becomes silent due to the pressure** of the hospital	Information inaccessibility from an authoritative source Lack of information coordination among multiple departments Inconsistent understandings of admission standards Distrust toward the authorities Pressure on information disclosure	OHIS to navigate information discrepancy

> hospitalize her. We have contacted many hospitals, only being told that there is no vacant bed. Please contact me if you have information about vacant hospital beds. (post by family member)

Turning to the hashtag, patients and their families were asking for 'help' and 'information'. Such information need was prevalent among the postings, as many users recounted being told that 'there is no bed in all the designated hospitals', despite the serious conditions of the patients, including 'coma', 'recurrent fever' and 'unable to eat'.

Due to the shortage of healthcare resources, confirmed test was required for the patients to be admitted. However, the posts showed that access to such test was also scarce. Turning to the hashtag, posters were desperately seeking information because 'no confirmation means no hospitalization'. Postings showed the difficulties encountered by the patients for case confirmation originating from the stretched healthcare system in Wuhan. In addition to the difficulties for confirmation and hospitalization, the patients and their families also experienced feelings of uncertainty and helplessness as the healthcare resources were under centralized control of the municipal government. This meant that they still needed to wait for official arrangement even after obtaining confirmed test result.

Moreover, barriers to health information existed mostly due to the patients' unfamiliarity with the rules of the centralized healthcare allocation system, such as how cases were reported, how long to expect before hospitalization and where to find designated hotels. Due to a lack of disclosure of such information from the official source, the patients went online to seek information and help, as explained in the following post:

> My father is completely bedridden. We have called emergency service. The ambulance took us to several hospitals. They were all full. We could only take him back home. He suffered a lot in the process. Please tell us a place that can admit. (post by family member)

'Please contact me', 'please tell us' and 'please help us' were common messages that were posted using the hashtag. In these posts, the users shared their experience of running around for medical treatment, only being denied service and/or a bed, not knowing how to proceed and lacking understanding of the official process to seek healthcare services. Ultimately, the increased uncertainty due to lack of information from the local government and healthcare providers triggered OHIS.

OHIS to manage self-quarantine

Due to the shortage of offline healthcare, the neighborhood committees/hospitals usually suggested the patients to stay at home in self-quarantine, during which they took 'a large amount of antibiotics', used 'fever-reducing medication' and bought 'breathing machine' and 'globulin'. The neighborhood committees/hospitals tried to deter patients from using hospital resources, but they did not help the patients make strategic decisions about self-treatment. Many posters shared information about the difficulty of maintaining health condition while in self-quarantine. Such that the patient's illness deteriorated due to a lack of proper treatment and nutritious food in self-quarantine.

Moreover, many posters recounted experience of infection among family members living under the same roof, such as the following post:

> Now my wife, my granddaughter and I are all infected. My daughter has passed away at home due to a lack of proper treatment. We are forced to get infected by each other. Now how can we, as two elders, look after my granddaughter? We eagerly ask for help to save my granddaughter. (post by patient)

Multigenerational living arraignment often made it impossible for families to self-quarantine effectively. Some users recounted their difficulties, such as 'no extra room for isolation', 'no separate bathroom' and 'need to look after the patient at any time', all of which led to challenges in ensuring proper self-quarantine measures. As a result, many turned to online for suggestions for more effective isolation measures to prevent spread of family infection.

The situation was especially difficult for the families with children and elderly, whose needs for daily care made isolation impossible. Turing to the hashtag, a patient posted: 'Now all my family members are infected, except my ten-month-old baby. She may get infected anytime staying with me. But the problem is that there is nobody can look after her. Please save her, she is only ten-month-old.' 'Please save her' is a desperate call of a parent, showing her willingness to let the baby stay with a stranger if that meant saving a life. Many patients sought similar help on the platform. Self-quarantine was easier suggested than done, because patients with underlying conditions could not be isolated from family members, or their medications can run out or family members had to provide care to the patients. OHIS provided an opportunity to seek help and advice for ways to manage these difficulties.

