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'And I thought having a cancer diagnosis was hard': A descriptive phenomenological study of family caregiver experiences navigating the pre-hospital system during COVID-19

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ABSTRACT

Purpose: Cancer patients usually need frequent hospitalization for diagnosis and treatment. However, the unprecedented outbreak of the Omicron wave in Shanghai pressured local communities and hospitals to enforce strict control measures. This qualitative study aimed to investigate cancer family caregivers' experiences of navigating the pre-hospital system during the lockdown in Shanghai.

Method: This is a substudy of a larger study investigating the experience of 20 caregivers of hospitalized cancer patients during the lockdown in Shanghai. This study was based on findings from a subset of 14 semi-structured face-to-face interviews with cancer family caregivers. Inductive thematic analysis was used to analyze the data.

Results: The outbreak of the epidemic and lockdown measures created additional challenges for caregivers, which extended beyond their daily concerns. Uncertainties of the situation, risks of infection, and income loss, along with the strict restrictions in their community and hospitals, added to their burden and compromised their abilities to seek help for their significant others. Yet, in an attempt to reduce undue concern and worry, caregivers were eventually allowed to accompany their family member to the hospital using reliable information, and telemedicine techniques based on an updated governmental policy governing access to care and support for cancer patients.

Conclusions: The lockdown in Shanghai significantly affected cancer family caregivers' experience navigating the pre-hospital system. Policy support for cancer care, reliable information, and telemedicine techniques have been identified as essential facilitators of improved access to cancer care.

1. Introduction

The original severe acute respiratory syndrome-coronavirus 2 (SARS-CoV-2) has been constantly mutating since its first detection at the end of 2019. The Omicron variant that emerged in early November 2021 is a highly mutated version, which has posed a significant threat to public health and the health care system in many countries (World Health Organization, 2021a). Although the clinical outcomes of the Omicron variant are generally less severe than previous variants, the possibility of developing severe COVID-19 and long COVID could not be ruled out (Ludvigsson, 2021; Wang et al., 2022). Meanwhile, the highly contagious Omicron variant spreads rapidly, inundates hospitals with COVID positive patients, which has been shown to overwhelm the health care system, Hong Kong being an example of this.

Shanghai is the financial hub of China with approximately 26 million residents. In late February 2022, the city experienced a severe wave of omicron BA.2. infection. During the peak of the outbreak in April, Shanghai recorded over 27,000 new confirmed cases per day (Shanghai

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Municipal Health Commission, 2022a). To tackle the rapid spread of the Omicron variant and achieve a dynamic zero-COVID-19 goal, Shanghai resorted to "static management" and implemented strict preventive and control measures to reduce its spread. Part of these restrictions included a complete lockdown and mass COVID-19 testing. Public transportation was suspended, all schools and public places were shut down, and companies and factories were either closed or underwent closed-loop management (Xu et al., 2022). Except for individuals with special permits (e.g., medical needs), all residents were requested to stay in their residential communities or at home to minimize the risk of getting or spreading the virus. At the same time, the health care system prioritized COVID-19 responses that could inevitably affect hospitals' routine services. Some hospitals operated closed-loop management and suspended face-to-face consultations, and all staff were requested to live and work in the hospital. Individuals with health care needs had to shift to online consultations or be transported to hospitals in a closed-loop manner. Additionally, to fight against COVID-19, including a large number of people with COVID-19, health authorities had to deploy their human resources to support mass testing and man isolation facilities. They also transformed 48 city/district-level hospitals into designated hospitals for COVID-19 patients. The restricted movement coupled with significant strains on healthcare services significantly contributed to difficulties in patients' access to healthcare services.

Cancer patients usually need frequent hospitalization for diagnosis and treatment, such as surgery, chemotherapy, radiotherapy, immunotherapy, targeted therapy, clinical complications related to cancer or its treatment, and other clinical complications (Feliciana Silva et al., 2020; Sadik et al., 2014). Timely access to healthcare services is essential for cancer patients. However, having a cancer diagnosis during COVID-19 could be challenging for cancer patients and their families. A recent systematic review reported that cancer patients from ten countries struggled with long waiting times, disrupted communication with health service providers, and delayed and interruptions in screening and treatment during the pandemic and lockdown periods (Dhada et al., 2021). China accounted for approximately 30% of cancer-related death worldwide in 2020 (Cao et al., 2021). From a global perspective, the ongoing "zero-COVID" policy could affect the healthcare experience of a significant number of cancer population.

