Understanding the experiences of patients with cancers in hospitals during COVID-19 pandemic in China: A qualitative research study

Xing Chen1 | Wenyu Deng2 | Wenjuan Zhou3 | Ying Liu4 | Jinfeng Chen4 | Yuan Gao4 | Kuirong Xiao4 | Lin Man4 | Wanting Qu4 | Hongjuan Zeng4 | Sha Ye4

Abstract
Aim: To explore the experiences of patients with cancers in hospitals during the COVID-19 pandemic.
Design: A qualitative research study.
Methods: Using a phenomenological approach, we enrolled 22 patients with cancers in the Hunan Cancer Hospital from 20 February 2020 to 10 April 2020. The interviews were conducted face-to-face and were analysed by Colaizzi’s 7-step method. This study aligns with the COREQ checklist.
Results: The experiences of patients with cancers in hospitals during the COVID-19 pandemic can be categorized into four major themes: (1) emotional changes; (2) delays in visiting hospital; (3) barriers to accessing medical care services, and (4) inconvenience related to logistics services.

Keywords: cancer, COVID-19, patients, qualitative research
1 | INTRODUCTION

The patient experience encompasses a range of interactions that patients have with the healthcare system, including medical planning, care from doctors, nurses and staff in the hospital, medical practice and associated healthcare facilities. It is important for the prognosis and quality of life of people with cancer. The COVID-19 pandemic changed the routine of people with cancer in hospital and daily life. The Chinese government has issued many policies such as social distance to control the epidemic.

In December 2019, pneumonia cases of novel coronavirus infection first emerged in Wuhan, China (Zhu et al., 2020), and then the novel coronavirus has been spreading all over the world. The World Health Organization (WHO) named it as 2019 Coronavirus Disease (COVID-19), also known as Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) (WHO, 2020). Up to now, SARS-CoV-2 has infected more than 100 million people worldwide, resulting in nearly 3 million deaths, and the distribution of SARS-CoV-2 infections is in 192 countries/regions (Johns Hopkins, 2021). Currently, the prevention and control of SARS-CoV-2 is still an urgent and critical task that cannot be relaxed (Pascarella et al., 2020). To prevent and control the COVID-19 pandemic, China has taken a series of public health measures, including travel restrictions, family isolation, social distance and nucleic acid testing (Niud & Xu, 2020), and hospitals at all levels have also put in place new outbreak control measures to protect patient and medical staff safety (Pan et al., 2020).

Studies have reported that droplet transmission and contact transmission are the main transmission routes of SARS-CoV-2, with high transmission and high risk of infection (Li et al., 2020; Yang et al., 2020). People with cancer may be at higher risk of infection due to their systemic immunocompromised state and are likely more prone to developing severe complications or at higher risk of death (Liang et al., 2020). A retrospective study showed (Zhang et al., 2020) that the risk rate of infection with COVID-19 among the cancer population was 3.56 times higher than were among the general population. In another multicentre retrospective cohort study found that people with cancer infected with COVID-19 were 3.611 times more likely to have severe symptoms than COVID-19-infected patients without cancer (Tian et al., 2020). A cohort study of cancer data from four countries showed that people with cancer were at 38% fatality risk compared with those without cancer at 5% risk of COVID-19-related death (Williams et al., 2021). People with cancer usually need to travel to and from the hospital and home periodically to complete cancer treatment. Due to the impact of the pandemic, the diagnosis and treatment arrangement of people with cancer may be disrupted, and the choice of medical treatment and medical procedures may change (Shaohua et al., 2020). A survey of medical staff in gynaecological oncology showed that during the COVID-19 pandemic, limitations in medical resources reduced the number of gynaecological oncology clinics and surgeries, and triage was used to minimize personnel flow (Bogani et al., 2020).

In the service of health care and numerous patient interactions, patient experience is an important benchmark for evaluating and improving the quality of medical care (Piper & Lamb, 2014). Understanding patient experience, as a dynamic process, is essential not only to give more realistic perspective and guide medical service improvement but also because people’s experiences of medical care may be linked to clinical outcomes and costs (Cathal Doyle et al., 2013). This qualitative study explored people with cancer experience during the COVID-19 pandemic, in order to highlight and also the areas that need to be improved in clinical practice.