OHIS for tangible support

The patients' OHIS was characterized by a high reliance on weak social ties, i.e. the social media, as their strong interpersonal ties were often cut off by the lockdown policy. The hashtag was used not only for information and advice but also to seek tangible resources such as childcare and/or transportation to healthcare services. Since public transportation was suspended and driving was forbidden, many patients had to walk to hospitals, which was especially difficult considering their health condition and the distance from the nearest health facility. Some posts even recounted the patients struggling to walk for 1 h every day for injection. Many others also recounted the difficulties of the patients in seeking healthcare offline, such as 'my mom is seriously sick and cannot go to the hospital herself', 'in serious illness, my parents just held each other and moved step by step to the designated location' and 'after walking for more than 1 km, my old wife just fell over in physical weakness'.

In addition to the long distance to test clinics and the lack of public transportation, many were prevented from accessing healthcare services due to the neighborhood committees' rejecting transport help. The frustration with lack of ability accessing help and information offline triggered them to turn to OHIS. 'Please help us' was a common request for not only information and advice but also, if possible, ways to provide tangible support such as transportation to seek healthcare.

In addition, the lockdown policy also cut off the patients' family and social support network. Families were isolated in different provinces, different cities or different districts. People were not allowed to go out or leave the city, and visits across districts or neighborhoods were also forbidden. Cutoff from their network added to feelings of depression, anxiety, isolation and helplessness. And such they turned to OHIS. Needs for tangible support were especially pressing for elderly parents living in Wuhan. Many requested for tangible support to check in on the elderly, to take them to the hospital or to help them with their medication. Online platform provided a possibility to seek support from anyone who could possibly be of any help.

OHIS to navigate information discrepancy

Due to lack of information coordination between different health institutions, many turned to OHIS for advice and help to address their information gap. An analysis of the postings showed that the neighborhood committee was in charge of reporting cases, arranging hospital admission as well as providing transportation service according to the quarantine policy enforced in Wuhan. The centralized control of healthcare resources required patients' test confirmation be reported to the municipal COVID-19 prevention and control

headquarter for hospitalization. However, there was a lack of coordination among the departments and organizations, making the patients' offline information seeking processes complicated and confusing.

Many posts expressed confusion caused by the inconsistency in the information offered by the neighborhood committee, disease control center and the hospital. This confusion not only generated frustration but also delayed the patient's reception of medical treatment. Turning to OHIS, patients asked for 'help' to resolve this discrepancy so that they could seek the proper treatment.

Discussions also showed an inconsistency between neighborhood committees and the hospitals in their understanding of admission standards. Some patients experienced being arranged by the local entity but being returned by the hospital, which showed the lack of coordination between organizations. The misunderstanding between the neighborhood committee and the hospital led to feelings of anger, confusion, misinformation, increased anxiety and frustration as well as worsening conditions as the patients struggled for hospitalization.

Overall, a lack of information synchronization and coordination made it especially hard for the patients and families to get accurate information about the medical treatment. Information inaccessibility from an authoritative source was shared such as 'they just kept ignoring us and kept telling us that they were verifying'. Lack of consistent information created distrust especially as this post noted: 'after several days of waiting, the neighborhood committee said they lost the list of patients and needed to report again. Can [I] get help from any channel?' Posts of this kind illustrated the anger over the practice of neighborhood committee to follow the province government's decree but without really helping the patient. With the difficulties and lack of support, many turned to OHIS to fill their health information, support and resource needs. These posts like 'thank all the kind-hearted people sending me clues and suggestions. Thank you for your empathy' and 'my grandpa has been hospitalized. Hope every patient seeking help could be as lucky as me. Thank you all for your kind help' summed up how OHIS enabled information sharing, advice and support. Table 2 demonstrates example quotes under each of the four themes.