Shanghai, being a first-tier city in China, has some of the most advanced medical technologies and the best medical systems and resources. It provides cancer care to locals and patients from other cities in China. Currently, approximately 490,000 cancer patients are receiving treatment in Shanghai (Shanghai Municipal Health Commission, 2021). During the lockdown period, Shanghai health authorities had implemented guidelines to ensure optimal care of patients requiring emergency care, including cancer patients. For example, it was decreed that local hospitals cannot reject or delay treatment for patients who need emergency care due to a lack of a negative nucleic acid test result (Shanghai Municipal Health Commission, 2022b). However, the experience of accessing healthcare services among cancer patients and family caregivers amid Shanghai's strict lockdown measures remains unknown. More importantly and despite the unique situation in Shanghai and indeed China with the current COVID restrictions, it could be suggested that health care access in the 'post-COVID world' in other countries still exist. Pramesh et al. (2021), for example, in their editorial identified that post-COVID health care access saw a major increase in demand, significantly affecting health care delivery leading to fragmentation of services (Pramesh et al., 2021). Likewise, nonessential cancer surgery during the COVID crisis led to a backlog of procedures being undertaken resulting in lower overall survival, an increase in complication rates and a progression of their disease, which resulted in more complex and high risk procedures being undertaken (Billig and Sears, 2020; Kaltenmeier et al., 2021).

Family caregivers play a significant role in supporting cancer patients across their illness and treatment trajectories. It has been reported that approximately 90% of family caregivers accompany cancer patients during their hospital admission (Cho and Kim, 2006). During the lockdown in Shanghai, cancer patients were allowed to have a caregiver accompany them at the emergency department and the bedside during hospitalization. There is increasing evidence about the challenges of accessing health care services during the lockdown (Topriceanu et al., 2021; Mynard et al., 2022). Yet, what is unclear is how family caregivers navigate the pre-hospital admissions process aimd strict pandemic control measures and supportive policies for cancer care. Therefore, having a good understanding of their pre-hospital experience will provide insights into how to best support cancer patients' hospital admission during the current or future public health emergencies. Thus, this qualitative study aimed to investigate and better understand the family caregivers' of cancer patient's experience navigating the pre-hospital system during COVID-19 in Shanghai.

2. Methods

2.1. Study design

A descriptive phenomenological approach was used to understand family caregivers' experience of navigating the pre-prehospital system during the lockdown. The study was reported according to the checklist of Consolidated Criteria for Qualitative Studies (COREQ).

2.2. Setting and participants

The study was conducted in a 1,500 bed tertiary hospital in Shanghai. Purposive sampling was used to recruit the participants. The inclusion criteria were: 1) aged 18 or above; 2) primary family caregivers of cancer patients receiving treatment at the study hospital; 3) engaged in the hospital admission process during the large-scale 2-month COVID lockdown; 4) understood the participant information sheet (PIS) and agreed to provide a written consent; 5) were able to speak mandarin Chinese. Family caregivers who failed to meet the above-described criteria were excluded from the study.

2.3. Data collection

The individual interview took place in May 2022. The participants were recruited by a nurse manager (TZ) at the hospital, who has 16 years of experience in cancer care. After explaining the aims of the study and providing a participant information sheet, informed was consent was obtained. The face-to-face individual interviews were conducted in a private room where the participants felt comfortable. During the lockdown, hospitals allowed one family member to provide essential care for their family member. To allow the participants completely concentrate on the conversation with the nurse manager, the cancer patients of the participants were taken care of by other nurses during the interview.

The interview guide was developed collaboratively by the research team, which included two nurse managers (TZ & FL) and two qualitative researchers in nursing (HXM & MC). The main interview question was: 1) How did you feel as a family caregiver before the hospitalization during the lockdown period? And was guided by additional questions 2) How was your access to hospitalization affected by the lockdown measures? 3) What factors influenced your access to hospitalization?

All the interviews were conducted by the nurse manager (TZ) in mandarin Chinese and were audio-recorded with consent. Moreover, one of the qualitative researchers fluent in mandarin (HXM) participated in the first three interviews using video conferencing (Voov) to supervise the interview. Prompt feedback was provided after listening to the audio recordings in the following interviews. Data saturation was reached after interviewing 14 participants. The average interview duration was 39 min.

2.4. Data analysis

Data was analyzed by using the six-phase inductive thematic analysis method (Braun and Clarke, 2006). The audio recordings were transcribed by two authors (HXM & TZ). To minimize bias, data analysis was conducted by two qualitative researchers (HXM & MC) who were not involved in the most of the interviews, and cross-checked by the rest of the research team. First, the transcripts were repeatedly re-read to gain an overall picture of the participants' experience. Then, the participants' significant statements were extracted and summarized into code. After that, the codes were organized into potential subthemes and themes through an iterative process of refining and revising the codes and reorganizing subthemes and themes. Meetings were held throughout the process among all authors to ensure subthemes and themes were organised in a precise and consistent format. After the data analysis, the selected quotations were translated in English by a bilingual researcher (HXM).

Ethical approval

Ethical approval was obtained from the Human Subject Subcommittee of the studied hospital in Shanghai (Ref No.: EHBHKY2022-K-038).

3. Results

3.1. Characteristics of the participants

The participants were admitted to the hospital from 1st April to 28th May. The characteristics of the family caregivers are shown in Table 1. Their ages ranged from 25 to 67 years. The majority of them were female (n = 9), were spouses of cancer patients (n = 9), and had received a university-level education (n = 9). Six of them were either retired or unemployed. Four reported a monthly household income of less than RMB 5,000 (≈ USD 700). Eight were non-local residents from other cities. Seven participants were taking care of patients with stage III/IV cancer. The duration of care ranged from 2-weeks to 60 months.