2 | METHOD

2.1 | Design

In our study, we employed the method of descriptive phenomenological research. Phenomenology pursuits of cottoning on people’s daily life experiences by unveiling what lies “hidden” in them (Matua & Van Der Wal, 2015). Descriptive phenomenology (Edward & Welch, 2011) was chosen for its emphasis on the “pure” description of people’s experiences and not based on the researchers’ interpretation of people’s descriptions of their experiences. We interviewed 22 eligible participants to understand the experience of patients with cancers in hospitals during the COVID-19 outbreak. The entire research process was conducted following consolidated criteria for reporting qualitative research (CROEQ) (Tong et al., 2007).

2.2 | Research team

The research team consisted of a faculty member (Associate Professor) and two research assistants (Master students) from the nursing school of University, a nursing supervisor and six nurses in the Tumor Hospital, all of whom are trained in qualitative research. Liu, Jinfen Chen and Gao conducted the interview. Xiao, Man and Qu transcribed word by word. Xing Chen and Deng performed data analysis and drafted the manuscript. Zhou and Ye critically revised the date analysis and manuscript. The researchers are female and experienced in research and in interviewing vulnerable people. The researcher had no relationship with the participants before the study.

2.3 | Setting and participants

Participants were recruited using convenience sampling via an advertisement in the Hunan Cancer Hospital of China, which is a tertiary first-class cancer specialized hospital. In China, the tertiary first-class hospital is the highest-level hospital, which can give high-level specialized medical and health services for surrounding areas (China., 2012). The hospital that has 1,490 beds as planned, 41 clinical departments and 2,189 in-service employees gives high-quality, highly effective medical services for people with cancer of the province and neighbouring provinces. However, the resources for cancer treatment, such as chemotherapy drugs and radiotherapy
machines, was still partly restricted at this hospital during the time of interview. The hospital has also taken many measures to control the epidemic, including providing health and sociodemographic information (including consideration of symptoms and travel history), taking temperature, a Computed Tomography (CT) of lung before hospitalization. The aim for a lung CT before hospitalization was to further investigate suspected COVID-19 patients. There was no better way to investigate suspected COVID-19 patients during the time of interview in China.

Patients were eligible whether they had a diagnosis of cancers; were hospitalized patients during the COVID-19 pandemic; more than 18 years old; and were able to fully express feelings and informed consent. Exclusion criteria were serious mental or psychological disorders and participation in similar studies.

We interviewed twenty-two patients with different cancers who were hospitalized in Hunan Cancer Hospital between February and April 2020. In addition, the sample included ten men and twelve women. No one dropped out of the study, and no repeat interviews were carried out.

2.4  |  Data collection

This research uses individual and semi-structured interviews. The authors formulated the following interview outline based on the relevant policies, literature review and expert advice during the pandemic: (1) How did you decide to visit the hospital for medical help? (2) How was your experience while waiting for admission? (3) How was your experience during hospitalization? (4) What challenges have taken place in hospital during the COVID-19 pandemic? (5) Who helped you to deal with these challenges and how did you deal with these challenges? Also, we asked some questions like “Could you please tell me more about...” to obtain more information related to our topic. Before our formal interview, Zhou and Ye conducted a pilot interview. The questions were planned but flexible so that when required, the researcher altered the sequence of questions. The researchers recorded the entire interview using two audio recorders. At the same time, they recorded as much as possible the nonverbal behaviour (tone, facial expression) of the participants in their notebooks. The interviews were conducted in a quiet and comfortable conference room with no other people in the hospital. The sample size is based on data saturation when no new information from the participants appeared (Saunders et al., 2018). The interview lasted approximately 30–40 min.