DISCUSSION

Summary of key findings

In this study, we examined the health information seeking behaviors on the social media platform Weibo among those patients living in or with family in Wuhan, China at the initial stages of COVID-19 pandemic. Previous research indicates that an information need can arise when a patient experiences health-related uncertainty, and she or he in turn might engage in health information seeking behavior to get reassurance, to manage uncertainty and to reconcile oneself with a new health situation (Lagoe and Atkin, 2015; Quinn *et al.*, 2017). However, existing studies have rarely paid attention to health information seeking behaviors during a pandemic, especially at the onset of a pandemic coupled with a lockdown (Xie *et al.*, 2020). Our findings highlight that the pandemic led to a significant surge of health and medical information seeking from patients and their family members on social media. This supports the research that following an outbreak there is often an increase in activities on social networking sites (Ginsberg *et al.*, 2009), especially when there is social isolation and information deficit due to lockdown (Zhao *et al.*, 2020).

Our findings provide insights into the relationship between OHIS and the functioning of the offline healthcare services and institutions, especially when there are information urgency and high uncertainties. In our study, we identified a rapid increase in posting using the *#COVID-19 Patient Seeking Help* hashtag at the onset of the pandemic outbreak, and a decrease following the government's effort to admit every patient to a hospital. The steep curve of the hashtag indicates that OHIS behaviors such as posting, commenting and reposting are useful markers of public reactions (Tausczik *et al.*, 2012). The findings draw attention to the need for public health practitioners to pay attention to online space in their responses, especially when up-to-date and quick information is necessary.

Under normal conditions, OHIS behaviors emphasize staying informed in preventing diseases, understanding more about diseases, finding various treatment options and making treatment decisions (Swar *et al.*, 2017). However, our findings showed that during the pandemic people were anxious being in lockdown, especially when the healthcare system was stretched causing lack of access to information, hospital beds, offline support, transportation and other resources. Patients and their families sought medical information to manage home quarantines and information for navigating the centralized healthcare allocation system, such as how cases were reported, how long to expect before hospitalization and where to find designated hotels for patients. Barriers to health information were introduced as healthcare resources of the whole municipal of Wuhan were put under centralized control (Lin, 2020), and there was delayed response from public health officials (Zhong *et al.*, 2020). Feelings of uncertainty and anxiety were heightened due to the lack of coordination among different organizations and lack of access to accurate and consistent information from an authoritative source. In the posts, the users