3.2. Themes

Having a cancer diagnosis had already placed an enormous burden on family caregivers. In addition, the implementation of stringent lockdown measures added an extra challenge to them especially when accompanying the family cancer patients navigate the hospital admission procedures and processes. Two themes were generated on family caregivers' experience navigating the pre-hospital system, including 1) Theme 1: And I thought having a cancer diagnosis was hard, and 2) Theme 2: Seeing the light at the end of the cancer tunnel.

3.3. Theme 1: and I thought having a cancer diagnosis was hard

The outbreak of the epidemic and strict lockdown measures added tremendous emotional burden on family caregivers. Challenges the participants encountered extended beyond daily concerns. Rigorous control in the residential community and the hospital further reduced their timely access to healthcare services.

3.4. Subtheme 1: challenges extended beyond daily concerns

Cancer care is physically, emotionally, and financially demanding, and being a cancer family caregiver on most occasions are stressful. The outbreak of the epidemic and lockdown measures created additional challenges for the participants that extended beyond their daily concerns. They felt stressed and avoided healthcare services because of uncertainties of the COID-19 situation, the risk of exposure to the virus, and increased financial hardships.

Table 1
Characteristics of the participants.

	Age	Gender	Education	Residence	Marital status	Religion	Employment status	Monthly house-hold income (RMB)[a]	Relationship with the patient	Cancer Type	Cancer stage	Caring duration (months)
1	47	F	High school	Non-local	Married	No	Employed	<5,000	Spouse	Colorectal cancer	3	6
2	37	M	University	local	Single	Buddhism	Employed	5,000–10,000	Child	Gallbladder cancer	3	3
3	39	F	High school	Non-local	Married	No	Unemployed	<5,000	Spouse	Liver cancer	4	20
4	57	F	Primary school	Non-local	Married	No	Retired	>20,000	Spouse	Liver cancer	4	3
5	66	M	University	Non-local	Married	No	Retired	10,001–15,000	Spouse	Liver cancer	4	60
6	65	F	Primary school	local	Married	No	Unemployed	<5,000	Spouse	Cholangiocarcinoma	4	6
7	27	F	University	Non-local	Single	No	Employed	10,001–15,000	Child	Pancreatic cancer	2	3
8	42	F	High school	local	Married	Buddhism	part time	5,000–10,000	Child	Liver cancer	2	39
9	58	F	University	local	Married	others	Employed	>20,000	Spouse	Cholangiocarcinoma	4	2
10	34	M	University	local	Single	No	Employed	5,000–10,000	Child	Liver cancer	1	5
11	46	F	University	Non-local	Married	No	unemployed	10,001–15,000	Spouse	Cholangiocarcinoma	4	21
12	67	M	University	local	Married	No	retired	15,000–20,000	Spouse	Gallbladder cancer	1	0.5
13	25	M	University	Non-local	Single	No	Employed	>20,000	Child	Duodenal cancer	4	6
14	36	F	University	Non-local	Divorced	No	Employed	<5,000	Sibling	Cholangiocarcinoma	2	7

[a] Latest Currency Exchange Rates: 1 RMB = 0.14 USD.

Many participants felt anxious when witnessing cancer patients' progression and health deterioration and wished for immediate health care access. However, the substantial uncertainties surrounding COVID-19 management policies and restrictions made them feel stressed about possible disruptions of routine care, such as lack of information related to the health care policies and services for cancer patients, duration of the lockdown, suspended public transportation, shortages of food, accommodation, and other daily necessities. As a non-local participant described:

Of course, we had a lot of concerns and hesitations. Although we could find some information online, "Seeing is believing", righ? What should we do if the online information is proved to be wrong? (#17)

Fear of the infection was another reason that discouraged participants from seeking timely treatment for cancer patients. The severity of the outbreak and the sharp rise in COVID-19 cases in Shanghai kept the participants on the edge as they lived in fear. Considering cancer patients' weakened immunity and vulnerability of contracting the virus, some participants decided to delay the treatment until the situation became more under control. For example:

During the peak of the outbreak, there were tens of thousands new cases every day. At that time, my father had a Gastro-Jejunal (GJ) tube and a T-tube and was very weak. Although the doctor assured us that we could come to the hospital for treatment as long as we got a PCR test. For fear of infection, we decided to stay at home. (#17)

The economic impact of the lockdown would further reduce the participants' intention to seek treatment for cancer patients. Cancer treatment usually involves a large monetary investment. Many participants who had already bore substantial financial hardships, were susceptible to experience a further loss of income due to the lockdown. Uncertainties related to treatment costs and hotel quarantine expenses significantly influenced the participants' decision-making regarding access to healthcare services. For example:

Financial difficulty is our main concern. My husband and I were financially dependent on my mother's meager income from selling vegetables after his cancer was diagnosed. However, my mother could not make money following the lockdown, and all the vegetables had rotten. (#3)