2.5  |  Data analysis

Data analysis and collection were carried out simultaneously until the data reaches saturation. After the interview, the researchers transcribed the records into text data word-by-word in 24 hr, and feedback to the participants via WeChat (a Chinese cell/web app for messaging or communications) to verify the authenticity of the content after checking. Finally, all data will be input into the qualitative research data management software NVivo 12.0 for analysis. Two authors analysed and coded the data independently. The data analysis was carried out according to the Colaizzi seven-step method in phenomenological research (Sanders, 2003); (1) Read all the interview data several times and understand the interview data roughly; (2) Mark meaningful statements that are consistent with the research question; (3) Summarize and refine meaningful statements and code them; (4) Summarize the coded opinions, find common concepts, and form themes, subject groups and categories; (5) Link the subject to the research object for detailed description; (6) Describe the essential structure that constitutes the phenomenon; (7) Return the final analysis result to the research object for verification. Pilot interviews are not included in the analysis.

2.6  |  Ethical statement

The study was approved by the Ethical Review Committee of Hunan Cancer Hospital. Before the start of each interview, the investigator introduced the purpose and content of the study to the participants and sign an informed consent form. At the same time, to protect the privacy of participants, each participant has only one code (N1, N2... N12) for further data processing, and all research data are stored in a password-protected computer file. Participants could withdraw from the study at any time without any consequences for their treatment and care in the department.

2.7  |  Validity and Rigour

For validity, all interviews were transcribed verbatim without adding any precise standard notions, and data encoding was performed by three researchers independently. To assure credibility of the data analysis, researchers exchanged and discussed their opinions on the discrepancy between codes during the coding process, and invited third-party members to arbitrate and reach a consensus.

3  |  RESULTS

Of the 22 participants, ten were male and the rest were female. The interview invited seven types of people with cancer, namely lung cancer, breast cancer, colorectal cancer, stomach cancer, thyroid cancer, liver cancer and cervix cancer. The demographic characteristics of the participants are shown in Table 1. The patients’ age ranged between 30–65 years, and the average age was 47.36 ± 9.16. They all had formal education to at least the junior High School (JHS) level. Twenty of the patients were Han nationality, and two were minority. Thirteen were employed, six were unemployed, and three were retired. Eighteen of the patients were married.
Four themes were identified from the data analysis: emotional changes; delays in visiting the hospital; barriers to accessing medical care services, and inconvenience related to logistics services (Figure 1).

### TABLE 1 Demographic characteristics of the participants

| Variable       | Category       | N (%) |
|----------------|----------------|-------|
| Gender         | Male           | 10 (45.5%) |
|                | Female         | 12 (54.5%) |
| Age            | 30–40          | 5 (22.7%)  |
|                | 41–50          | 9 (40.9%)  |
|                | 51–65          | 8 (36.4%)  |
| Education level| Junior high school | 10 (45.4%) |
|                | Senior high school | 6 (27.3%)  |
|                | College or above | 6 (27.3%)  |
| Marital status | Married        | 18 (81.8%) |
|                | Divorced       | 2 (9.1%)   |
|                | Widowed        | 2 (9.1%)   |
| Diagnosis      | Lung Cancer    | 4 (18.2%)  |
|                | Breast Cancer  | 4 (18.2%)  |
|                | Colorectum Cancer | 3 (13.6%) |
|                | Stomach Cancer | 3 (13.6%)  |
|                | Thyroid Cancer | 2 (9.1%)   |
|                | Liver Cancer   | 3 (13.6%)  |
|                | Cervix Cancer  | 3 (13.6%)  |
| Stage of the disease | Stage I | 7 (31.8%) |
|                | Stage II       | 2 (9.1%)   |
|                | Stage III      | 6 (27.3%)  |
|                | Stage IV       | 4 (18.2%)  |
|                | Unknown        | 3 (13.6%)  |

Participants defined their experience of emotion during this period as: statistically significant emotional upheaval relying on the circumstances they were faced with.

#### 3.1 Emotional changes

3.1.1 Emotional distress before visiting hospital: anxiety and fear

Almost all participants expressed negative emotions before visiting the hospital. Their family also expressed concern about them. Their concerns were mainly related to two aspects. First, most patients expressed concern that they would not be able to go to the hospital and receive treatment in time as the strict social distancing measures during this special time. Also, some patients were worried about the risk of coronavirus exposure when travelling to the hospital. These worries also led to their psychological and physical changes. They could not even eat and sleep normally.