Table 2: Example quotes under each theme

Theme 1: OHIS for medical treatment
My mom has to get up at 4 am every day to register in the hospital. The hospital is overflowed with pneumonia patients. It has been 8 days since my mom was confirmed, but the doctors still refuse to hospitalize her. We have contacted many hospitals, only being told that there is no vacant bed. Please contact me if you have information about vacant hospital beds.
We have been rushing between hospitals every day but cannot get confirmatory testing. On February 2, we arrived at the Seventh hospital as early as at 7 am, when we heard that they are open for the test, but only being told that the test for that day had been used up.
After rounds of negotiation, we got the infection confirmation. [….] The current situation is that you could by no means get treatment even if you get confirmation result, unless it is through the unified arrangement of the organization. It is also unknown whether the so-called designated hotels really exist.
My father is completely bedridden. We have called emergency service. The ambulance took us to several hospitals. They were all full. We could only take him back home. He suffered a lot in the process. Please tell us a place that can admit.
Theme 2: OHIS to manage self-quarantine
The doctor suggested that we stay home and take medicine. But after taking a large amount of antibiotics for one week, her condition is getting worse. She has continuous fever with serious diarrhea and vomiting. We are in lack of food at home, with only some rice and noodles. Cannot supplement nutrition to her. She is getting worse and worse. She cannot even move for return visit to the hospital.
Now all my family members are infected, except my ten-month-old baby. She may get infected anytime staying with me. But the problem is that there is nobody can look after her. Is there any volunteer in Wuhan can look after my baby? Please save her, she is only ten-month-old.
My mom could not get out of bed, so I cannot be absolutely isolated from her. Now the neighborhood is locked down and the medicine is gone. Is there any suggestion for urging the neighborhood committee to carry out effective and professional quarantine?
Now my wife, my granddaughter and I are all infected. My daughter has passed away at home due to a lack of proper treatment. We are forced to get infected by each other. Now how can we, as two elders, look after my granddaughter? We eagerly ask for help to save my granddaughter.
Theme 3: OHIS for tangible support
Due to the shortage of healthcare resources, my uncle had to stay home in self-quarantine. He walked for 1 hour every day to the hospital for injection because the public transportation is suspended, and driving is not allowed. The neighborhood committee does not provide vehicle for us. We called the mayor's hotline and helpline, and they just do not answer the phone. Everything is just illusory.
'My mom is seriously sick and cannot go to the hospital herself'; 'in serious illness, my parents just held each other and moved step by step to the designated location'; 'after walking for more than 1 km, my old wife just fell over in physical weakness'.
The neighborhood committee insisted that my mom had to be confirmed before getting hospitalized. But how could I take a paralytic old woman for test all by myself? My husband is in Guangdong and could not come back due to the lockdown policy. I have also had fever for several day. Please help us. Thank you for reposting for solutions.
My father could not get out of bed for injection after three days of fever. We are so anxious but cannot go back home due to the traffic restriction. My father is almost giving up. There is no family with him, and my father is emotionally broken down. Is there any volunteer with medical skills can go to help with injection, or help take my father to the hospital for injection? And hope the neighborhood committee could give some priority to him for medical treatment.
Theme 4: OHIS to navigate information discrepancy
We have received oral notification of case confirmation from the hospital yesterday. But the neighborhood committee asked for paper test report or short message before reporting our case to the municipal. But the hospital told me they could only provide telephone notification. They also told me that my case has been reported to the disease control center, saying that I could search for my case on the official website. But the neighborhood committee insists on a paper report or short message for hospitalization arrangement. Please help us get hospitalized as soon as possible.
She was first sent to a cabin hospital but was further returned to the neighborhood committee at midnight, as her blood pressure was too low to measure. She is in bad condition and did not get good rest after rushing around for a whole day.
The neighborhood committee told us that there was vacant bed for my mother. […..]But soon we realized there was no bed at all after arriving at the hospital. There were several hundreds of patients queuing before us. […..] Too weak to wait longer, my mother had to come back home. Why did the neighborhood committee tell us firmly that there was vacant bed for us while actually there was only endless waiting in the hospital? [….] Please help us contact the hospital for treatment.
After the province imposed a command to admit all the patients before February 9, the neighborhood committee notified us in the evening that my grandma could be hospitalized. However, it turned out to be a community clinic with no medical workers or treatment. It is also unknown when we could be transferred to a qualified hospital. It is just for completing the provincial command. Patients are all admitted, but not in hospitals. Can anyone here tell me how we can transfer to a professional hospital?

shared their experience of running around for medical treatment, only being denied service and/or a bed, not knowing how to proceed and lacking an understanding of the official process to seek healthcare services. The inaccessibility of healthcare services in traditional settings has influenced patients' motivation for seeking health information on the Internet (Peddie and Kelly-Campbell, 2017). An analysis of web behaviors can provide insights into individuals' information seeking as public reactions are visible more quickly online than offline (Weeks and Southwell, 2010; Tausczik *et al.*, 2012). This is of particular relevance during a pandemic that is marked by fast changing information needs, high uncertainties and increase in anxiety as seen in our findings.

The lockdown policy also introduced a threat to people's offline social network by cutting off their interpersonal ties. While previous studies on the lockdown strategy in China have mainly focused on their effectiveness in preventing the spread of infection (Chinazzi *et al.*, 2020; Liu, 2020), our findings highlight the significant challenges facing the patients under lockdown for accessing information and social support. Many were cut off from their family members who lived in a different province, different city or different district. Tangible support including transport to hospitals and daily care for especially the elderly was unattainable because families were apart and face-to-face communication was suspended. The lack of ability to access help and information from offline sources not only triggered frustration but also delayed the patient's reception of medical treatment. Although the lockdowns have been found to be effective to combat the virus (Chinazzi *et al.*, 2020; Tian *et al.*, 2020), the patients had to navigate the uncertainties and fear of a pandemic through mostly relying on social media and non-family members for information, which further added to their feelings of uncertainty and anxiety.