3.5. Subtheme 2: rigorous control doesn't make it easy

COVID-19 and associated strict community measurement made access to healthcare services difficult. The residential communities imposed strict management protocols that made entering or leaving the residential community difficult. It often took overly complicated procedures to simply gain permission from the community officer to leave. The participants felt pressured when they applied for medical treatment leave and felt "trapped" in the community because of the strict protocols governing movement. As a participant described:

It wasn't easy to get to the hospital. Firstly, I informed the staff of the community management office about the patient's health needs. Then they reported to the community leader. After that, the community leader had to report to the next level. After many procedures, we could finally leave the community. Moreover, on our way to the hospital, we were stopped and checked by officers. (#16)

The suspension of public transportation also contributed to the additional challenges experienced in being able to access healthcare services especially for those who relied on this mode of transport. This was also compounded by a variation in transportation requirements between the communities to hospitals with transportation being inconsistent from place to place. Some communities required the patient to take an ambulance, while others insisted the patient use a private car to reduce the risks of cross-infection in the ambulance. Many participants had to either wait for an ambulance or contact their relatives to drive them to the hospital. If it was the latter, their relatives also had to endure the complicated procedure to get the permission to leave their community.

Moreover, the participants thought of the "big picture" of their community and the whole society. During the lockdown, if one case was detected, the entire residential community would undergo 14 days of lockdown. The awareness of social responsibilities and fear of a significant community impact of one's infection kept the participants and cancer patients from seeking help when they believed they needed it. For example:

The omicron variant is everywhere, I am scared and take precautions to prevent infection. Once infected, not only myself will be affected, the whole community has to suffer the consequence. I felt pressured to go outside to seek help. [#16]

3.6. Subtheme 3: unexpected difficulties of accessibility at the hospital

Unaccounted challenges at the hospital rose due to the difficult situation of the outbreak and lockdown. The inpatient procedure became complex, and admissions were carried out with a great many additional precautions. Many had been rejected by hospitals or had to wait a considerable amount of time to be admitted.

This was complicated for the cancer patient because of hospital closures or a change in functions of the hospital. For example, during the outbreak, when a hospital had a positive COVID-19 case, it would undergo closed-loop management and temporarily suspended its services for approximately two days. In addition, as 48 city/district-level hospitals in Shanghai had been transformed into designated hospitals for COVID-19 patients during the lockdown, the participants were forced to seek treatment for cancer patients from other non-designated hospitals. They were understandably frustrated with the inconvenience this brought as one participant describes:

When there was no lockdown, we could freely choose any hospital or the nearest hospital we liked. However, since the lockdown of the city, the hospital we usually visited has been converted to a designated hospital. We had to travel long distances to seek health care from another hospital. (#16)

In addition, cancer patients from a "high-risk" COVID-19 area might face rejection from their local hospital. In April, Shanghai introduced a three-tier epidemic control system that categorized residential communities based on the level of COVID-19 cases. Namely, precautionary zone (i.e., no reports of COVID-19 infections in compounds over the past 14-days), controlled zones (i.e., no reports of COVID-19 infections in compounds over the past 7-days), and locked-down zones (i.e., reports of positive COVID-19 infections in compounds over the past 7-days). Only residents living in the precautionary zone could leave their neighborhoods and undertake limited activities. One participant who was from a "locked-down zone" was told by a doctor that people in their zone were not allowed to come to the hospital and was advised to wait until the COVID-19 situation in their community had improved, meaning when their zoon had been reclassified into a "precautionary zone."

The participants described that access to the hospital became even tighter because the routine hospital admission procedure for cancer patients had also been disrupted. To prevent nosocomial infection of COVID-19, patients who needed hospitalization were required to undergo two rounds of a risk screening test. First, patients should undergo a double nucleic acid test within 48 h of presenting at the outpatient and/or the emergency department. After that, they would be admitted to a 'buffer ward' for another three days of screening before being finally transferred to the inpatient ward. Although the participants understood the purpose of the infection control measures, they worried that such strict rules would delay the patient's diagnosis and/or treatment and described how every day was hard for them. Considering the inconvenience of obtaining permission from the residential community, limited

access to transportation, or lack of accommodation (i.e., non-local participants), they either slept in a tent or lived in their private cars with the cancer patients outside the hospital. They were consistently worried about the patient's health, particularly their nutritional needs, as they had limited access to high-quality nutrition during this period. What was worse, the participants felt 'tortured' when their afflicted loved ones must go through strict inpatient procedures and therefore wait longer to receive the treatment. As a carer describes:

> *The most challenging thing to go through was the long waiting time for admission. My wife had been delayed for six days due to the screening requirement. I felt so powerless that I couldn't help when she felt pain. (#8)*

3.7. Theme 2: seeing the light at the end of the cancer tunnel

Despite all the challenges experienced, all participants tried to make efforts to navigate the hospitalization process to save the lives of their loved ones. They commented favorably on the policy support for cancer treatment, reliable information, as well as adjuvant cancer care.