"At that time, I was very anxious after a few days of delay due to this (pandemic), and couldn't even help crying." (N17)

"I haven't been out for more than a month since the outbreak, and my son's biggest worry is getting infected while seeing a doctor." (N8)

"I'm tearful and losing sleep before visiting hospital." (N10)

3.1.2 Comfort and safety after receiving medical care

While the pandemic has brought anxiety and depression to patients, most participants said they felt relieved and safe after receiving medical care. Correspondingly, there are two reasons that can be
accounted for. First, patients were satisfied with the work related to COVID-19 pandemic prevention and control of the hospital. Most participants believed that their risk of COVID-19 exposure was reduced. In addition, patients who received medical care felt confident in the medical capability of the hospital.

“I don’t worry about being infected (COVID-19) anymore, because the hospital is doing a good job.” (N4)

“I think it’s safe in hospital and my mental state has been much better.” (N19)

3.2 Delays in visiting the hospital

Most people with cancer have treatment in cycles after cancer diagnosis. The interval between treatment breaks is fixed in the treatment plan. However, most participants depicted a delay in the treatment plan for at least one week and up to 1 month due to the COVID-19. Despite some patients experiencing pain, cancerous fatigue, and other symptoms burden, most of them chose to delay medical care, which may reflect adherence to community mitigation efforts such as transport restrictions and stay-at-home orders during pandemic. At the same time, some patients who have delayed medical treatment said they felt unwell and worried about their condition or its symptoms recurring or worsening.

Hospitals in China were classified into three degrees: tertiary hospitals, second-tier hospitals and primary hospitals. Tertiary hospitals have the most healthcare resources and represent the highest medical care level of the province and neighbouring provinces. Primary hospitals are located in a community, which give generalist health services. Patients are easy to reach primary hospitals. Nevertheless, many primary hospitals did not have the resources for cancer treatment, such as no enough stock of chemotherapy drugs as the traffic restrictions and block during the pandemic. Some patients had to rush to the higher-level hospital far away from home for treatment. The process was more difficult for those patients.

“I was diagnosed at the end of December last year, and then we delayed the treatment for a month, 1 because the pandemic was very severe at that time.”(N6)

“... I thought we were going to hospital 7 days ago according to the medical plan, I put it on hold because of concerns related to COVID-19.”(N4)

“I first checked in at a primary hospital near my home. The doctor said that my physical condition was not very good. And he recommended that I go to a major hospital. Because of the pandemic, I didn’t dare to go out. I was afraid of being infected. So I waited at home for a month before coming to the hospital for treatment.” (N11).

“If there is no COVID-19, I will rush to the hospital for an examination if I feel a little uncomfortable. But now everyone is waiting for the weather to get better and the pandemic is gradually contained before they want to go to the hospital for a check-up. So the pandemic still has a certain impact on us. In fact, I was delayed at home for a long time. When I was at home, dysuria (pain when passing urine) was more obvious than before. And I was worried that my cancer would be back.”(N1).

3.3 Barriers to accessing medical care services

The procedures for patient registration, outpatient check-ups and administrative procedures have all changed due to the COVID-19 pandemic. Correspondingly, there were some barriers to accessing medical care services including difficulty registering and complicated procedures before getting medical care.

3.3.1 Difficult to register

Participants described a longer wait time than before while registering to see a doctor. As with many emerging infectious cases, medical resources have been more focussed on the COVID-19 prevention and control process during the pandemic. To mitigate the risk of COVID-19 spread, the amount of appointments in the outpatient department per day has been reduced to minimize patients flow. Besides, on-site registration was replaced by online appointment registration to obey the rule of social distance. Some patients said that they realized that they could not register on the spot until they came to the hospital, which caused them to go home and register online again.