Ultimately, the increased uncertainty due to lack of information from the local government and healthcare providers triggered OHIS. While some studies have identified the preference for authoritative and professional information sources (Kitchens *et al.*, 2014; Peddie and Kelly-Campbell, 2017), there is also increasing evidence that social media has replaced traditional media as the major source of information in disasters (Tim *et al.*, 2017; Beaunoyer *et al.*, 2020) for offsetting real-world uncertainties (Lin *et al.*, 2016). Our findings highlight that at the early stages of the pandemic, where the governmental and health departments failed to communicate with the public openly, timely and honestly about the pandemic, OHIS provided an avenue to fill this information gap. With OHIS on Weibo using the hashtag, patients and families were provided an opportunity to seek help and advice to manage their information needs and make decisions. Turning to OHIS, patients asked for 'help' to resolve information deficit and discrepancy and for tangible support for the elderly who were isolated from family and could not access healthcare offline. Overall, our findings reveal the importance of social media in a pandemic for the public to seek timely information advice, to help manage their information gap, to sort through the inconsistent information as well as to provide a place for expressing their frustrations, which is also vital for reducing morbidity and mortality during outbreaks of pandemic (Van den Broucke, 2020; Abel and McQueen, 2021).

Practical implications for health promotion

The findings should inform future pandemic preparedness planning so that timely and transparent communication can be implemented. An understanding of citizens' health information seeking behaviors should be integrated into the decision-making over pandemic control strategies. For example, transparent communication at local level is especially important, given that it is the first establishment patients and families often encounter. This should be coupled with easily accessible information online. Rather than relying on individual experiences, online resources can be essential to help the public to manage and navigate the uncertainties created by a pandemic. The findings also suggest the need to build and sustain information consistency and transparency among public health agencies at different levels over the course of a pandemic. Messages should be communicated with consistent information that is coordinated across the national and local authorities (Basnyat and Lee, 2015; Wang *et al.*, 2020; Généreux *et al.*, 2021) coupled with readily accessible information online.

It is equally important to pay attention to group-specific health information needs and their ability to act upon the information provided. Previous studies found that people of different age groups vary in their approaches and challenges in seeking information (Beaunoyer *et al.*, 2020), particularly when it comes to online sources (Pan *et al.*, 2020a). In any crisis, people who are already in vulnerable positions are also most likely to suffer more (Beaunoyer *et al.*, 2020; Xie *et al.*, 2020). For example, our findings highlight that younger family members sought information online for elderly patients with age-related information needs such as transport service, chronic disease condition, tangible support and medication help. Therefore, future pandemic communication should also consider reaching the aging populations who may not necessarily be able to rely on social media for health and medical information. Family members can be a proxy to this information, but the information needs to be tailored to the specific health needs of the aging population.

Limitations and conclusion

One of the limitations of our study is the lack of our ability to establish direct links between information needs and patients' health outcomes. More in-depth discussion is needed to explore whether and how the information seeking behaviors online can result in better health outcomes. This study focused on identifying themes surrounding seeking health information online and how related to offline experiences of access healthcare during the lockdown. In doing so, another limitation of our study is the lack of our ability to engage in discourse and conversation analysis of the text and the language used in the posts. Future research should embark on a critical study on the statements which are discursive, irony or postulating, to explore how language is used in the context.

At the early stages of the COVID-19 pandemic, China relied on lockdowns to curb the infections, but at the same time this caused information crisis for people in social isolation. The patients and their families turned to social media to seek health information, to express frustration and to find ways to cope and manage uncertainties while they were isolated at home. OHIS on Weibo using the hashtag was motivated by the dire need for health information, the need to manage their and families' health during the self-quarantine, the lack of empathy when interacting with local authorities and the lack of consistent and reliable information. Our study presents lessons from OHIS behaviors and provides practical implications for future communication and preparedness during the emergence of a pandemic.

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Conflict of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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