3.8. Subtheme 1: feel grateful for the prioritization of cancer care

The participants felt grateful for the health policies prioritizing cancer treatment for cancer patients during the lockdown and appreciated their access to hospital services. However, considering the great deal of uncertainty of the COVID-19 situation in Shanghai, some participants doubted the access to cancer treatment at the beginning, and had been psychologically prepared for all kinds of challenges when they decided to seek treatment. The "green light" on their way to the hospital was a great comfort to them. As a non-local participant stated:

> *We had prepared all kinds of documents that might be needed when we drove to Shanghai, such as the hospital transfer request from our local hospital, vaccination certificate, and PCR negative test result. Things went surprisingly well. We were allowed to leave immediately when we got off at the highway exit and showed the traffic officers the documents mentioned above. (#8)*

3.9. Subtheme 2: being better informed makes it easier to plan

Bing better informed about COVID-19 and cancer care-related information made their health-care-seeking journey easier. The participants sought relevant information via various channels, such as friends and relatives, social media, and the internet, and further confirmed what they had received with a more trustworthy authority, such as public service hotlines. They commented favorably on the reliable information provided by the hotlines, such as "12345", which connected the participants to government services directly who provided credible information and practical solutions to their concerns. For example:

> *The 12345 hotline assured me we could drive to Shanghai for treatment as long as we had a hospital transfer request from our local hospital. It is a government hotline, and the information provided was accurate. We were successfully getting admitted to the hospital." (#17)*

Being well-informed and prepared were perceived essential among the participants navigating the pre-hospitalization system. Based on the collected information, they thought carefully about the logistics and planning. In addition to the necessary supporting documents to leave their community or access Shanghai, other daily necessities, such as food, clothing, accommodation, and transportation, had also been arranged well beforehand. They prepared sufficient food and some even brought a "refrigerator" for fear of food shortages. Some also drove to Shanghai from another city to reduce the risks of infection. Well planned preparations for a hospital admission significantly lowered the participants' worry and stress.

3.10. Subtheme 3: adjuvant cancer care at its best

Effective and efficient communication between cancer patients and doctors was crucial during the lockdown. Although standard cancer care had been affected during this period, the participants described that the hospital tried alternative ways to provide healthcare services for those who experienced obstacles to hospitalization, such as internet hospitals, and virtual care with video or telephone consultations. Moreover, as cancer patients needed frequent hospitalization, their doctors usually shared them with their contact details, even personal contact details, to ensure timely communication and support. To facilitate the patients' access to care, the doctors also helped reserve a bed for them. Being virtually connected with health care providers offered participants with up-to-date diagnosis/treatment information. The compassionate care and emotional support greatly reduced their stress and anxiety. As one participant stated:

> *Our doctor was very patient and kind. He told us we could call him whenever needed. During the critical moment of combating the Omicron variant, telephone support is precious to us. We are grateful for the compassionate and empathic care provided by the doctor. (#17)*

4. Discussion

This qualitative study aimed to understand the experience of accessing hospitalization from cancer family caregivers' perspectives during the lockdown in Shanghai. Findings from this study suggested that the rapid spread of the virus and strict lockdown measures had compounded the daily challenges of cancer family caregivers, which led to a dramatic disruption of routine treatment options, and significantly reduced their access to cancer care. While they could find a 'silver lining' amid the chaos of lockdown, policy support of cancer care, reliable information, and telemedicine facilitated the cancer patients' admission to hospitalization.

The enforced lockdown and reduced access to cancer care had placed an additional challenge on family caregivers when they accompanied the cancer patient on their journey to the hospital. This is in line with the extensive literature describing how the COVID-19 pandemic and lockdown measures further overwhelmed the lives of family caregivers (Mitra and Basu, 2020; Marshall et al., 2022). Their increasing anxieties of burden and the psychological stress arising from the uncertainties of the situation, the consistent balancing of risks and the benefits of cancer treatment versus exposure to the virus, and financial struggles due to the lockdown-related income loss was challenging. Frustration and anxiety around complicated procedures of obtaining permission, transportation barriers, and reduction or closure of healthcare services seemed to hamper their intention to seek help and access to cancer care. This study further highlighted a difficult situation where policymakers should ideally balance the public health benefits and individual health care needs during the COVID-19 outbreak, but because of the uncertain trajectory of the Omicron variant made it difficult for any definitive policies to be effectively enacted.

Findings from this study also drew attention to how rigorous management in the community might have contributed to diminished access to cancer care services. The community has historically played a key role in response to epidemic/pandemics outbreaks (Gilmore et al., 2020) by ensuring that the wider community is kept safe from harm. However, the COVID-19 outbreak has been unprecedented in its trajectory and its quick and highly contagious transmission globally has meant that policies and procedures have struggled to keep up. China is no different from any other country in the world. Since the outbreak of the COVID-19 pandemic, the Chinse government has successfully adopted a Community-Based Crisis Management (CBCM) model by collaborating with local community to curb the transmission of the virus (Shangguan and Wang, 2022). The community serves as a cornerstone and a basic unit of successful pandemic response (Wang and Zhou, 2022), including

pandemic surveillance, temperature monitoring, information dissemination, community entry, disinfection, and other logistics (Shangguan and Wang, 2022; Gilmore et al., 2020). The unprecedented outbreak of the Omicron wave in Shanghai placed undue pressure on the communities to enforce strict control measures, which had inadvertently brought significant level of inconvenience to the vast majority of the residents (Zhang et al., 2022). To mitigate the negative health implications during the lockdown, especially among patients with a critical health condition, community officers were recommended to support patients and families in a more efficient and flexible way and some were able to achieve this successfully.