“The registration time is longer than before, this is a problem that has been bothering me.”(N3)

“This is the fourth time we have come to the hospital. The first time we did not make an appointment online...”(N16)

3.3.2 Complicated procedures before getting medical care

Participants were clear that, in contrast to previous hospitalization procedures, they need to give health and sociodemographic
information (including consideration of symptoms and travel history), take temperature, and undergo a Computed Tomography (CT) of lung to distinguish if they were in a state of COVID-19 infection during the pandemic. They had to make different appointments for these examinations, which took a certain amount of time. Patients were admitted only if all test results were negative. If the result was positive, they would need to be treated for the COVID-19 first. These requirements make patients wait longer than before. At the same time, patients have to pay for the cost of new examination items related to COVID-19 themselves, which adds a certain financial burden to patients.

“We mainly feel that the waiting time for the examination is too long. For example, I have to wait a few days for a CT. Just queuing for this process is very long. Today is the third day I came to the hospital. I only did a blood draw and a lung CT, and then there are two CTs of other parts and ECG that have not been done yet. I wasted a lot of time waiting.”(N12).

“This is too much trouble during the pandemic. After the blood test, I had to do the CT twice. The first time was lung CT due to the pandemic, and the second time was a CT related to my disease. We had to line up for a few days each time. We lived in a relative’s house nearby, but it was still not suitable for a long stay.”(N16).

“Except lung CT scans, we have to do three additional CT scans during this hospitalization. The cost of these examinations alone was more than 1,800 yuan (270 USD). Our financial situation is not very good, so we still want to reimburse part of it through medical insurance as much as possible.”(N19).

This concern was heightened for those who were from other cities. They had to stay in hotels as the long waiting time in the hospital before admission. However, hotel check-in management was very strict during the pandemic, and it was difficult for them to find a suitable hotel near the hospital. Some patients were even forced to live in the car.

“We wanted to find a cheaper hotel near the hospital, but many hotels were not open. We had no place to sleep, so we could only cope with it for two nights in the car until someone informed us to be hospitalized.”(N10).

3.4 Inconvenience related to hospital logistics services

This theme is specifically about participants’ experiences of hospital logistics services. Some of the logistics services routine were changed due to the pandemic process in hospital. Dieting is the most common topic among participants. Many participants explained that “social isolation” based on hospital requirements resulted in their only option for eating was the food service given by the hospital. They expressed concern about nutritional problems and made some suggestions such as a richer diet.

“There are limited types of dishes hospital provided during the pandemic, and then they are not as good as the previous dishes, and I feel that I have no appetite.”(N7)

“We must eat meals at the hospital during the pandemic. I hope there are more types of meals and a better taste.”(N13)

“I lost my appetite after chemotherapy, but I had to eat for nutrition. I feel like I can’t eat the rice here. It is difficult for me to tolerate the food here. But I have no choice. Anyway, I hope that they can add some soup.”(N12).

4 | DISCUSSION

This study described and categorized the experiences of patients with cancers in hospitals during the COVID-19 pandemic in China via descriptive phenomenological methods. The most obvious finding emerged from this research is that people with cancer experienced a delay in medical treatment and faced some inconveniences in hospitals during the COVID-19 pandemic. People with cancer not only face the threat of tumours but also face a higher risk of COVID-19 infections during the COVID-19 pandemic (Liang et al., 2020). Therefore, it is necessary to develop strategies to reduce the negative impact of COVID-19 among people with cancer.

Consistent with previous studies (Bogani et al., 2020; Frey et al., 2020; Nakayama et al., 2020), we found that most people with cancer chose to delay medical treatment between on-time treatment and risk of infection during the COVID-19. Although it is reasonable for them, there are studies that reported some of the negative effects of medical treatment delays. Medical treatment delays might increase the risk for life-threatening medical emergencies (Flores et al., 2021; Hasan et al., 2021; Savin et al., 2021. A meta-analysis also showed that treatment delay was associated with an increase in the risk of death (Hanna et al., 2020). These above consequences may become visible as the pandemic continues to spread. Thus, effective countermeasures are needed. First, we need to weigh the risks of COVID-19 against the magnitude of benefit of intended cancer therapies and schedule medical treatment depending on patients’ priority. Also, the development of “virtual” assessments may be helpful to solve this problem. Patients can keep in touch with their routine physicians via video-conference and/or telephone (Crouse et al., 2010). Several reports
have shown that virtual assessments and care for people with cancer are safe and effective (Levine et al., 2020; Pham et al., 2020). In addition, virtual dialogues could systematically comfort people with cancer and give them with comprehensive and reliable basic information (Harless et al., 2009).