One important consideration was access to reliable and accurate information. Information was crucial for family caregivers who felt stressed and powerless to prepare for cancer care during the lockdown. Reliable information has been highlighted in the literature in combating uncertainties, preparing for crisis management, and alleviating psychological stress of individuals (Brooks et al., 2020). Yet, as the overwhelming fake news and rumors spreading on social media, "infodemic" has emerged as a significant concern together with the pandemic and has been attributed to people's vulnerability to a range of psychological disorders and poor health-seeking behaviors (World Health Organization, 2021b; Islam et al., 2020; Mirek-Rogowska and Gajdka, 2022). In our study, the information provided by national or city-level government hotlines and hospitals was perceived as trustworthy and highly valued by the participants.

Consistent with the literature that telemedicine had greatly improved patients' health care experiences by addressing social and geographical barriers to access healthcare services during pandemic (Sonagli et al., 2021; Montenegro et al., 2021), this study also indicated that telemedicine technology substantially reduced services gaps during the lockdown. Before the COVID-19 outbreak, telemedicine had been implemented in China and many other countries as an essential approach to address the inequalities in the allocation of healthcare resources and access to healthcare services (Nouhi et al., 2012; Wang and Gu, 2009). The COVID-19 pandemic has accelerated the use of telemedicine globally. Assisted with this advanced technology, patients can access real-time virtual consultations, significantly reducing the time and space constraints. Meanwhile, telemedicine reduces the risks of exposure to the virus and contagion, and it is especially important for cancer patients who are immunocompromised.

4.1. Limitations

There are several limitations in our study. First, we recognise that significant COVID restrictions have been lifted in other parts of the world and lockdowns are now not part of everyday life. However, we would contend that there is perhaps some continued trepidation and fear about being exposed to or contracting the COVID virus given that COVID cases and COVID-related deaths still continue to be reported and against a background of the immune suppression in some cancer patients, this may be a major concern. Second, there is a potential selection bias as we only recruited cancer family caregivers who had been admitted to the hospital during the lockdown. Findings from the study may not represent those who did not or failed to seek care for cancer patients. Third, most patients were classified as having stage III or IV cancer. Thus, our participants may represent family caregivers of advanced cancer patients. Last, the participants were acquainted with the nurse interviewer. A social desirability bias might have occurred when participants described their experiences. Lastly, as the interview was conducted by a nurse manager working in a hospital with closed-loop management and experienced similar challenges as the participants, there is a risk of potential subjective bias. To maintain the objectivity of the study, the nurse manager (TZ) was trained to conduct a phenomenological interview from one of the research team competent in this interview technique. This also included being able to 'bracket' current beliefs, thoughts, and assumptions based on their experience in the form of a reflective diary. Also, the interview was supervised by an experienced qualitative researcher throughout the interview process.

4.2. Implications for practice and future research

COVID-19 has challenged how patients can access healthcare services in a timely and efficient manner and this evident from the results of this study where lockdowns continue to be a reminder of the dangers of exposure to COVID for this group. Moreover, it corroborates other reports that demonstrated the continued difficulties of cancer patients and their caregivers in accessing cancer services peri-COVID restrictions and the long-term effects it has on morbidity and mortality, disease progression and psychosocial wellbeing. In addition, despite the lifting of COVID restrictions globally, there still remains concerns around COVID contagion against a background of immune suppression in this vulnerable group, which prevented individuals from seeking help when it was probably most needed. As yet, there appears to be very little published evidence regarding these ongoing concerns around access in a 'post-COVID world' specifically and perhaps, on the surface, this is some indication that services have seemingly returned to normal. Yet, what this study has identified is that access to cancer care services, like elsewhere (Billig and Sears, 2020; Pramesh et al., 2021), remains challenging and fragmented for this patient group, especially in this context and perhaps as of yet this has not been realised in other countries. Nevertheless, the implications for practice more broadly is to consider the advent of additional approaches using technology such as telehealth, the virtual patient room or nurse led cancer services hotlines alongside the more traditional approach of face-to-face contact, so that care received in a timely fashion. Therefore, the implications for future research could include the following:

- An evaluation of how technologies that have been used to improve cancer access outside of those requiring emergent care, such as surgery peri-COVID;
- The development and evaluation of online real-time symptom-screening tools that relay information to health care teams so that appropriate and timely intervention/s can be initiated;
- To further explore the patient and/or caregiver voice in how a rethinking of cancer services delivery post-COVID can be developed into other programmes of accessibility, especially in times of crisis, for example the centralizing of cancer services.

5. Conclusion

The lockdown in Shanghai significantly affected cancer family caregivers' experience navigating the pre-hospital system. Uncertainties of the situation, increasing cases of COVID, risks of infection, and loss of income, along with strict restriction measures in communities and hospitals, have added their burden and psychological stress, negatively influencing their access to cancer care. Fortunately, policy support for cancer care, reliable information, and telemedicine technique strengthened family caregivers' abilities to cope with this challenging situation and contribute to cancer patients' admission to the hospital.

CRediT authorship contribution statement

Haixia Ma: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing. **Tuan Zhao:** Investigation, Project administration, Resources, Validation. **Chuchu Wan:** Project administration, Validation. **Fang Liu:** Project administration, Resources, Validation. **Martin Christensen:** Supervision, Formal analysis, Writing – review & editing.

Declaration of competing interest

None declared.

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References

Billig, J.I., Sears, E.D., 2020. The compounding access problem for surgical care: innovations in the post-COVID era. Ann. Surg. 272, e47.

Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3, 77–101. https://doi.org/10.1191/1478088706qp063oa.

Brooks, S.K., Webster, R.K., Smith, L.E., Woodland, L., Wessely, S., Greenberg, N., Rubin, G.J., 2020. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. Lancet 395, 912–920. https://doi.org/10.1016/S0140-6736(20)30460-8.

Cao, W., Chen, H.-D., Yu, Y.-W., Li, N., Chen, W.-Q., 2021. Changing profiles of cancer burden worldwide and in China: a secondary analysis of the global cancer statistics 2020. Chinese Med J 134, 783–791.

Cho, S.-H., Kim, H.-R., 2006. Family and paid caregivers of hospitalized patients in Korea. J. Clin. Nurs. 15, 946–953. https://doi.org/10.1111/j.1365-2702.2006.01342.x.

Dhada, S., Stewart, D., Cheema, E., Hadi, M.A., Paudyal, V., 2021. Cancer services during the COVID-19 pandemic: systematic review of patient's and caregiver's experiences. Cancer Manag. Res. 13, 5875. https://doi.org/10.2147/CMAR.S318115.

Feliciana Silva, F., Macedo Da Silva Bonfante, G., Reis, I.A., André Da Rocha, H., Pereira Lana, A., Leal Cherchiglia, M., 2020. Hospitalizations and length of stay of cancer patients: a cohort study in the Brazilian Public Health System. PLoS One 15, e0233293. https://doi.org/10.1371/journal.pone.0233293.

Gilmore, B., Ndejjo, R., Tchetchia, A., DE Claro, V., Mago, E., Lopes, C., Bhattacharyya, S., 2020. Community engagement for COVID-19 prevention and control: a rapid evidence synthesis. BMJ Global Health 5, e003188. https://doi.org/10.1136/bmjgh-2020-003188.

Islam, M.S., Sarkar, T., Khan, S.H., Kamal, A.-H.M., Hasan, S.M., Kabir, A., Yeasmin, D., Islam, M.A., Chowdhury, K.I.A., Anwar, K.S., 2020. COVID-19–related infodemic and its impact on public health: a global social media analysis. Am. J. Trop. Med. Hyg. 103, 1621. https://doi.org/10.4269/ajtmh.20-0812.

Kaltenmeier, C., Shen, C., Medich, D.S., Geller, D.A., Bartlett, D.L., Tsung, A., Tohme, S., 2021. Time to surgery and colon cancer survival in the United States. Ann. Surg. 274, 1025–1031.

Ludvigsson, J.F., 2021. Case report and systematic review suggest that children may experience similar long-term effects to adults after clinical COVID-19. Acta Paediatr. 110, 914–921. https://doi.org/10.1111/apa.15673.

Marshall, A.T., Hackman, D.A., Kan, E., Abad, S., Baker, F.C., Baskin-Sommers, A., Dowling, G.J., Gonzalez, M.R., Guillaume, M., Kiss, O., 2022. Location matters: regional variation in association of community burden of COVID-19 with caregiver and youth worry. Health Place 77, 102885. https://doi.org/10.1016/j.healthplace.2022.102885.

Mirek-Rogowska, A.E., Gajdka, K., 2022. The Challenges of the COVID-19 Infodemic: Consequences and Information Management. *Innovative Strategic Planning and International Collaboration for the Mitigation of Global Crises*. IGI Global.

Mitra, M., Basu, M., 2020. A study on challenges to health care delivery faced by cancer patients in India during the COVID-19 pandemic. J. Primary Care Comm. Health 11, 2150132720942705. https://doi.org/10.1177/2150132720942705.

Montenegro, P., Pinillos, L., Young, F., Aguilar, A., Tirado-Hurtado, I., Pinto, J.A., Vallejos, C., 2021. Telemedicine and the current opportunities for the management of oncological patients in Peru in the context of COVID-19 pandemic. Crit. Rev. Oncol. Hematol. 157, 103129 https://doi.org/10.1016/j.critrevonc.2020.103129.