People with cancer also experienced some inconveniences in hospitals during the COVID-19 pandemic. First, they experienced barriers to access medical services. Consistent with previous studies, these problems have been ongoing before the outbreak of the pandemic (Shen et al., 2020; Xie & Or, 2017). But, the problem has become more pronounced during the pandemic. To mitigate the risk of transmitting COVID-19, the inpatient procedures and outpatient procedures have been changed. Before being allowed to be hospitalized, in addition to routine examinations, patients also needed to do some additional pandemic-related examination items such as lung CT (Computed Tomography). Lung CT can detect early changes in the lungs after COVID-19 infection, which helps medical staff to further investigate suspected COVID-19 patients. But these have led to an increase in the waiting time for patients to be admitted. And long-term waiting would invisibly increase the patient's medical costs, and further aggravate the patient's physical discomfort, which would easily leave a negative experience in the hospital for the patients (Huang et al., 2004). Therefore, as mentioned in prior study, we have to assess the condition of these patients, and allocate limited medical resources to patients whose survival and the outcome will be statistically significantly affected by the delay in seeking medical care during the pandemic (Hanna et al., 2020). In addition, many patients mentioned the problem of eating during hospitalization. Inpatients could only choose the food service arranged by the hospital due to hospital infection control policies. Many interviewees said that the type of food delivered by the hospital was relatively simple and the taste was bland. It has been demonstrated that nutrition is an important factor affecting the quality of life and prognosis of people with cancer (Doyle et al., 2006; Rock et al., 2012). It is therefore essential that medical institutions should combine the needs and suggestions of patients to give them with improved meals.

Interestingly, although most people with cancer had negative emotions such as fear, anxiety and worry before admission. After admission, positive emotions prevailed in most of the patients. The people with cancer felt extreme physical fatigue and helplessness caused by the COVID-19 pandemic, which was consistent with the studies on other people(Hyland & Jim, 2020; Philip et al., 2020). This may stem from patients’ concerns about the unknown of the COVID-19 pandemic and delays in treatment. Therefore, it is particularly important to actively pay attention to the psychological conditions of people with cancer and give relevant psychological counselling on time in a pandemic. All medical staff should be vigilant for emotional distress in people with cancer and ensure their psychological health is discussed and treated during the periconceptional period. Further research is also needed to talk about the management of emotional distress during the pandemic. But after admission, patients have gained a sense of security from the hospital’s strict epidemic prevention and control and gained confidence in fighting the disease from the hospital’s treatment. Many patients felt relieved of anxiety and gradually felt safe at the hospital. The result indicates the importance of strict hospital infection control policies and optimization of care to improve the quality of life of people with cancer in the hospital.

4.1 | Limitations

This study in this report is subject to several limitations. The study focussed on patients seeking medical treatment at a single, tertiary-level public sector hospital. When applying the results to primary hospitals, it is necessary to take into account the differences in medical procedures, outpatient visits and patient conditions in different hospitals.

5 | CONCLUSION

This study explored the experiences of patients with cancers in hospitals during the COVID-19 pandemic in China. People with cancer are facing increasing challenges than ever before in medical treatment. In this study, it was determined that people with cancer experienced fear and worry, due to the risk of infection with COVID-19 and postponed medical examination and treatment. It is crucial to realize how to use limited medical resources to meet the medical needs of different patients in the future public health emergencies.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

AUTHOR CONTRIBUTIONS

Zhou, Liu, Chen, Gao, Xiao, Man and Qu: Collection, analysis and interpretation of the data. Chen, Deng and Ye: Drafting, writing and revising the manuscript. All authors: Research idea, designing and final approval.

DATA_AVAILABILITY_STATEMENT

The data sets used and/or analysed during the current study are available from the corresponding author on reasonable request.

ORCID

Wenyu Deng https://orcid.org/0000-0003-2797-4481

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