Mynard, N., Saxena, A., Mavracick, A., Port, J., Lee, B., Harrison, S., Chow, O., Villena-Vargas, J., Scheff, R., Giaccone, G., 2022. Lung cancer stage shift as a result of COVID-19 lockdowns in New York City, a brief report. Clin. Lung Cancer 23, e238–e242.

Nouhi, M., Fayaz-Bakhsh, A., Mohamadi, E., Shafii, M., 2012. Telemedicine and its potential impacts on reducing inequalities in access to health manpower. Telemed. e-Health 18, 648–653. https://doi.org/10.1089/tmj.2011.0242.

Pramesh, C., Seshadri, D., Fernandez, E., Rao, G.N., Dutta, M., Mohan, P., Consortium, E.H.A., 2021. Healthcare in post-COVID India: a call for a decentralized healthcare system. J. Fam. Med. Prim. Care 10, 4337.

Sadik, M., Ozlem, K., Huseyin, M., Aliayberk, B., Ahmet, S., Ozgur, O., 2014. Attributes of cancer patients admitted to the emergency department in one year. World J. Emerg. Med. 5, 85. https://doi.org/10.5847/wjem.j.issn.1920-8642.2014.02.001.

Shangguan, Z., Wang, M.Y., 2022. China's community-based crisis management model for COVID-19: a zero-tolerance approach. Front. Public Health 10. https://doi.org/10.3389/fpubh.2022.880479.

SHANGHAI MUNICIPAL HEALTH COMMISSION, 2021. Five-year Cancer Survival Rate in Shanghai 55% Continues to Rise for More than a Decade (2021-04-15 [Online]. Shanghai: Shanghai Municipal Health Commission. Available: http://wsjkw.sh.gov.cn/xwfb/20210415/3bae5eb22d61411c82a6bf9d38eed431.html. (Accessed 6 September 2022).

SHANGHAI MUNICIPAL HEALTH COMMISSION, 2022a. Notice on the COVID-19 Epidemic from the Shanghai Municipal Health Commission. Shanghai Municipal Health Commission, China, 2022-04-14) [Online]. Shanghai. https://wsjkw.sh.gov.cn/xwfb/20220414/083cc562d92d4641b8acf1eccaf38420.html. September 5 2022 2022.

SHANGHAI MUNICIPAL HEALTH COMMISSION, 2022b. Notice on the COVID-19 Epidemic from the Shanghai Municipal Health Commission. Shanghai Municipal Health Commission, Shanghai, 2022-04-15) [Online]. http://wsjkw.sh.gov.cn/rdhy/20220416/c8a6284c49d6444aadba6bd7db11576f.html. (Accessed 6 September 2022).

Sonagli, M., Cagnacci Neto, R., Leite, F.P.M., Makdissi, F.B.A., 2021. The use of telemedicine to maintain breast cancer follow-up and surveillance during the COVID-19 pandemic. J. Surg. Oncol. 123, 371–374. https://doi.org/10.1002/jso.26327.

Topriceanu, C.-C., Wong, A., Moon, J.C., Hughes, A.D., Bann, D., Chaturvedi, N., Patalay, P., Conti, G., Captur, G., 2021. Evaluating access to health and care services during lockdown by the COVID-19 survey in five UK national longitudinal studies. BMJ Open 11, e045813.

Wang, B., Zhou, R., 2022. Urban form, neighbourhood governance, and real estate management: Chinese cities fighting a pandemic. In: Eur. Cities After, COVID-19. Springer, pp. 55–66.

Wang, L., Berger, N.A., Kaelber, D.C., Davis, P.B., Volkow, N.D., Xu, R., 2022. COVID infection severity in children under 5 years old before and after Omicron emergence in the US. medRxiv. https://doi.org/10.1101/2022.01.12.22269179.

Wang, Z., Gu, H., 2009. A review of telemedicine in China. J. Telemed. Telecare 15, 23–27. https://doi.org/10.1258/jtt.2008.08050.

WORLD HEALTH ORGANIZATION, 2021a. Classification of Omicron (B.1.1.529). World Health Organization. *SARS-CoV-2 Variant of Concern* [Online]. World Health Organization. https://www.who.int/news/item/26-11-2021-classification-of-omicron-(b.1.1.529)-sars-cov-2-variant-of-concern. (Accessed 26 November 2021).

WORLD HEALTH ORGANIZATION, 2021b. Infodemic Management: an Overview of Infodemic Management during COVID-19. January 2020–May 2021.

Xu, Z., Lu, H., Zhou, J., Feng, X., Hambly, B., Fan, J., Bao, S., 2022. Implementation of emergency general practitioner management of patients during the complete lockdown consequent to the COVID-19 Omicron outbreak in Shanghai. Aust J Gen Pract 2022 (4), 51. https://doi.org/10.31128/AJGPCOVID-51-5.

Zhang, X., Zhang, W., Chen, S., 2022. Shanghai's life-saving efforts against the current omicron wave of the COVID-19 pandemic. Lancet 399, 2011–2012. https://doi.org/10.1016/S0140-6736(22)00838-8.